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Understanding place of death for patients with non malignant disease: a systematic literature review

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Understanding place of death for patients with non malignant conditions – a systematic literature review

Review Protocol

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with input from the Project team

Date: 21 April 2010

BACKGROUND

The numbers of UK deaths are predicted to rise by 17% between 2012 and 2030 (1). Planning and providing the health and social services to address this rise is an urgent priority, and will require either substantial increase in provision for institutional end of life care, or considerable expansion of community services to support home deaths, or both. Understanding the factors which influence home deaths in non malignant conditions will play a significant part in informing this planning process. Overall, health care towards the end of life places major resource burdens on the NHS. Approximately 10% of healthcare expenditure is spent on care in the last year of life (2) (3) (4); this is currently £8,000 million per annum in the UK (5). Much of this cost relates to hospital and residential care, rather than home care (4) (6). End of life care at home is, in general, less costly than end of life care in hospital (7), and a recent National Audit Office report highlights the considerable cost savings which could be achieved in acute healthcare by reducing hospital admissions and increasing home and community care in the last year of life (6).

However cost, while important, is only one consideration. The quality of life, care, and death of patients at the end of life is a growing public priority, and is at the forefront of NHS health policy for England, as highlighted in the End of Life Care Strategy (8). Attention is focused on improving end of life care for all, regardless of diagnosis (8), with the aim of delivering high quality care (9), responsive to patient choice (10). In the context of increasing public awareness and demand for choice, to be cared for and to die at home (if this is the preferred option) has become a key NHS objective (10). The recent End of Life Care Strategy from the Department of Health emphasises choice in place of death, and encourages commissioners to provide the services to support an increased number of home deaths (8). The Marie Curie ‘Delivering Choice’ programme has also recognised this priority, and seeks to enable local service development to support home deaths (11). Delivering high quality care in the setting of choice represents best use of the considerable resources expended on care towards the end of life.

A key component of high quality care is the extent to which care is adapted to the preferences, expectations and values of patients and their families (12). Understanding preferences for place of care and death, along with factors influencing place of death, and transitions in place of care is essential to both improve care and ensure it is of the highest quality. Reviews of the evidence on preferences, factors, and influences on place of death for cancer patients have informed the provision and development of generalist and specialist end of life services (13) (14) (15). However, less attention has been given to these aspects of care for the greater numbers of people dying with non malignant conditions. It is timely therefore to review this evidence in those with non malignant disease, especially given the future changes in mortality in an ageing population, with increasing numbers dying at older ages and with chronic non malignant conditions (1).

Among cancer patients and their families, most (50-70%) prefer to die at home (14) (16), although there is variation across studies, and according to whether the views of patients, or relatives are sought (17). Despite the overall high preference for home death (at least among cancer patients), hospital death remains the most common occurrence in developed countries (16). In the UK in 2005, 59% of all deaths occurred in NHS hospitals, but only 18% occurred at home, rising to 35% if care homes are included (18) (19). While 23% of cancer deaths were at home, only 12% of deaths from respiratory causes and from neurological causes occurred at home (18). The proportion of home deaths is also falling over time, from 31% in 1974 to 18% by 2005 (1), and this fall is most pronounced among those with non malignant disease (1) (18).

But in the UK, most people die from causes other than cancer, with only 27% of deaths in 2005 from cancer (18). What proportion of those with non malignant disease prefer home death, and what influences these preferences, has not been systematically appraised. Factors associated with home death have been reviewed in cancer (13) (15), but not in non malignant conditions. In the latter, symptomatology and dependency may be a more important influence on place of death than, for example, age or disease type (20). There may be clear distinctions between preferences for place of care and place of death (21). Some studies also report somewhat unexpected findings: For instance, Seymour and colleagues report high preference for hospital care and death among Chinese people (22), and Tang et al report considerable discordance between patient and family carers preference for place of death (23). This evidence needs to be understood in order to determine how end of life care can best be delivered.

Understanding the current evidence on preferences for place of care and death, and factors which influence both the preference and the reality of place of death will contribute to developing best models of care, both through the synthesis of evidence and through the identification of gaps in it. Several authors have identified the need for different models of end-of-life care, in end-stage heart failure (24) (25) (26), and advanced chronic obstructive pulmonary disease (27), (28) (29). Evidence reviews on end-of-life care in dementia raise the challenges of prognostication (and hence achieving appropriate emphasis on and timing in provision of end of life care), of achieving good symptom control, and of high quality communication (30), and again emphasize the need for different models of care (31) (32) (33). Some of the evidence is focused on populations in one particular setting (34), or on older people (35) (36), rather than on specific disease groups. Overall, the predominant focus has been on drawing together evidence on symptoms and other needs in the different non malignant conditions, and considering how models might differ from that established for cancer patients, rather than on understanding the current evidence on preferences about and factors influencing place of care and death, and transitions in care.

There are several reasons why considerations of place of care and death for those with non malignant conditions may be very different for those with cancer. First, those with non malignant conditions are often older, especially for diseases such as dementia or organ failure (37) (18). Second, the trajectory of illness differs for those with non malignant disease, with, for instance, a more fluctuant course in organ failure (38), and poorer function and protracted decline in dementia (30). This may influence treatment and other preferences (39), affect advance planning (40), and hinder appropriate transitions in care (41). Third, prognostication is more difficult for those with non malignant disease, which makes prediction and anticipation of end of life more challenging (42) (43) (44). And fourth, communication with patient and family about this more uncertain prognosis may be particularly difficult (45) (30) (46). Models of end of life care in non malignant disease, where they exist, are largely derived from the cancer model, with limited evaluation of how suitable they might be in advanced non malignant disease (47), and generalist end of life care for those with non malignant conditions remains diffusely conceptualised, with a limited evidence base and little testing or evaluation of interventions (48) (49).

In the face of these considerations, there is some evidence on the preferences for place of care and death, influences on place of death, and transitions in care for those with non malignant disease. Older patients (50) and those dying of certain non malignant diseases (51) are less likely to die at home. They do experience similar (or even greater) levels of symptoms and distress as those with cancer (52) (53) (46) (54) (55) (56). But despite these considerable needs, they access fewer services towards the end of life than cancer patients (57), and their preferences for place of death are often not met (51). Factors that influence place of death, include illness-related factors such as illness trajectory (50), and service-related factors, such as availability of hospital beds (51). But to date this evidence has not been systematically reviewed, and in particular, comparisons between diseases and across ages to inform care as patterns of disease and mortality change have not been made.

We aim to identify, critically appraise and synthesize the evidence on preferences regarding place of care and place of death, and factors influencing place of death, for patients with non malignant conditions. Specifically, we will:

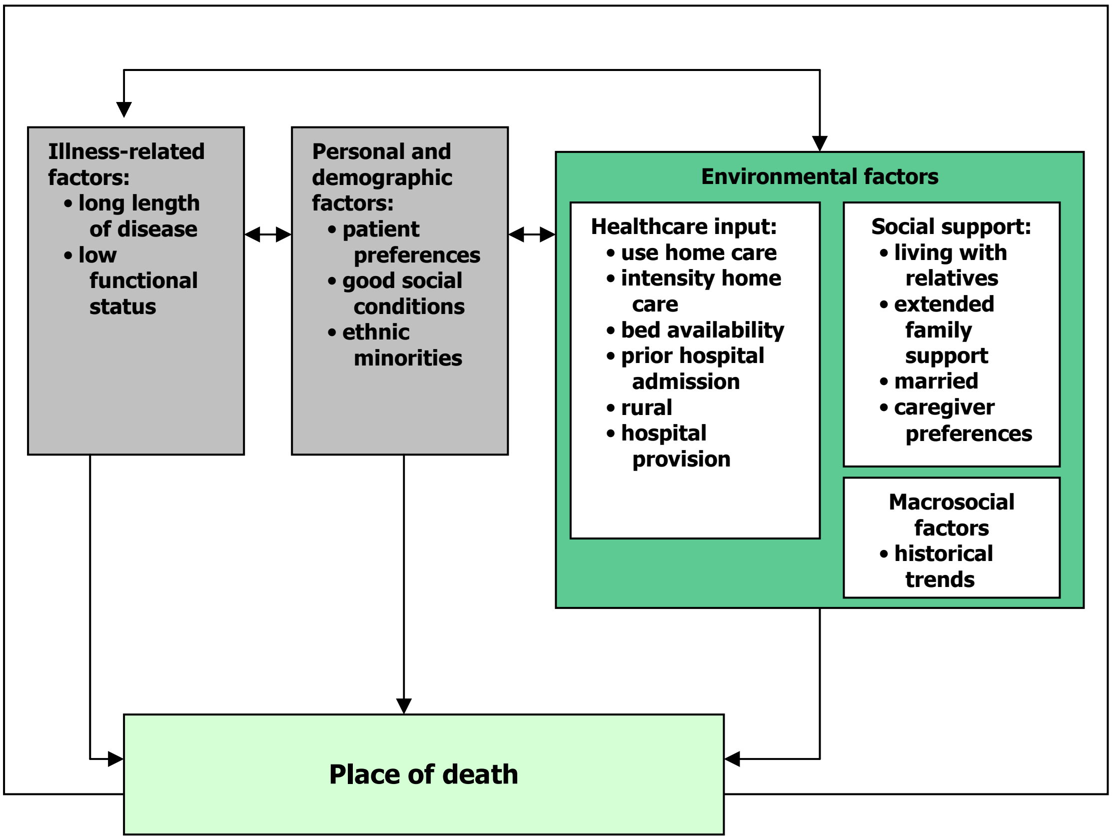
1. Identify the extent to which people with non malignant disease actually want to die at home, describing the proportion with a home preference, the quantity, quality, and strength of the evidence, and identifying gaps in the evidence;
2. Identify what determines preferences for place of care and place of death among those with non malignant conditions and their families, and how preferences change according to different influences and over time;
3. Determine which factors are associated with place of death (and hence reasons for variation in place of death) for patients with non malignant disease, with a focus on the influence of health and social care resources at home;
4. Identify key transitions in care at the end of life for patients with non malignant disease, and perceived barriers/facilitators to these transitions.

THEORETICAL MODELLING

An explanatory model for the factors influencing the place of care and death for patients with advanced cancer has already been published (58) – see Figure 1a. This incorporates patient, family, and professional perspectives, but is essentially patient-centred, placing the patient in the heart of the model. It adopts a bio-psychosocial framework, appropriate for the integrative, comprehensive and multidimensional study of the individual, as well as a useful conceptual framework for provision of health services. It is also appropriate to palliative care, as it comprises the holistic principles of care based on the whole person. It can be described as a multi-theoretical model that comprises contributions from an ecological perspective (59) and from crisis theory applied to coping with physical illness (60). Place of care and death are analysed taking into account the physical environment and its relationship to people at individual, interpersonal, organizational and community levels. Crisis theory enables understanding of serious illness as a life crisis or disruption which people have to cope with in order to (re)-establish a balance. Adaptive coping with illness has already been conceptualised as depending on the characteristics of the patient, aspects of the illness, and specific features of the physical and social environment (60).

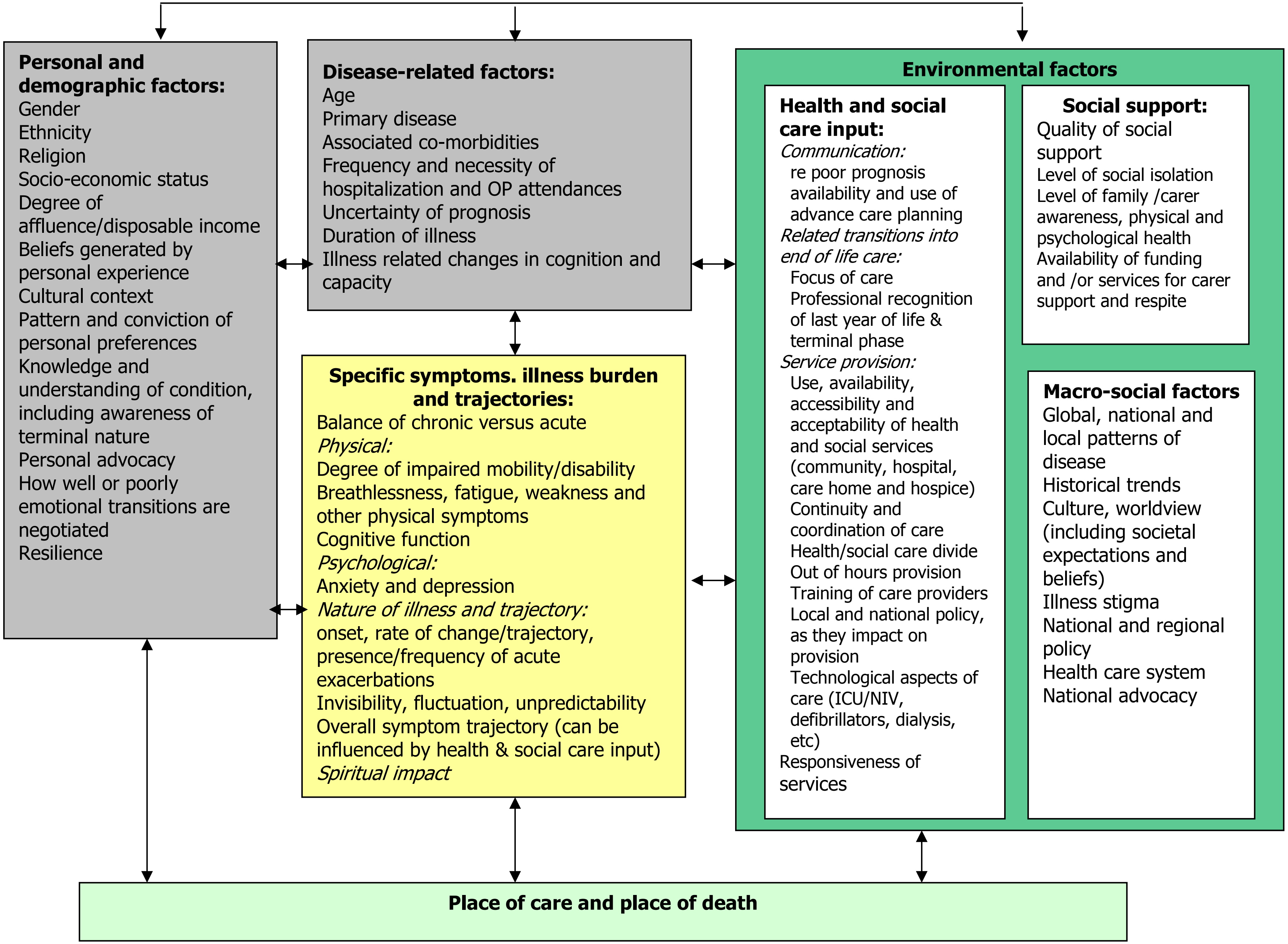
Bearing these perspectives in mind, the model developed by Gomes and Higginson has been used to explain place of care and place of death for cancer patients, based on dynamic interactions between three groups of factors. We have refined this model, using both theoretical and clinical perspectives on the potential factors which influence place of care and death for those with non malignant conditions. This incorporates contributions from the chronic illness literature (61-63), including a broader experiential and societal perspectives pertinent to non malignant disease. In addition, and because of the limited theoretical context for non malignant end of life care, we conducted a detailed consultation exercise to incorporate those factors considerations most relevant for non malignant conditions. An extended model (see Figure 1b) was derived from this 1) knowledge of the evidence and 2) expert consensus from clinicians, and was drawn together through extensive consultation with the Project Advisory Group and invited experts in the different disease areas (see Appendix 1 for details of those who participated in the consultation).

Figure 1a: Model of the factors affecting place of care and place of death
(from Gomes & Higginson, BMJ, 2006)



The extended model in Figure 1b will be used to interpret the findings of the systematic review. The evidence will be identified, assessed and synthesized, and interpreted in the light of the model, to support, refute or refine it, and we anticipate the model will be markedly simplified given the considerable limitations of the evidence. We anticipate that the evidence may support some elements of the model and refute others. Given the complexity and diverse of the questions addressed in this review, we believe this approach is important in making our theoretical and conceptual approach explicit from the outset.

Figure 1b: Proposed theoretical model of the factors affecting place of care and death in non malignant conditions
Adapted from Gomes & Higginson, BMJ, 2006, and informed by theory and wide clinical consultation



Personal and demographic factors:
Gender
Ethnicity
Religion
Socio-economic status
Degree of affluence/disposable income
Beliefs generated by personal experience
Cultural context
Pattern and conviction of personal preferences
Knowledge and understanding of condition, including awareness of terminal nature
Personal advocacy
How well or poorly emotional transitions are negotiated
Resilience

Disease-related factors:
Age
Primary disease
Associated co-morbidities
Frequency and necessity of hospitalization and OP attendances
Uncertainty of prognosis
Duration of illness
Illness related changes in cognition and capacity

Specific symptoms. illness burden and trajectories:
Balance of chronic versus acute
Physical:
Degree of impaired mobility/disability
Breathlessness, fatigue, weakness and other physical symptoms
Cognitive function
Psychological:
Anxiety and depression
Nature of illness and trajectory:
onset, rate of change/trajectory, presence/frequency of acute exacerbations
Invisibility, fluctuation, unpredictability
Overall symptom trajectory (can be influenced by health & social care input)
Spiritual impact

Environmental factors

Health and social care input:
Communication:
re poor prognosis
availability and use of advance care planning
Related transitions into end of life care:
Focus of care
Professional recognition of last year of life & terminal phase
Service provision:
Use, availability, accessibility and acceptability of health and social services (community, hospital, care home and hospice)
Continuity and coordination of care
Health/social care divide
Out of hours provision
Training of care providers
Local and national policy, as they impact on provision
Technological aspects of care (ICU/NIV, defibrillators, dialysis, etc)
Responsiveness of services

Social support:
Quality of social support
Level of social isolation
Level of family /carer awareness, physical and psychological health
Availability of funding and /or services for carer support and respite

Macro-social factors
Global, national and local patterns of disease
Historical trends
Culture, worldview (including societal expectations and beliefs)
Illness stigma
National and regional policy
Health care system
National advocacy

Place of care and place of death

REVIEW QUESTIONS

Our review questions are:
Among those with non malignant disease and their families:

1. What is the prevalence of a home death preference?
2. How does this preference (and the evidence relating to it) vary by age, type of disease, stage of disease, and co-morbidity?
3. What determines, shapes, or changes preferences for place of care and place of death?
4. What factors are associated with actual place of death?
5. How do health and social care resources influence actual place of death?
6. What are the key transitions in care at the end of life?
7. What influences these transitions?

For each question, we will, according to availability of evidence, report the answer to the question, and also the quantity, quality, and strength of the evidence. We will also identify the gaps in the evidence.

STUDY INCLUSION CRITERIA

Studies will be included in the systematic review on the basis of the following criteria, which are explained more fully below:

1. Outcomes
2. Population
3. Study design

These are modified from the PICOS (Population, Intervention, Comparator, Outcome, Study design) criteria laid out in the CRD's revised 'Guidance for Undertaking Reviews in Healthcare', published by the NHS Centre for Reviews and Dissemination in Jan 2009.

(1) STUDY OUTCOMES

The paper will be included if it relates to any of these outcomes:

- Place of death ☐
- Place of care ☐
- Preferences for place of care or death ☐
- Transitions in care ☐

(A transition is defined as change in setting or place of care, change in focus of care, or marked change/movement in the patient's emotional or psychological journey)

(2) STUDY POPULATION

The paper will be included if the study population includes participants:

- Over 18 years
- With non-malignant disease (any proportion)
- With advanced disease

(The definition of advanced disease varies between conditions, but in general is defined as when treatments and other interventions are predominantly palliative and/or focused on improving quality of life rather than curing the condition)

(3) STUDY DESIGN

All studies which include original data will be included. We will aim to include all studies, regardless of publication status, and will approach the authors where necessary for the full study details. Systematic and non systematic reviews, discussion papers, commentaries or editorials which relate to the population and outcomes of interest, but which do not contain original data will be excluded, but retained for reference list and cited reference searching.

APPLICATION OF THE INCLUSION CRITERIA

Studies containing original data which meet the population, outcome and study design criteria above will be included, regardless of the country in which the research took place. We will include both English and non English language papers, and make every effort to incorporate the non-English papers into the review through translation by members of the wider team, and our collaborators (through which we have access to a wide range of language skills).

Three reviewers will be involved in the selection process of the primary studies. One reviewer will first apply the selection criteria to the title and abstract of each identified study, and categorise into: (a) 'definitely included', (b) 'definitely excluded', (c) 'uncertain', and (d) 'excluded but of interest' (this category relates to any systematic or non-systematic reviews, discussion papers, commentaries or editorials, which do not contain original data). All papers in the category (c) 'uncertain' will be reviewed by the second and third reviewers (independent of each other) to assess separately for inclusion. In cases of disagreement, inclusion/exclusion will be discussed between the three reviewers to reach consensus. In order to assess the reliability of the inclusion/exclusion decision process, a random sample (10%) of the retrieved titles/abstracts will be reviewed for inclusion/exclusion independently, and the agreement reported.

Included studies will be categorized by the three criteria: (1) population (and by the six selected non-malignant conditions, i.e. COPD, Chronic Heart Failure, End-stage Chronic Kidney Disease, Long Term Neurological Conditions, Dementia, Stroke, or 'other'); (2) the outcomes of interest, namely place of care, place of death, preferences, and transitions, and (3) study design.

If limited information about the diagnosis or stage of disease for the study population is given, the authors of the paper will be approached in order to clarify this. Although the search concentrates on the above six conditions as exemplars of non-malignant conditions, we will include studies with focus on other non-malignant illness. However, our search is not targeted to these other conditions, and conclusions in relation to these conditions will inevitably be somewhat constrained.

SEARCH STRATEGY

A variety of data sources and procedures will be used to identify relevant research: electronic databases will be searched, reference lists of relevant primary studies identified in the electronic search will be analysed, cited reference searching will be undertaken, and key journals (either all volumes if not available online or the volumes prior to electronic database indexing) will be hand searched (see Table 1).

Table 1 Sources of data: electronic databases and journals

Electronic Databases	Journals (hand-searching)
MEDLINE (OVID Medline ® In-Process & Other Non-Indexed Citations and Ovid Medline ® from 1950 to 30 March 2010)	Palliative Medicine
EMBASE (OVID From 1980 to 6 April 2010)	Journal of Palliative Care (not indexed)
PSYCINFO (OVID, from 1806 to 30 March 2010)	Journal of Pain and Symptom Management
CINAHL (From 1980 to 7 April 2010)	BMC Palliative Care
British Nursing Index and Archive (BNI) (OVID from 1985 to 7 April 2010)	Palliative and Supportive Care
Applied Social Sciences Index and Abstracts (ASSIA) from 1987 to 13 April 2010	American Journal of Hospice and Palliative Care

ELECTRONIC DATABASES

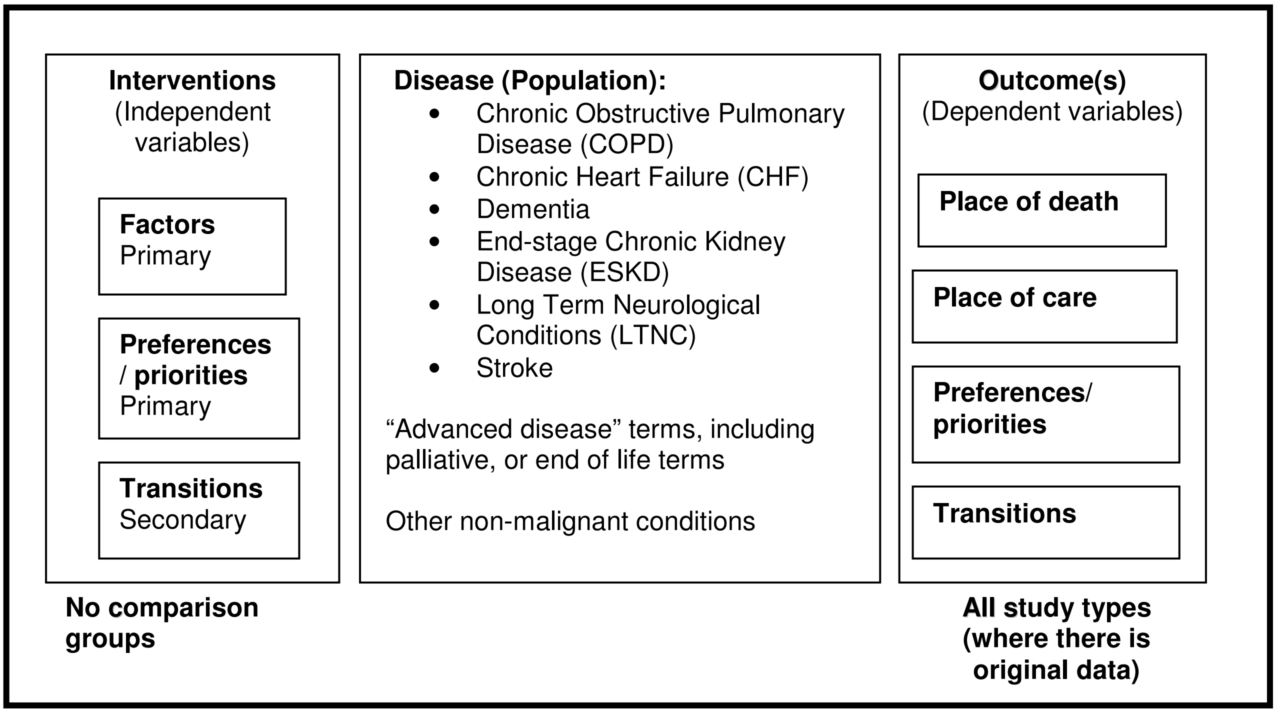
Six electronic databases are selected to ensure a diversified and comprehensive search, including databases with different traditions and backgrounds: medical (MEDLINE); biomedical and pharmacological (EMBASE) psychological (PSYCINFO); nursing and allied health literature (CINAHL); nursing and midwifery (BNI); and social (ASSIA). Given the large number of studies identified in the preliminary literature scoping, it was decided to use a search strategy with mid range precision, appropriate to the aims and time constrains of the review, and to include reference list and cited reference searching for all included studies. The search strategy is developed and refined in all six databases according to the terms used in each database, due to differences in subject headings and/or Boolean characters in each database.

The electronic databases search will be updated before the final writing of the review.

SEARCH TERMS

The search strategy will begin with identification of terms, adapting the PICOS (Population, Intervention, Comparator, Outcome, Study Design) approach from the NIHR Centre for Reviews and Dissemination (CRD), York, to the aims and objectives of this review. Figure 2 below provides a graphical representation of these adapted criteria.

Figure 2 Search strategy terms (using PICOS)



This systematic review focuses on actual and preferred place of care and death for patients with non-malignant diseases, as well as preferences and transitions in relation to this. Therefore the search strategy aims to use terms within the following areas:

(1) **Non-malignant** diseases (six main examples: Chronic Obstructive Pulmonary Disease (COPD); Chronic Heart Failure (CHF); Dementia; End-stage Chronic Kidney Disease (ESKD); Long Term Neurological Conditions (LTNC) and Stroke)

(2) **Advanced** disease

(3) **Outcomes** (place of death; place of care; preferences for place of care or death; transitions in care)

(4) **Factors and variables** influencing the outcomes

(5) **Study design** (no limitations on design included in the search strategy)

For the purpose of this systematic review, we consider the outcomes as dependent variables. Factors that may influence the outcomes will be considered independent variables. Some variables may be considered to be operating both as dependent and independent variables – for example, the review is interested in preferences about place of death as an outcome, but preference for place of death may also operate as an independent variable influencing actual place of death. So preferences for place of care or death, as well as transitions in care, are regarded as both outcomes *and* as factors that may influence the outcomes (i.e. both dependent and independent variables).

A transition is defined as change in setting or place of care, change in focus of care, or marked change/movement in the patient's emotional or psychological journey. This review is interested mostly in transitions of setting, care, or focus of care i.e. change in focus from active to palliative care, recognizing that most of the published literature concerns changes in the setting of care. A note needs to be made of some country differences in palliative care provision, which can influence the definition of "transitions" and the search as a result. For instance, if we take a Canadian definition (see Lawson et al, 2006), transition is defined as: 1) A change in location of where the patient was cared for; or 2) A change in which service (specialist groupings, primary care) provided care. We have adopted the wider definition above, because of feedback from our clinical consultation for the theoretical model that the transition of a patient in terms of their emotional acceptance or denial of their illness can be one of the key determining factors in the outcomes of interest (i.e. place of care or death).

We do not include “preferences” in the search terms for the outcome “preferences for place of care or death” because our scoping searches indicated that this did not improve the sensitivity of our searches, while making them less specific. Instead we searched more broadly for all terms for “place of care or death”. This simplifies the search yet has similar sensitivity to studies that include place of care or death, including aspects relating to preferences.

The disease terms were discussed and refined extensively with experts in the six non-malignant conditions, and the final search strategy is in Appendix 2.

REFERENCE LIST AND CITED REFERENCE SEARCHING

In addition to the above database searches, the reference lists of all included papers will be searched. Cited reference searching will also be undertaken for all included studies, using Scopus and Web of Science.

The reference lists of studies which fulfil the inclusion criteria apart from containing original data (i.e. relevant systematic reviews, discussion papers, editorials and commentaries, but not books, letters, guidelines, authors’ response, case reports or case series, will also be searched.

HAND SEARCHING OF KEY JOURNALS

Hand searching of six key journals will be conducted in order to identify articles that may have been missed in the databases and reference list searches (with attention to journals or years not indexed electronically).

A list of relevant journals was drawn based on the journals with the highest number of papers identified in the preliminary electronic searches, advice from subject experts and information specialists, and resources suggested by the International Association for Hospice and Palliative Care and the National Council of Hospice and Specialist Palliative Care Services. The decision was taken not to hand-search disease specific journals, given the diversity of conditions, and the concentration of evidence into more recent years (and hence greater likelihood of electronic indexing of this evidence).

STUDY QUALITY ASSESSMENT

(not yet completed)

We anticipate that most identified evidence will be cross-sectional surveys or qualitative research, with infrequent longitudinal studies. The quality of included studies will be assessed using quality criteria adapted from two sources: 1) criteria recommended by the NHS Centre for Reviews and Dissemination in evaluating the quality of observational studies (73), and 2) the Framework for assessing qualitative research evidence developed for the UK Government's Chief Social Researchers Office (76).

Two specific quality scales will be developed to assess the quality of the studies (for quantitative and qualitative research) according to the scope and aims of the review. Using these, a quality score will be applied to each included study.

For observational studies, the criteria will include: study design, uniformity or heterogeneity in disease stage, sample and group description, representativeness of sample, explicit inclusion/exclusion criteria, acceptable response rate, adjustment for confounders, and reliability and objectivity in outcome assessment. In reviewing factors, methods to control for confounding, and use of multi-variable analysis, if appropriately conducted, will be rated more highly. Longitudinal design, especially with regard to preferences, will be more highly rated.

For qualitative studies, criteria will include credibility of findings (transparency, coherence, resonance with other knowledge, and corroboration/triangulation), rationale and appropriateness of design, degree of coverage (details of coverage, maximising inclusion, reasons for non-participation, discussion of access), transparency of reporting, rationale/rigor in analysis, and context/interpretation.

Study grading

Grading of evidence will be undertaken 1) at the level of each included study, and 2) to grade the synthesized evidence addressing each review question. Individual studies will be graded using criteria developed to evaluate evidence for the National Service Framework for Long Term Conditions (77). These reflect clinical research which addresses the challenges of research in long term conditions (the nature of complex interventions, small numbers within studies, and often impaired capacity of participants), similar to the challenges of research near to the end of life. 2) Overall strength of evidence for each review question will be deduced using the same typology (77).

DATA SYNTHESIS

(not yet completed)

Findings will be summarized descriptively, and conclusions drawn as to the quantity, quality, and strength of the evidence, for each review question in turn. In addition:

1. *What is the prevalence of a home death preference?* Data on prevalence of preference will be grouped and mean prevalence weighted by study size and range will be reported.
2. *How does this preference (and the evidence relating to it) vary by age, type of disease stage of disease, and co-morbidity?* Evidence will be broken down by age, type of disease, stage of disease (early or late stage), and (where available) co-morbidity. We will make comparisons across the six non malignant diseases: Chronic Cardiac Failure (CCF), Chronic Obstructive Pulmonary Disease (COPD), Dementia, Stroke, End-stage Chronic Kidney Disease (ESKD), Long-term Neurological Conditions, [as defined for the National Service Framework for Long Term Conditions (80): motor neurone disease (MND), multiple sclerosis (MS), Parkinson's disease (PD), multiple systems atrophy (MSA), and progressive supranuclear palsy (PSP)]. Evidence in other diseases will be reported more briefly. For CCF, COPD and ESKD, late stage disease will be defined as Class III & IV New York Heart Association classification (for CCF) (78), Stage III & IV disease (for COPD) (79), end-stage disease (for chronic kidney disease) (80). For dementia, stroke, or progressive degenerative neurological conditions, this analysis may not be possible, in view of the lack of distinction or consensus on stages of disease in the literature.
3. *What determines, shapes, or changes preferences for place of care and place of death?* For this largely qualitative evidence, a meta-ethnography will be undertaken, if feasible. This is a rigorous procedure for deriving substantive interpretation from any set of ethnographic or interpretative studies (81). Findings from included qualitative studies will be coded and summarised, with consideration of the quality assessments for the individual studies. Findings on preferences will then be integrated in order to summarize the available evidence and also provide new insights from the process of integration itself, while retaining the character and essence of the observations from participants in the studies or made by the authors of the studies.
4. *What factors are associated with actual place of death?* We will group factors according to the theoretical model (Figure 1b) and analyse for the

direction of effect (for and against home death) and consistency of findings (number of studies reporting the effect out of total studies included). We anticipate being able to undertake only a limited meta-analysis, because of heterogeneity between study populations. If the volume of evidence allows, we will also compare direction and consistency of factors between diseases, and according to other key variables (age, proximity to death, and type of disease). We will aim to extract odds ratios (if available) reported in included studies for those factors supported by sufficiently strong evidence. We will also conduct a sensitivity analysis to determine if a different grading threshold alters findings.

5. *How do health and social care resources influence actual place of death?* We will analyse included studies relating to health and social care resources, again for direction of effect (home or hospital) and consistency (number of findings reporting the same effect out of the total number of studies), but also report the relative impact of different health and social care resources, using odds ratios where sufficiently strong evidence exists.
6. *What are the key transitions in care at the end of life?* We will describe the key transitions identified, and the evidence which supports this.
7. *What influences these transitions?* Again, for this largely qualitative evidence, a meta-ethnography will be undertaken, if feasible. Findings from included qualitative studies will be coded and summarised, with consideration of the quality assessments for the individual studies. Findings on transitions in care will then be integrated in order to summarize the available evidence.

In a final step, conclusions will be drawn about the extent of the evidence and gaps in it. This will be aided by the Knowledge Exchange Seminar, in which findings on each individual research questions (including the quantity, quality. and strength of the evidence) are presented to policy-makers, commissioners and care providers, and conclusions are jointly derived as to evidence gaps.

APPENDIX 1

Participants in the consultation to develop the theoretical model

Title	Surname	Name	Position	Area of expertise and input into the theoretical model
Prof	Banerjee	Sube	Professor of Mental Health and Ageing, Institute of Psychiatry and Clinical Director MHOA, South London and Maudsley NHS Foundation Trust Head, Centre for Innovation and Evaluation in Mental Health	Dementia
Dr.	Bausewein	Claudia	Cicely Saunders Foundation Research Fellow	Breathlessness, COPD
Mrs	Blackwell	Kara	Head of Nursing for Cancer and ***Palliative Care,*** King's College NHS Trust	Transitions
Dr	Burman	Rachel	Consultant in Palliative Care/Hon Senior Lecturer, King's College NHS Trust	Long Term Neurological Conditions
Ms	Gomes	Barbara	Research Associate, KCL	Factors affecting place of death; analysis; research; systematic reviews
Dr	Gysels	Marjolein	Senior Research Fellow, Associate Research Professor	Qualitative research; Breathlessness; Chronic Obstructive Pulmonary Disease (COPD)
Mrs.	Hansford	Penny	Director of Nursing, St. Christopher's Hospice; Management Fellow with the project	Dementia; Various aspects of palliative care
Prof.	Higginson	Irene J	Head of Department, Professor of Palliative Care and Policy, Honorary Consultant King's College Hospital	All aspects of palliative care
Dr	Jackson	Diana	Senior Research Fellow, King's College London	Long Term Neurological Conditions
Dr	Johnston	Bridget	Senior Research Fellow, Cancer Care Research Centre, University of Stirling	Health policy, Palliative care nursing perspective
Prof	Kalra	Lalit	Professor of Stroke Medicine, King's College London	The acute treatment of patients with stroke and their rehabilitation; prevention of stroke and reducing risks
Prof	Murray	Scott	St Columba's Hospice Chair of Primary Palliative Care, Primary Palliative Care Research Group, Centre for Population Health Sciences, University of Edinburgh	All aspects of palliative care, and special interest across all non malignant conditions
Dr	Murtagh	Fliss	Consultant and Clinical Senior Lecturer in Palliative Care, Systematic Review Project lead, KCL	End Stage Chronic Kidney Disease; All aspects of palliative care
Dr	Petkova	Hristina	Research Associate, KCL	Qualitative Research; Health care policy

Mrs	Sam	Emily	Deputy Director of Policy Development The National Council for Palliative Care, NCPC	Parkinson’s Disease; Health care policy
Dr	Shipman	Cathy	Senior Research Fellow, KCL	Palliative care in primary care; patient experiences and preferences; medical sociology, transition to community settings; Qualitative Research; Health care policy
Dr	Simon	Steffen	Research Fellow, King's College London	Palliative care for non-malignant conditions; Stroke; Chronic Heart Failure, Breathlessness
Mrs	Shepherd	Kate	Nurse, King’s College NHS Trust	End Stage Kidney Disease
Mrs	Stacpoole	Min	Southwark Primary Care Trust,	Dementia, Palliative care nursing
Prof	Turner-Stokes	Lynne	Herbert Dunhill Chair of Academic Rehabilitation	Long Term Neurological Conditions
Dr	Williams	David	Research Associate, King’s College London	Replacement (respite) care among carers of people with long term neurological condition

In addition the Management Fellow organised two focus groups of relevant clinicians for discussion and feedback.

APPENDIX 2: FINAL SEARCH STRATEGY

The terms used in the final search strategy are presented in Table 3:

Table 3: Terms used for the final search strategy
(these are refined and adapted to each electronic database)

CRITERIA APPLICABLE ACROSS CONDITIONS	
(1) Advanced disease terms and their synonyms	palliative care OR terminal care OR terminally ill OR hospice OR end-of-life OR (advanced adj3 (disease or condition or illness)) OR (progressive adj3 (disease or condition or illness))
(2) Factors influencing the outcomes	demography OR population OR birth OR (stage or phase) of disease OR co-morbidity OR (quality of life) OR (daily activity) OR (functional status) OR prognosis OR (life expectancy) OR (health service) OR facilities OR rehabilitation OR respite OR access OR cost OR (resource allocation) OR compensation OR (social care) OR caregiver OR relative OR family OR support OR spiritual OR ethnicity OR culture OR hospitalization OR (social environment) OR rural OR urban OR attitude OR preference OR choice OR priority Or factor OR determinant OR predictor OR effect OR influence OR cause OR (transition or transfer or change or referral or move) OR (communication or language) OR (minority or group*) OR (advance care plan*) OR ACP OR (living will) OR (clinical pathway)
(3) Outcomes	(place adj3 (care or caring or death or dying)) OR (site adj3 (care or caring or death or dying)) OR (location adj3 (care or caring or death or dying)) OR (setting adj3 (care or caring or death or dying)) OR (change adj3 (care or place or site or location or home or hospital or hospice or setting)) OR (transition adj3 (care or place or site or location or home or hospital or hospice or setting)) OR (admission adj3 (care or place or site or location or home or hospital or hospice or setting)) OR (admission adj3 (care or place or site or location or home or hospital or hospice or setting)) OR (home or house or flat or residence or dwelling) OR (nursing home) OR (care home) OR (day care) OR facility
SPECIFIC DISEASE TERMS	
(4) COPD	(chronic obstructive pulmonary disease) OR chronic obstructive lung disease) OR COPD
(5) CHF	chronic heart failure OR chronic cardiac failure OR congestive heart failure OR CHF OR CCF
(6) Dementia	Dementia OR alzheimer's disease
(7) ESKD	Chronic kidney failure OR Chronic Kidney Disease OR CKD OR chronic renal failure OR end stage kidney failure OR end stage renal failure
(8) LTNC	amyotrophic lateral sclerosis OR motor neuron disease OR ALS OR MND OR multiple sclerosis OR Parkinson's disease OR multiple system atrophy OR progressive supranuclear palsy OR Huntington's chorea OR Huntington$
(9) Stroke	Stroke OR cerebrovascular disease OR brain ischemia OR brain hemorrhage OR brain infarction

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