Transitions between services at the end of life for older people - patient and provider perspectives

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1. Aims/Objectives:

The aim of this project is to understand the patterns and causes of health service transitions and their association with older people’s experiences at the end of life.

The main objectives are:

- To map transitions in and out of hospital at the end of life for older people in England and estimate the financial costs.
- To identify individual and service level factors associated with frequency of transitions.
- To explore the effect of transitions towards the end of life on health status, quality of life, symptom control and satisfaction with care.
- To understand the factors that influence decisions about transitions in the nature and location of care.
- To elicit patient, bereaved carer and provider views on the appropriateness of different transition patterns and the factors that constrain or shape decisions.

2. Background:

The last year of life is a time of high service utilisation for older adults and represents a high proportion of older adult care. The number of deaths at older ages is increasing significantly in the UK. More than two thirds of the population can now expect to be over 75 years old when they die (Office of National Statistics, 2002). By 2030, over 40% of people in the UK will die when they are over 85 years old (Gomes & Higginson, 2008). The proportion of people admitted to hospital in their last year of life rises with age, and in a longitudinal study from a German sickness fund, over 80% of people between the ages of 55 and 84 were admitted to hospital in the 12 months before they died (Busse et al. 2002). Over the age of 85 years, people are less likely to be admitted to hospital in their last year, but when they do, they stay for longer periods than younger adults (Henderson et al. 1990). Although improved detection and treatment of disease means that some older adults are surviving with multiple co-morbidities and complex health care needs, recent decades have seen reductions in morbidity and functional decline amongst older adults (Fries 1983; Fries 2005; Mor 2005). Increasing survival has not invariably led to more years of sickness and disability and the total time spent in hospital at older ages has not increased (Busse et al. 2002; Himsworth & Goldacre 1999; Dixon et al. 2004). Predictions of rapid increases in the costs of end-of-life care may, therefore, not be realised, but the sheer number of older decedents will mean that costs are considerable. Findings from time-to-death cost analyses are not entirely consistent across different health systems and study methodologies. Generally, approaching death is associated with increased health service expenditures, and costs of care for decedents are greater than for comparable survivors (Roos et al. 1987; Werblow et al. 2007; Zweifel et al. 1999; Seshamani & Gray 2004; Breyer & Felder 2006). In some countries, this effect is diminished in extreme old age, which may result from substitution of care in other settings for hospital admission (Seshamani & Gray 2004; Hogan et al. 2000). The
overall effect of increased survival appears to be to delay the years of high spending to the end-of-life, with some shift away from acute care costs (Payne et al. 2007). There are no national studies from the UK, and extrapolation from health systems in North America and Europe to the National Health Service (NHS) should be cautious. Nevertheless, it is clear that ensuring that care provided in the last year of life is appropriate and of high quality has great potential to make a significant contribution to improving patients’ experiences of the NHS, and promote prudent use of resources.

3. Need:

This study will provide the first national estimate of transitions and hospital resource use in the last year of life, enhance our understanding patients’ experiences and the consequences of transitions. It will provide insights into the perspectives of service commissioners and providers, including the challenges that constrain their work. The synthesis of data from the component parts of the study will enable us to clarify the implications of our findings for the NHS, and make evidence based recommendations for change.

4. Methods:

a. Setting
A three phase study is planned, using mixed methods to analyse routine quantitative data, conduct and analyse in-depth interviews with older people (30), conduct and analyse semi structured interviews with bereaved carers (90) and conduct and analyse telephone interviews with health professionals (40). Each phase is described in further detail in ‘Plan of Investigation (6)’

b. Design
See Plan of Investigation (6)

c. Data collection
See Plan of Investigation (6)

d. Data analysis
See Plan of Investigation (6)

5. Contribution of existing research:

What is already known?
Qualitative work exists to suggest that transitions may be determined by systems imperatives, primarily costs, rather than quality-of-life outcomes (Cartier, 2003; Kralik et al. 2006; Larkin, 2007). They are also known to have a deleterious effect on a person’s sense of personal identity (Rogers et al. 2000). In-depth longitudinal analyses of interviews with a sample of older cancer patients living in the North West of England indicates that most had preferences of hospice or home deaths but that transitions in place-of-care were highly dependent upon availability of family carers and patterns of symptoms (Thomas, 2005). Many people in this study died in hospital, despite their wishes, and this had a negative impact on families’ views of the death. Large-scale empirical work to map the number, frequency and nature of transitions is lacking. A small number of studies outside of the UK have shown that it is possible to estimate the number of transitions at the end-of-life on a large scale. They all suggest that movement between settings is common and happens near to death. A study of 882 non sudden deaths in Belgium found that only 37% of people were not transferred between settings in the last three months of life. Of all the
patients who were transferred, 80% moved within the last month and 33% within the last week (Van den Block et al. 2007). In the Netherlands, half of the 270 decedents in the Longitudinal Aging Study Amsterdam were transferred in the last three months of life, and 39% of transitions were within a week of death (Klinkenberg et al. 2005). In the US, more than half of a representative sample of cancer decedents were transferred between settings in the last month of life. More importantly these movements did not result in any improvement in the reporting of distressing pain (Trask et al. 2006). The proposed study will consider three conditions, lung cancer, heart failure and stroke that are the focus of current NHS policy. They differ in their disease trajectories and in the extent to which specialist palliative and terminal care services are available, ranging from comprehensive care for lung cancer to limited facilities for people with stroke. The applicants' clinical experience in the NHS leads us to a hypothesis that transitions in place-of-care near to death may be determined by factors in the provision and delivery of services rather than the best interests of the patient and their caregivers.

6. Plan of Investigation:

**Phase 1.**

**Quantitative analysis of linked mortality - hospital episode statistics (HES) data for England.**

**Overview**

In England, the Office for National Statistics registered deaths data from 2001 have recently been linked to Hospital Episode Statistics (HES) data. The proposed study will be the first to utilise these linked data for England to:

- Analyse movement into and out of hospitals at the end of life, from home, residential or nursing care and hospice.
- Identify demographic, diagnostic and geographic factors associated with frequent admissions near to death.
- Identify typical patterns of patient transitions at the end of life for the three diagnoses
- Estimate hospital end of life care costs in England. Data will be obtained via the NHS Information Centre for Health & Social Care.

**Study population**

Analysis will be restricted to all people in England aged 75 years and over who died in the years 2001-[2008 or most recently available year of data], with a certified underlying cause of death of either lung cancer or stroke or heart failure. For certified heart failure deaths, we will also include those where heart failure was a contributory cause of death. The applicants' previous work on death certification indicates that underlying cause alone would underestimate the burden of heart failure deaths by up to 80%, (Hanratty et al. 2007; Goldacre et al. 2005) whilst having minimal effects on the ascertainment of lung cancer and stroke deaths (Goldacre et al. 2004; Goldacre et al. 2005). Overlap between heart failure and the other causes of death is expected to be small (Goldacre et al. 2003). Selection of the study population by cause of death will include some sudden deaths and those who died soon after or during first admission to hospital (Cleland et al. 2002; Goldacre et al. 2004). However, analysis of national data over five years will provide a sufficiently large sample to enable us to build a robust picture of transitions at the end of life.

**Data analysis**

Date of death will be ascertained for all patients, and data analysed which relate to the last 12 months of life. The decedents will be grouped according to their certified
cause of death and compared using the following variables: number and type of admissions to hospital, source of admission and discharge destination, length of stay, diagnoses at discharge, length of time between discharge and death, place of death. Multivariate analyses will be employed to explore the associations between the frequency of transitions and pre-specified factors. The costs of hospital care used by each group of decedents will be estimated by applying the cost per average bed day from Standard NHS reference costs to the number of bed days used by decedents (Department of Health, 2007).

**Phase 2a. Patient perspective on end of life transitions - an in-depth interview study (30 patients)**

**Overview**

Interviews with 30 patients, thought to be in their last year of life, will help us understand how different transition patterns identified in the first phase of the study (analysis of linked mortality and hospital data for England) affect patients and their families. Qualitative data to be collected will include: the number and nature of transitions in the preceding three months; receipt of services; perception of pain control and quality of life; the person’s understanding of the aims of any service contacts or interventions in the preceding three months, their perspectives on appropriateness of transitions; their perception of distress/benefits resulting from a given transition.

**Study population**

We will interview 30 people aged over 75 years, who fulfil the following criteria:

- They have been given (and are aware of) a diagnosis of lung cancer, heart failure or stroke and are well enough to be interviewed.
- They have experienced a transition between care settings in the last three months (e.g. admitted to, or discharged from hospital, care home or hospice or moved to live with relatives).
- The responsible clinician believes that their survival may reasonably be expected to be fewer than twelve months.

**Exclusion criteria:**

- Mental or physical condition means that they are unable to participate in an interview
- Inability to be interviewed in English
- Significant cognitive impairment

**Recruitment process**

The participating clinical teams will support the research team by:

- Identifying suitable patients aged 75 and above who have a diagnosis of lung cancer, heart failure or stroke.
- Passing written information about the study to the patient, which invites them to participate in an interview.

Potential interviewees who are hospital out-patients or in-patients will be given an information sheet and brief verbal explanation by their nurse or doctor. They will be invited to indicate their willingness to be interviewed by contacting the researcher by telephone or post. The most appropriate, least disruptive way of maintaining contact.
with the clinical team will be agreed at the beginning of recruitment. For example, the research assistant may be available after weekly multidisciplinary team meetings, when potential participants may have been identified. For all patients, there will be no uninvited telephone calls or approaches by post after the first invitation to participate.

Phase 2b. Carer perspectives on end-of-life transitions – A structured interview study

Overview
In order to gain insight into the patients’ experience of end of life transitions, we will conduct a mortality follow-up survey of bereaved respondents of people with a certified cause of death of lung cancer, heart failure or stroke. This will help us understand how different transition patterns identified in phase 1 affect patients and their families. Using methods and tools that have been developed and validated over many years by one of the applicants and others, (Addington- Hall & McCarthy, 1995; Seale & Cartwright, 1994; Cartwright et al. 1973) with specific questions that have been used to explore transitions in the USA, (Trask et al. 2006) we will collect structured data on:

- The number & nature of transitions in the last three months of life
- Receipt of services
- Perception of pain control
- Perception of quality of life

Less structured data will be collected on the respondents' understanding of the aims of any service contacts or interventions in the last three months of life, their awareness of their relative or friend’s position on the disease trajectories, their perspectives on appropriateness of transitions; their perception of distress/benefits resulting from a given transition and the decisions underlying them.

Study population
We will work with general practices to identify caregivers for people aged 75 years and above who died in two geographically distinct NHS regions (North West and South Central). Causes of death will be lung cancer, stroke and heart failure, as in phase 1. All patients will have experienced at least one transition in the final three months of life.

Recruitment procedures
Caregivers will be identified by primary care health professionals. A letter will be sent from the general practice to the next-of-kin, to introduce the study and locate the principal carer. Caregivers who are interested in participating will be invited to opt into the study by post. This will prompt an explanatory telephone call from the research team, prior to a meeting at a place of their choice. We will aim to conduct face-to-face interviews with 90 caregivers. Previous experience suggests that up to 180 bereaved carers may have to be approached to achieve this sample size (Elkington et al. 2004). Taking into account the annual death rate for the specified conditions (Office of National Statistics, 2004) and anticipated participation rate, this should be feasible within the study timescale, over the two health regions. The agreement between bereaved respondent and patient views in end-of-life research is known to be best for service use, satisfaction and observable symptoms, (Addington- Hall & McPherson, 2001; McPherson & Addington-Hall, 2003) which are most important to this study. Respondents also recount their own concerns, which are important in their own right.
Face-to-face interviews are appropriate for a survey of older adults and they produce a more complete dataset than postal questionnaires (Addington-Hall et al. 1998). Standard descriptive statistics will be calculated from the data gathered by questionnaire, and analysed using STATA (2008). The interviews will be transcribed and analysed using Framework, a matrix based approach to qualitative data management (Richie & Spencer, 1994). One of the researchers will have lead responsibility for the analysis, with the lead applicant, assisted by the second researcher. All the applicants will read a sample of transcripts. Initial and developing analyses will be discussed at study management meetings.

Retrospective accounts have a range of well-recognised potential methodological limitations, (Addington- Hall & McPherson, 2004) but they offer an ethically acceptable, practical means of studying the period before death. Inviting participants to opt into the study may introduce some bias into the sample, but other approaches are unlikely to gain approval from Research Ethics Committees. The applicants have extensive experience with these methods. One of the co-applicants (JAH) developed the ‘VOICES’ survey, (Young et al. 2007) which has been used across the world, and will be adapted for use in this study. ‘VOICES’ has been shown to be able to detect changes over time and differences in care study. ‘VOICES’ has been shown to be able to detect changes over time and differences in care quality and patterns of service delivery between settings.

We underestimate neither the sensitivity of the data required to initiate the study, nor the care needed in approaching bereaved respondents, and have expertise and experience in both. In previous work, the applicants have developed effective, sensitive strategies to minimise distress to participants. The psychological well being of the researchers will be safeguarded with regular de-briefing and if required, access to specialised counselling support within the employing university.

**Phase 3. In depth interviews with providers and commissioners**

**Overview**

Interviews will be conducted with commissioners and providers of end of life care for older adults in the North West Region. Data provided by participants in phase 2 will be summarised into short clinical scenarios, chosen to be representative of differing transition patterns. These will be used to initiate an interview to:

- Elicit professional perceptions of what is happening in practice, with respect to transitions in place and modes of care for each of these disease groups at the end of life.
- Explore the models of care they believe to be operating in their health economy.
- Explore the models used to categorise older adults at the end of life and factors that should initiate a transition.
- Explore awareness of any critical incidents described spontaneously or prompted by the clinical scenarios from phase 2.
- Compare what the professionals believe to be happening with the current national strategies for each disease group.
- Elicit barriers and facilitators of good end of life care for each disease group.

**Study population**

Interviewees will be selected to represent the pathway from commissioners at PCT and local authority level, through the management of services, to care delivery in the home and hospital. Local structures may vary, but interviews will include board level representation of the PCT and Local Authority, service managers in health and social care, specialist and district nurses, and social service providers. Doctors in general
practice and hospital elderly care will also be approached. The total number of interviews will not exceed forty. This sample size will be sufficient to enable the collection of rich qualitative data while also representing the diversity of stakeholders’ roles and perspectives.

Data analysis for qualitative phases
These methods of collecting and analysing data are well developed and provide nuanced accounts that shed light on the implementation of policies and practices at ground level (Payne et al. 2002). Two of the co-applicants (SP and JS) have extensive experience in these techniques and will lead this phase. The interviews will be transcribed in full, checked for accuracy and coded using the Framework approach. This method of analysis will generate a comprehensive account of the data which will be linked, where possible, to phase 2 findings.

The Framework approach enables the mapping of a complex matrix of factors both within and across disease categories to identify commonalities and differences. The project advisors from within the health service will be asked to participate in the validation of our interpretation and analysis of data. The limitations of qualitative interviews are well recognised, including social desirability, language competence and former relationships (Payne, 1999). However they are a cost effective way to elicit comprehensive accounts from service providers and all new issues to emerge. This phase will provide insight into normative perspectives on appropriateness of transitions, what the aims of any service contacts are at different points in disease trajectory, the factors they consider important when making decisions on the level of care and intervention needed.

7. Project Management:

The Chief Investigator is Dr Barbara Hanratty, Clinical Senior Lecturer in Population and Community Health, University of Liverpool.

The co-applicants of the project are:

- Professor Julia Addington-Hall, Professor in End of Life Care, University of Southampton,
- Professor Michael Goldacre, Professor of Epidemiology, University of Oxford
- Dr Gunn Grande, Senior Lecturer in Palliative Care, University of Manchester,
- Professor Jane Seymour, Professor of Palliative and End of Life Studies,
- Professor Sheila Payne, Help the Hospices Chair in Hospice Studies.

The Chief Investigator will oversee the day to day running of the project, and directly supervise two research assistants, who will work on the project full time. The co-applicants will meet with the CI and researchers at quarterly day long meetings, and have more informal, regular meetings via telephone conferences and email correspondence.

8. Service users/public involvement:

This proposal focuses on engagement with three key groups;

1. Collaboration with members of the public in developing the research started with discussion of the research idea. Four of the applicants are members of the NCRI-funded Cancer Experiences Collaborative (CECo) Older Adults Theme, an initiative funded to develop research capacity and quality in palliative and supportive care. The
CECo older adults research partners group have contributed to the development of the research questions and refinement of the methods, and will join in a project advisory group.

2. The applicants have a range of long standing relationships with non-governmental organisations that represent public and patient interest, who form our second key stakeholder group. Consultation with organisations such as Help the Hospices and Help the Aged will complement the ongoing collaboration with service users; provide different perspectives, and an additional means of disseminating our findings.

3. Ruth Hussey, Regional Director of Public Health, NHS North West is an advisor to this project. She will provide a vital link to policy makers and high level management within the National Health Service, in addition to ensuring that our research is highly relevant to service delivery.

9. References:


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