Original Article

Older Adults’ Experiences of Transitions Between Care Settings at the End of Life in England: A Qualitative Interview Study

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Abstract

Context. Providing care that is shaped around the needs of patients, carers, and families is a challenge in the last months of life, as moves between home and institutions may be frequent. Despite this, there have been few studies of end-of-life transitions in the U.K.

Objectives. To explore older adults’ experiences as they move between places of care at the end of life.

Methods. In-depth qualitative interviews and thematic analysis of the data were performed. Thirty adults aged between 69 and 93 years took part. All were judged by their physicians to be in the last year of life, diagnosed with heart failure (13), lung cancer (14), and stroke (3). Sixteen participants were from the lowest socioeconomic groups.

Results. Four themes were identified from the data relating to 1) the prioritization of institutional processes, 2) support across settings, 3) being heard, and 4) dignity. As they moved between different settings, much of the care received by older adults was characterized by inflexibility and a failure of professional carers to listen. Liaison between and within services was not always effective, and community support after a hospital admission was perceived to be, on occasions, absent, inappropriate, or excessive.

Conclusion. Qualitative study of transitions provides valuable insights into end-of-life care, even in countries where there are few financial barriers to services. This study has highlighted a need for continued attention to basic aspects of care and communication between professionals and with patients.

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Introduction

As life expectancy has increased, the end of life is increasingly associated with comorbid conditions, frailty, and smaller family units to provide support.\(^1,2\) For many people, the last few months of life involve the most intensive contact with health and social services.\(^3,4\) Evidence from the U.S. indicates that transfers between care settings are frequent at this time but may produce little improvement in symptom control or quality of life for patients.\(^5,6\) Each transfer represents a potential threat to continuity and safety of care.\(^7\) The availability of information on past events, knowledge of the individual personal and social context, and a consistent approach to management are all important aspects of continuity of care that may be lost when someone is admitted to or discharged from institutional care.\(^8\) An older adult with complex health care needs is likely to be particularly sensitive to the consequences of inadvertent alterations to their care, for example, failure to maintain existing medication regimens or perform follow-up blood tests.\(^9\)

Welfare systems that do not present significant financial barriers to services should be well placed to maintain good quality, appropriate care as patients move between home, hospital, hospice, or care home. The provision of a seamless service, one shaped around the needs of patients, carers, and families, is a core principle of the National Health Service in England,\(^10\) reiterated by successive governments. But, despite efforts in research and practice over decades, continuity of care is not clearly defined and our understanding is incomplete regarding how to evaluate and improve these aspects of service delivery so that the patient receives coherent consistent care.\(^11\) Extensive research has been conducted into older people’s experiences of transitions in the U.S. The relative neglect of this issue in the U.K. may reflect an assumption that a universal health system will overcome most problems posed by transitions between different settings. Tools do exist to measure many different aspects of patients’ experiences, such as waiting times, communication with staff, and quality of care.\(^12–14\) A well-validated questionnaire is available for use with family carers to gather retrospective data on end-of-life care in a full range of settings.\(^15\) All of these are useful measures for service evaluation, but they fail to capture the patients’ overall perspectives of their journey through the care system.

This study used qualitative methods to explore patients’ experiences, forming the first part of a three-phase study funded by the U.K. National Institute for Health Research Service Delivery and Organisation (NIHR SDO) Programme to look at transitions in care in England. In-depth interviews with older people with lung cancer, heart failure, or stroke were conducted. These conditions have different disease trajectories, are common causes of death, and present a high burden of symptoms to patients and the health system. Together, they are likely to present a broad range of different needs and challenges to welfare services. The aim was to explore the experiences of moving between care settings for older adults in their last year of life.

Methods

This study took place in northern England in 2009–2010. It forms part of a larger project on transitions in health care settings at the end of life for people with stroke, heart failure, and lung cancer. The study was reviewed and approved by the Sefton National Health Service Research Ethics Committee (Study number 09/H1001/51).

Procedures

We sought a purposive sample of people older than 75 years, who had moved between at least two care settings in the previous three months; were aware that they had been diagnosed with heart failure, lung cancer, or stroke; and were thought to be in their last year of life. Participants were identified by medical consultants and specialist nurse teams, if the
A responsible clinician was able to answer “no” to the question, “Would you be surprised if this patient were to die within the next 12 months?” Four patients below the specified lower age limit were included in the study, as they had been invited to participate by their responsible clinicians. To ensure that experiences from a range of care settings were represented in our data, we also interviewed patients identified from hospices (three) and rehabilitation facilities (three). The sociodemographic composition of the sample was monitored to ensure that people from disadvantaged areas participated, but no intervention was needed. The last reported occupation was used to allocate the participant to one of the five categories within the National Statistics Socioeconomic Classification.16

Participants were approached by their nurse or doctor with an invitation letter, and those who agreed to be contacted by the researchers received a phone call to explain the study and, if appropriate, further written information. All the interviews were conducted by one researcher, a trainee health psychologist, experienced in qualitative research interviewing. Interviews took place in a location chosen by the participants. In all cases, this was their current residence: home for 26 participants, care home for two participants, hospice for one participant, and an intermediate care facility for one participant. The interviews were recorded with permission and transcribed verbatim by a professional transcriber. Informed written consent was obtained from all participants immediately before the start of the interview. The participants were offered an opportunity to terminate the interview after one hour or at any time if they were tired. The average duration of the interview was 90 minutes.

The interviews were semistructured. A broad topic guide was developed by the research team to guide the interviewer, covering the participants’ social context and relevant life history, their understanding of their illness, the nature of any transitions they had experienced, and how they understood and interpreted their experiences of transitions. The interviewer had a comprehensive list of prompts under each topic to ensure consistency between interviews. We asked participants to talk about their experiences, good and bad, of health and social care as they moved between care settings in the last six months. We sought perceptions of the quality of care in each setting in addition to the experience of moving between places and the care received immediately after a transfer.

The questions were phrased to encourage the interviewees to express themselves freely and raise issues of importance to them. For example, a typical question would be “Could you tell me something about the care you received in hospital and the people who looked after you there?” Follow-up probing questions were asked to explore issues of interest in more depth.

Analysis

The data were analyzed using the principles of Framework, a modified form of thematic analysis that is designed to provide a systematic and transparent approach to data management and analysis.17 First, the transcripts were read and reread by two researchers. Line-by-line coding of each transcript was completed by hand. These codes were used to generate a coding index of initial categories, which were then grouped into initial themes. Data were assigned to the themes and categories in the coding index, using an Excel spreadsheet to manage the data. Each major theme was allocated to a chart, with a row for every case, and a category in each column. This format allows easy access to summarized data from the transcripts and great flexibility in moving between case-based and thematic analyses. The initial themes and categories were refined to ensure that they summarized and synthesized the breadth and diversity of the coded data and associations between themes sought. To develop explanatory accounts, the summarized data were examined repeatedly to find patterns across the themes and cases and reflect on the meaning and explanation of the data. References were made back to the original transcripts and field notes at this stage to ensure that the participants’ accounts were represented accurately and to allow the researchers to reflect on their interpretation.

To ensure the rigor of the analysis, five of the transcripts were coded by two researchers, and a third researcher coded a further two transcripts. The emerging categories and themes were refined in discussion with the study team, who had all read a sample of the
original transcripts. The detailed coding index was applied to data from three interviews by two researchers independently and minor discrepancies in approach resolved by discussion. As all the participants were thought to be in their last year of life, no respondent validation was planned. However, the findings and their interpretation were discussed with an external group of research partners. This group comprised people who had been caregivers to older people themselves and were interested in advising on research design and conduct to ensure that it is relevant and sensitive to patients’ needs.

In this article, we focus in particular on findings that reflect participants’ experiences of moving between care settings.

**Results**

Thirty people agreed to be interviewed; they were aged between 69 and 93 years, diagnosed with lung cancer (13), heart failure (14), or stroke (three) (Table 1). More than half were living in disadvantaged areas of northwest England (spearhead administrative areas, in the bottom fifth nationally for life expectancy, premature mortality, or deprivation). Collectively, the interviewees had moved 67 times between care settings in the three months before being interviewed. Four main themes emerged from the data, relating to 1) the prioritization of institutional processes, 2) support across settings, 3) being heard, and 4) dignity. Implicit criticism of the overall experience was a cross-cutting theme. In a number of the accounts, this coexisted with descriptions of care from individual health professionals that was noted to be good or exceptional, but in no cases was the responsibility for perceived deficiencies in the system attributed to specific professional carers.

**Prioritization of Institutional Processes**

Many of the interviews conveyed a sense that the care system was imposing processes on patients with limited recognition of or flexibility to the individuals’ needs or wishes. The problems ranged from administrative procedures, such as outpatient appointments, to the provision of aids and appliances. In some situations, the imposition of rules intruded directly into life at home. One 80-year-old female participant with lung cancer described how a bed was installed in a downstairs room of her house against her wishes while she was in the hospital. She was later deposited onto the bed when taken home from the hospital, unable to get off.

...They told me I could come home when they brought a bed in, and I said I don’t want a bed downstairs, because there isn’t room. Anyway they sent people out while I was in hospital and [my husband] showed

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>Heart Failure</th>
<th>Lung Cancer</th>
<th>Stroke</th>
</tr>
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<td>80 (73–89)</td>
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<tr>
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<td>6</td>
<td>4</td>
<td>3</td>
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<td>3</td>
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<td>1</td>
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<td>No. of people reporting adverse events related to health and social care</td>
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<tr>
<td>Total number</td>
<td>13</td>
<td>14</td>
<td>3</td>
</tr>
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</table>

*U.K. National Statistics Social Classification, based on reported occupations, where 1 is the most affluent and 5 is the most disadvantaged: 1 & 2 managerial & professional, intermediate; 3 small employers and own account workers; and 4 & 5 lower supervisory and technical, routine and semiroutine.
them round. And a particular person came and said that it could be done, so eventually they brought this bed, and it was a very expensive one and it had a mattress on it which went up and down it was regulated, went up and down. Anyway when I did come home, the nurses came, they lifted me onto this bed, ... So and they said they would put me on the bed, and they had to leave me, they couldn’t take me off ... that was the law, I suppose or something. They just said they had done what they were told to do, and so I would just have to stay, so that was it. Anyway [my husband] got me off. (Female, aged 80 years, lung cancer)

The same interviewee described how they had to ask for fewer social service carers to visit, as they, too, intruded on her day-to-day routine. Another interviewee of similar age had taken to sleeping downstairs because the ambulance staff had warned her that their insurance coverage would prevent them from helping her downstairs.

...But I haven’t to go upstairs, because the ambulance men can’t get me out, and I have to sleep downstairs and I have done. And apparently they are not insured to handle me unless there is two, because I can just go out on them like that. There seems to be this insurance that the carers have to abide by, and they do. (Female, aged 81 years, lung cancer)

Adherence to procedure is important for patient safety and the efficient running of a large organization, but it also may leave staff unable to respond flexibly to an individual’s needs or wishes. These issues emerged in discussion of the organization of visits to the hospital after hospital discharge. Appointments could be too early for people who waited for carers to arrive to help them get up and dressed in the morning. Bus travel was inflexible in its routes; ambulance transport was slow and meant traveling alone. Without a family member, patients who needed help with mobility, such as this 69-year-old participant, felt stranded within the hospital.

Yes getting in and out the taxis for me is harder now yes. See you could go by ambulance and that, but they might not take [my daughter] in with me, and I have to have her to push me round to my appointments and that. So, there is another, I forget the name of it, it’s a bus and they do take the carers with them but they don’t take you to the hospital. So, you can’t win can you ...

(Female, aged 69 years, heart failure)

Reliance on working family members for transport was common, and time spent waiting and time taken off work was a source of annoyance and guilt.

It was a long, long, long wait, you know we were there an hour and a half, of course my daughter was taking time off work to take me there you see, and when I got in there, the doctor asked me what was wrong with me and I said there is nothing wrong with me you know, I am in good shape. And he said well what are you doing here, I said you sent for me, I showed him the letter you know to prove it, [I was] annoyed. Apart from myself, my daughter had took time off work you know, which I mean she has got an important job herself, she is with the health service. (Male, aged 73 years, heart failure)

Support Across Settings

Some of the accounts suggested that the older adults felt that they were sent out of hospital without adequate time to prepare themselves, insufficient community support in place, and little knowledge of how to access the services they required. The account below implies a lack of participation in the discharge planning process.

They kept telling me I was going home and I was alright, I was going home. My legs hadn’t been seen to, the infections hadn’t gone, the swellings hadn’t gone down, but they were quite willing to send me home, and then they decided to keep me in, and that happened to me four times in hospital and in the end, it came that ...

(Female, aged 80 years, lung cancer)
This participant was able to advocate successfully for his own care but noted an apparent failure in communication between hospital and community.

They told me in the hospital before I left that the district nurses would be in touch, and the occupational therapist. Now I was home for a week, now I had to phone up the district nurses and ask them when they were coming out to treat my legs. They said we didn’t know you were out of hospital. We haven’t had a referral. ...Now ever since then I have been fighting for my own benefit. No one has been. I have had to get it all for myself, try and get it for myself ...(Male, aged 75 years, heart failure)

Many of the problems appeared to be minor, but the consequences for the elderly and unwell could be considerable. For example, one man was housebound for weeks by his inability to either put shoes on his swollen feet or find the appropriate help with footwear. Sometimes, it was unclear whether the problem lay with interdisciplinary communication or if the system was used by professionals as an excuse to cover inability or unwillingness to act. A female participant described a social worker explaining that she could not refer to another authority, causing delay in obtaining home adaptations.

...The social worker came to see me, and she said I can’t recommend you to [your local area] social services because they won’t take any notice of me, she said. ...we decided that the only thing I would need when I come out was a grab bar, whatever they call them for the shower really she said if you had been in [your local hospital] they would have recommended you but they won’t take my recommendation because they are under different authorities aren’t they, you know. So she tried, she tried her best to get them and doesn’t do anything, and then my son started trying to get them and they said we will, oh we will have an appointment for her, make an appointment to come out and see your mother. And it was for 6 weeks hence, to come out and see me and assess if I needed anything...—And then they didn’t know when it would get done. (Female, aged 78 years, lung cancer)

**Being Heard**

A good understanding of the purpose of any move into or out of an institution, and the associated practical arrangements, may help to minimize any distress associated with the transition. There were many examples of communication between health professionals and patients that was effective and well received by patients. The oncologists and specialist nurses were mentioned more often in this context than their colleagues in primary care. Sensitive discussion of prognosis and treatment options was recounted by most of the interviewees with lung cancer, for example. However, the feeling that, at times, no one was listening to patients or families emerged as a theme from patients with all three conditions. This was particularly apparent when they had just moved into or out of hospital. For some, a perception that no one has time to talk created a potential barrier to understanding their condition and prognosis, as well as the rationale behind therapies. One elderly woman had not understood why she needed to be in hospital to receive only tablets, for example. Others described the difficulty they felt as inpatients asking for information about their condition. Not being heard also created a barrier to basic care in the hospital and for this participant, a care home:

...They get very nasty when they come up here—we have got more to do than this, you know, there is other patients... they weren’t very pleased no... If it causes embarrassment they shouldn’t do it you know, I can’t help wanting to go to the loo all the time. I think somebody has been treating me for a bladder complaint and I want to go all the time, yes. (Female, aged 84 years, heart failure)

Family carers shared a sense of not being heard, either when advocating for their relative’s care to be modified or when discussing their own stresses involved in the responsibility of delivering care.

And then the doctor decided to swap and change her drugs, with some advice from the pain consultants. And then they do it and then they are away for the weekend and they are not around to see consequences and what effect it has on her. So
we sort of begged, because we could see a deterioration in my Mom, we begged them to swap them back to the drugs that she should be on. And they did after a load of arguing and getting the bed manager and everybody down, and then on the Monday the same doctor came back and changed the drugs back to the same drugs again. And then she went off again, and there was no communication between the... I think the problem is communication definitely. (Daughter of female, aged 82 years, lung cancer)

In addition, there were multiple accounts of literally not being heard and the associated struggle to obtain help with toileting or other essential aspects of life in the hospital.

**Dignity**

Clear examples of mistakes associated with transitions were rare in our study. Possible errors with medications were described by only two of our participants when they were leaving the hospital. A third interviewee was concerned that medication dispensed from a hospital pharmacy may not have been for her, as the tablets were dissimilar to medications that she had at home. But as older adults were placed into new and unfamiliar situations, they described care that may have lacked dignity. Loss of false teeth or being left unattended until early morning after an evening admission was not likely to have compromised patients’ health status. Similarly, being sent for an X-ray in a revealing gown or having a nurse discuss personal details in front of a crowded waiting room were sources of distress rather than concern over the quality of medical care.

**Discussion**

One of the most stringent tests of any welfare system is how well it works for some of the most vulnerable patients. Our interviewees were aged, coping with life-limiting conditions, and, in many cases, on low incomes. Their accounts appear to support the assertion in U.K. policy documents that convenience for the system sometimes takes precedence over convenience for the patients. Although the collective account suggests problems in different parts of the care system and how they link together, individual health professionals were singled out for praise by our interviewees and not held accountable for the overall experience provided. Whether this reflects loyalties to familiar professional carers or the difficulty of identifying weak points in complex systems, it is in keeping with long-standing support for the English National Health System (NHS) among older adults in particular.

Existing research has built a quantitative picture of frequent transitions between settings for older people. Medicare recipients have been shown to have high rates of readmission to the hospital and multiple transfers after discharge, for example. The few studies that have focused on the time before death, notably in Belgium and The Netherlands, found that a majority of people were transferred at least once in the last three months of life. However, a mortality follow-back study with relatives of cancer decedents in 22 U.S. states suggested that such transitions were not associated with reduced levels of distressing pain for many people. Our qualitative analysis provides complementary data on patients’ experiences that could inform the way in which care is delivered. Reports of deficiencies in elder care are not novel. The importance of our findings is in our focus on transitions between services at the end of life. This is a time when health and well-being may be at their lowest, and outcomes are sensitive to how well the components of the systems work together. As the older adults in this study moved between home and different institutions, they sometimes felt unsupported, unheard, and treated with insufficient dignity. Our participants were not selected with any prior knowledge of their experiences, but their accounts were similar to those reported by U.K. lobbying groups such as the Patients Association. Our findings also overlap with failures in the care of older patients after surgery that were reported in the National Confidential Enquiry into Patient Outcome and Death and a report by the Health Service Ombudsman into NHS Care of Older People. The standards of care in NHS hospitals are monitored by an independent regulator, the Care Quality Commission. Their large-scale annual surveys report that NHS care is well received and improving, but some of the persisting problems are similar to those described by our
interviewees. A high proportion of patients in their surveys lacked information on their medications, for example, and one in five needed more help with basic care, such as eating, while in the hospital. Older people make up a high proportion of service users, so the similarities between the experiences of our interviewees and a range of reports appear to suggest that suboptimal care may be the norm at older ages. The way in which the health system is structured may support and sustain poor care for older people.

Our findings are supported by research on experiences of health care from differing perspectives. Research into end-of-life care stretching back over decades has highlighted many of the issues raised by this study, such as the provision of information and care with dignity. Communication between patients and professionals and coordination across services certainly appeared to underpin some of the deficiencies in care for our interviewees. These are all characteristics of the emergency care system that are known to be important to patients of all ages. Along with relationships with professionals, personal agency, and the sense of being treated as a whole person, communication and coordination also have been identified by patients with cancer, stroke, diabetes, and mental health problems as important contributors to continuous care. Illness trajectories, individual characteristics, and social circumstances are known to influence patients’ experiences, particularly in relation to continuity of care, but expectations of services also are crucial. In this study, patients’ dissatisfaction with the system implies that they anticipated that the different services would work together as a coherent whole, providing the right amount of care, without too many social carers or inappropriate appliances. This may be peculiar to comprehensive systems, such as the NHS, where most services are free at the point of delivery. Patients who purchase their own health insurance coverage may have different expectations of how their end-of-life care will be delivered.

Limitations
Our participants were identified by a range of health professionals, so some variation in the application of selection criteria is possible. A disproportionate number of interviewees, particularly those with lung cancer, were from disadvantaged areas. This may explain some of the difficulties described in negotiating the system, but as experiences of health and social services should not vary with the social background of the care recipients, this also is a strength of our design. There were differences in the patterns of transitions between care settings by diagnosis. People with lung cancer had fewer inpatient episodes compared with those with heart failure or stroke. They also had more contact with hospital consultants than people with heart failure, in particular. We had anticipated that the different disease trajectories would be associated with varying needs for community and hospital or hospice care. In spite of this, the themes that emerged were common to all conditions and showed little or no variation with socioeconomic status. This gives us confidence that our data have relevance beyond the older adults we interviewed.

Implications
The future vision for the U.K. NHS is of a service that is genuinely centered on patients and carers, achieving quality and outcomes that are among the best in the world. Dignity and respect are fundamental components of such high-quality care. Considerable time, effort, and funding have been directed at improving both the organization and delivery of end-of-life care. An End-of-Life Care Strategy has been implemented in England and Wales, and, in family practice, financial incentives are offered for identifying patients at the ends of their lives and holding multidisciplinary meetings. Yet, if the experiences of individuals in this study are shared by others, major differences between theory and practice remain. Study of transitions between care settings provided a focus on particularly vulnerable points in the delivery of end-of-life care. The deficiencies identified in the experience of health and social services were in basic care: assessment and meeting of needs, good communication, and a sense of dignity and respect during interactions with care professionals. All our participants were aged, and whereas health professionals play an important role in delivering care, the possibility that the health system is structured in such a way to support the delivery of poor care to older people is worthy of future attention.
The planned transfer of responsibility for commissioning services to family doctors in England offers an opportunity for issues, such as closer working with social care and transfer of information between hospital and community health services, to be given renewed emphasis. But as health systems in many countries look to increased competition between service providers and initiatives, such as personal budgets, to reduce expenditure and widen choice, our findings imply that end-of-life care could have been improved for our participants with some very simple changes in practice, such as providing care with dignity, respect, and communication.

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References


