Transitions at the end of life for older adults – patient, carer and professional perspectives: a mixed-methods study

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Scientific summary

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Background

As life expectancy increases, older adults are living and dying with multiple conditions. Health-care needs are therefore complex, and care may be delivered by a range of professionals in different settings. At the end of life, a move into or out of hospital, a care home or a hospice is, potentially, one of the most disruptive events for an older adult, with consequences for the mental, physical and emotional well-being of the older adult and lasting memories for their family. Older adults' experiences as they move between places of care offer an opportunity to explore the extent of coherence and integration at interfaces between professionals, services and approaches to care, from the perspectives of the care recipient and their family. Ensuring that the experience for the patient is co-ordinated, and that any moves are defined by individual needs rather than by system imperatives, is crucial to their well-being. Existing evidence from outside the UK suggests that such transitions occur frequently in the months before death, contribute little to improving symptom control or well-being, and may be a source of distress to patients and unnecessary costs to services. This study sought to combine the perspectives of patients, family carers, providers and commissioners of care with analysis of activity data to understand the influences on, and consequences of, transitions between settings for older adults at the end of life.

Objectives

The aim of this study was to understand the experiences of, influences on and consequences of transitions between settings for older adults at the end of life, using heart failure, stroke and lung cancer as exemplar conditions. It addressed the following research objectives:

- to explore the effect of transitions towards the end of life on patient and carer experiences, including 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 and provider views on the appropriateness of different transition patterns and the factors that constrain or shape decisions
- to describe transitions in and out of hospital at the end of life for older people with lung cancer and heart failure in England
- to identify individual- and service-level factors associated with frequency of transitions.

Methods

This was a mixed-methods study, composed of four parts:

1. in-depth interviews with older adults in the last year of life, diagnosed with heart failure, lung cancer or stroke
2. qualitative interviews and structured questionnaire with bereaved carers of older adult decedents
3. telephone interviews with commissioners and providers of health, social care and ambulance services, with case scenarios derived from the interviews with carers
4. analysis of linked Hospital Episode Statistics and mortality data.

Participants and methods

Three groups of participants were recruited to this study:

1. **Patients**: thirty adults aged 69–89 years living in the north-west region with heart failure, lung cancer or stroke recruited via secondary care physicians and specialist nurses and judged to be in the last year of life. (The referring health professional answered 'no' to the question 'would you be surprised if this patient was to die within 12 months?'.) Patients were provided with written information about the study by health professionals and invited to contact the research team to opt in to the study.
2. **Bereaved carers**: one hundred and eighteen bereaved family carers of older adults who died in the previous year with heart failure, lung cancer or stroke (and small numbers with chronic obstructive pulmonary disease, breast and colorectal cancers). Participants in the north-west, south-central and south-west regions were identified and invited into the study by the general practitioners (GPs) of decedents. Around half of the participants were from the same generation as the decedent, and half were intergenerational carers.
3. **Health, social care and ambulance service providers and commissioners**: forty-three professionals (senior managers, consultants, GPs) were recruited by direct approach to heads of departments in relevant organisations, known contacts of the research team and self-referral following publicity about the study in professional and organisational networks in the north-west, south-central and south-west regions.

Qualitative in-depth interviews

Face-to-face qualitative in-depth interviews were conducted with patients and carers using separate topic guides. Professionals were interviewed by telephone in most cases, using a topic guide and case scenarios constructed from the data collected from carers. All interviews were recorded and transcribed verbatim. The data were analysed using a framework approach.

Structured questionnaire

A structured questionnaire, based on the validated 'VOICES' survey, was completed with bereaved carers and analysed with descriptive statistics.

Quantitative analysis of linked hospital and mortality data

Data were obtained on hospital admissions in the last year of life for people who died in England, aged over 75 years with a diagnosis of heart failure or lung cancer, between 2001 and 2010. Patterns in use of hospital care in relation to time to death were described by socioeconomic status and diagnosis.

Research findings

Qualitative interviews

- **Patients' and carers' experiences** of transitions were of a disjointed system, in which organisational processes were prioritised over individual needs. Carers felt unheard and unsupported, with little control or opportunities for effective advocacy.
- **Carers** were pivotal to patients' experiences across transitions, but there was no shared understanding with professionals of their role, experiences or expectations. Many of them lacked the knowledge and support to fulfil their role as they would like. There was a particular need for more support in arranging transfers to care homes. Patients perceived carers to be a flexible and essential component of their end-of-life care. Carers switched from being a service provider and co-ordinator, when the patient was at home, to a visitor role when the patient went into hospital. Staff had dichotomised views of carers, as either patients in their own right, requiring help, or resources who smooth the professionals' path.

- **Choice** was not a concept recognised by patients or carers, and a mismatch was observed between the rhetoric of choice and the selective application of end-of-life policies. Choice was offered to patients and carers by some staff, only if they were expected to make a professionally approved selection. An ability to purchase services could influence the timing and nature of transitions.
- **Out-of-hours GP services and care homes** were perceived by many to be promoters of transitions at the end of life. Care homes' isolation from the NHS, staff confidence and training were proposed as potential causes.
- **Older people without carers or those living alone** were restricted in their care choices, and it was widely acknowledged by staff that their care might have been disadvantaged by their circumstances.
- **GPs** saw themselves as central figures in end-of-life transitions. Other disciplines and carers concurred with this, but were critical of their abilities and expertise. Much of the conflict arose from different views on the importance of adhering to guidelines and protocols.
- **The quality of relationships and communication across settings** and between health and social care was identified by carers as an important influence on patients' experiences of transitions. Interviews with professionals highlighted differences in speed of working and approaches to patients or clients, as well as language and culture. Co-location was perceived to help build stronger relationships. The **dominance of the medical model** in end-of-life care was felt by those in social care to be a barrier to creating close working relationships between health and social care.
- **The impact of interprofessional tensions** on their own work was keenly felt, but the effect on patients' transitions went unacknowledged by staff.

The qualitative data identified patient, health service and interface factors that were associated with more frequent or problematic transitions, as follows.

Patient factors

- Older age.
- Absence of a carer.
- Unanticipated deterioration in health status.
- Non-cancer diagnoses.

Health service factors

- No ongoing relationship with a GP.
- Contact with out-of-hours doctors leading to hospital admission.
- Professionals' ability to prognosticate and communicate.

Interface factors

- Structural factors such as separate health and social care budgets.
- Differing approaches to protocols and guidelines.
- A lack of shared responsibility for patients across settings.
- Provision of information and support to aid family decisions.

Questionnaire with carers

Analysis of the structured questionnaire produced findings supportive of the qualitative data analysis, with positive views of staff but less satisfaction with overall experiences of transitions. Most decedents spent time at home in the last year of life, and were admitted to hospital at least once. One in five decedents in this study spent some time in a care home. A majority of hospital admissions were prompted by worsening symptoms or collapse (56%), and one in four respondents reported a change in quality of life (23%) or health status (24%) as a result of the transition. The GP was the main contact person for most families and the care they provided was rated highly. However, fewer than one in five respondents (17%) felt that all of the health and social services in the community worked well together (at least to some extent) and one in three (32%) reported that all or most of the community staff knew enough about the decedent's condition. One in four (25%) carers reported that they did not discuss their concerns as much as they would have liked, and a similar proportion were involved a little, or not at all, in decisions about care. Overall, a minority of carers reported that health and social services were not well co-ordinated (31%) but only 22% felt that any of the transitions in the last 3 months could have been avoided.

Use of hospital services in the year before death

Analysis of linked Hospital Episode Statistics and mortality data quantified the number of hospital transitions experienced by older adults in the last year of life. Between 2001 and 2010, 300,304 people aged over 75 years were admitted to hospital in England at least once in their last year of life with a diagnosis of lung cancer or heart failure. The median number of admissions per decedent in the 12 months before death was 1.0 (range 1–29 lung cancer, 1–39 heart failure). Eighty-five per cent of lung cancer patients and 72% of heart failure patients underwent a transition into hospital in the last 3 months of life. In multivariate analysis for heart failure cases, lower socioeconomic status, given by the Index of Multiple Deprivation (IMD), being male and younger age were associated with numbers of hospital admissions above the 90th centile. For lung cancer cases, younger age and male sex were associated with numbers of admissions above the 90th centile. People with lung cancer in the most disadvantaged IMD quintile were less likely to be admitted frequently, adjusting for age and sex. In this data set, residence in a care home was not associated with frequent admissions to hospital.

Implications

This study identified deficiencies in care across transitions for older people at the end of life, and a number of areas where intervention may enhance patient and family experiences. Transitions between settings occurred near to death and were characterised by a reliance on family members to co-ordinate the input and fill the gaps between services. In contrast to studies of end-of-life transitions in other countries, the organisation and way in which services were delivered were a greater cause of concern than other aspects of care, such as symptom control. Some of the issues noted, such as communication and providing care with dignity, were important to all patients, not only in relation to transitions. Others, such as the need for a shared responsibility for patient care in interprofessional working, were more specific to transitions. Patients described diverse experiences of care, whereas many of the challenges reported in carers' accounts were common to all.

One of the most important findings of this study was the observation that carers' experiences are similar to historical accounts, despite the introduction of relevant policies. There is a need among health and social care professionals to agree on and promote the role of caregivers in transitions. The data also point to the benefits of clarifying responsibilities for co-ordinating care from multiple sources and promoting self-management in care towards the end of life, as this is the preference of patients and families.

Our investigation into the care of older adults undergoing transitions at the end of life complements studies of transitional care for older adults from the USA. Combined with the existing literature, it provides a robust foundation for the design of an intervention appropriate to the NHS context that will enhance care across transitions for older adults with palliative care needs.

Recommendations on priorities for future research

Our findings suggest that the following should be high priorities for future research:

1. Investigation into why the experiences of end-of-life carers appear to be unchanged, despite the implementation of several relevant policies in recent years.
2. Exploration of the acceptability, potential scope and ways of facilitating self-management with patients and carers, to reduce unnecessary end-of-life transitions.

3. Exploration of the consequences for patients and families of interprofessional tensions and identifying ways to reduce them. This should include questioning or affirming the centrality of GP care.
4. Finding ways to ensure that people who live alone, or without carers, exercise choices and receive equitable end-of-life care.
5. Identification of any unmet needs for training for professionals involved in co-ordinating end-of-life care across settings.
6. Development and testing of an intervention to enhance patients' experiences across transitions. Our findings suggest that interventions in the following areas may offer the greatest potential benefits:

    - harmonising understanding of the carers' role and enhancing their ability to influence patients' experiences of care in hospital settings
    - improving carers' and patients' abilities to recognise deteriorating health and pre-empt an urgent need for a transition
    - promoting communication between professionals that is timely and crosses settings
    - developing models for shared responsibility for patients across settings.

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