

A qualitative, ethnographic study of frail, older patients' health care journeys through, and experiences of, ambulatory care settings in Oxfordshire

Executive Summary

The background to the research

There is a growing body of research which indicates that increased age is associated with increased Emergency Department (ED) attendance and emergency hospital admissions. However, while frail, older people may be heavy users of health care services there are concerns that those services may not recognise and meet their needs and that the acute hospital environment is not well suited to the older person.

The acute care pathway at the Emergency Multidisciplinary Units (EMUs) and the Acute Ambulatory Care Unit (AAU) in Oxfordshire, UK, is aimed in particular at older, frail patients and was designed as an alternative to emergency admission to an acute hospital, treating patients closer to their homes. This study aimed to explore the health care journeys of frail, older patients when they were assessed and treated in these settings. The main research aims were:

- To investigate frail, older people's experiences of visiting the EMU and the AAU and their journeys through care within those settings.
- To explore the main events and transitions in their care and how these impacted upon the patients and their carers.
- To identify how patients' experience of ambulatory care provision fitted with their expectations, needs and priorities.

Methods used to conduct the research

A qualitative, ethnographic approach was employed to explore frail, older patients' and their carers' experiences and perceptions of care in an ambulatory care setting, as it unfolded. A combination of data collection methods was used including observation and informal interviews with patients and carers during their time of stay. Semi-structured, follow-up interviews with patients were also conducted when they had been discharged from the ambulatory care setting. Permission was sought from patients to access their medical notes in order to capture the fuller clinical picture around their admission and treatment. Data were collected in the EMU between March and September 2016 and in the AAU between February and June 2017.

The research participants

Participants in the study were older people (> 65 years) who were referred to the ambulatory care settings for assessment and treatment of an acute illness, and were judged to be frail by the treating health care professional in that setting. Indicators of frailty among our recruited patients included:

- having already had or being at risk of falls
- experiencing difficulties with mobility and transferring
- experiencing difficulties in everyday functioning
- in receipt of a package of care at home
- cognitive/memory difficulties.

At the EMU, 20 patients and 7 carers were recruited to take part in the study and at the AAU, three patients and one carer were recruited. The majority of patients were in the 80-89 age band, with

three older than 90. All participants in our sample were white, with three patients originating from other European countries. Eleven participants lived alone, eleven lived with a spouse or family and one lived in a care home. Among our participants, the most common reasons for referral to ambulatory care were exacerbation of heart failure (HF) or chronic obstructive pulmonary disease (COPD) symptoms; infections or suspected infections; and difficulties relating to mobility and falls.

Findings of the research

The main findings of the study were:

- Frail, older people and their carers had often not expected the level of care they experienced in the EMU and the AAU and viewed the care delivered in those settings positively:

“And in general I mean I had a hundred percent attention you know so. It made me feel that, you know I'm being cared for and that was the main thing.”

“It's great...laid back...I love it...” The carer was very positive about the Unit and told me “These EMUs are wonderful. We need more of these. The difference is incredible... It's the best thing they ever come up with”

“But no, I would recommend anybody to go in with any problems to be treated at the AAU, definitely... It's just one hundred percent. I mean, as I said, if I was able to speak for them, I would say that the care is second to none.”

- Patients and carers expressed the view that care was more personalised in the EMU and the AAU than it would have been in other, larger departments and this was an important consideration for older people when they were unwell:

“The carer told me that she found it a “nice little unit”, that the care was “personal”, that the staff were “not aloof and didn't disappear” but were “friendly”.”

“The carer talked about their experience of the AAU and said he thought the care was “a little bit more personal” and compared this with what happens on the wards.”

- Our participants were appreciative of the ways in which members of staff communicated with them and their families and the friendly atmosphere of the settings:

“Well, I felt very well involved. I mean the nurses did the various things that needed doing and then the doctor would come and see me and talk about things and say that she was going to do this, that and the other. And so I felt that I knew what was going on, and each day they...I haven't got one now, but they actually wrote up what had happened and what was going to happen.”

“The carer explained how hospital, especially the main hospital could be “daunting” but that at the unit “everybody has explained what they are doing and that's important for the elderly”. The patient agreed and said it was “a very good set up” and that “it makes you feel at home, like coming to visit friends, like a family circle”.

- Depending on their needs, patients had access to the wider multi-disciplinary team and could receive assessment from physiotherapy, occupational therapy and social work. Often patients were keen to find out about how they could regain the level of independence and functioning they had managed before their acute illness:

“The patient told the OT that she hadn’t been able to go outside into the garden “last summer I didn’t get into the garden at all. Perhaps I could with a walker.” The OT told her that therapy services could come in to help her build up her confidence and independence. (S)he mentioned that a kitchen trolley was another option when the patient had built up her confidence on the zimmer. “What a good idea” the patient said.”

- While frail, older people sometimes struggled with the long periods of time they needed to spend at the EMU and the AAU, they were satisfied with what could be achieved for them during their health care journeys:

“The patient told me that she had had the “best attention – can’t complain” although she said it had been a “long day” and “I’ve had enough”...Of their visit the carer said “the one thing is...length of time you’re here but it is worth it””

“I think it’s better than going fully into hospital and then again having to wait and wait and wait. At least they do what they can within a few hours and I can’t fault them on that at all.”

- The majority of participants in our sample needed to return to the EMU or AAU for follow-up assessment and/or treatment over a period of days or sometimes weeks. Patients could often find such visits tiring and challenging:

“The patient had experienced multiple visits but while it had been tiring and her life had been “on hold” she did not complain. She felt that she had missed her friends during this period as he hadn’t been able to see them during the day and was too tired when she came back from the Unit in the evening.”

However, patients appreciated the discussions they had with EMU or AAU staff about the location of further care and the flexibility shown, including the option of going home:

“I was given the opportunity to either stay in hospital, or spend it as an outpatient from my own home for two days, and then one day as an outpatient at the hospital, and that was an offer that was given to me, and I chose to stay at home, and they were very good.”

Conclusions drawn from the research

From our findings, it became apparent that going to hospital was a possibility that older people living with frailty prefer to avoid, even at times when they knew they were unwell. Attendance at an ambulatory care setting was regarded as more acceptable alternative and many of our participants were surprised and delighted at what could be done for them there. Overall patients’ and carers’ responses showed that they viewed this type of ambulatory care as a model of service provision, which was especially suited to the needs and priorities of older people living with frailty. This was largely due to the fact, that dependent on the reason for referral, patients were able go home between visits (a number of patients were themselves caring for frail, older people), food and drink were provided during their stay and patients received support in maintaining independence and functioning through the involvement of the multi-disciplinary team present at these sites.

Our research demonstrated that key to patients’ and carers’ positive view of ambulatory care was the size of the settings. The small size of the EMU, where up to around 10 patients could be cared for at one time, was greatly valued and substantially contributed to patients’ and carers’ perception of it

as a comfortable, friendly place, with a more relaxed atmosphere particularly suited to the needs of frail, older people. It also contributed to the feeling that the care they received was more 'personalised', which was a hugely significant feature for the patients and carers. Although bigger, and able to treat more patients at any given time, the AAU was still perceived as a pleasant, relaxed environment.

The importance of communication with health care professionals for patients and their carers was emphasised across the ambulatory care settings. The many opportunities for communication and interaction between patients and staff appeared to be a factor in making EMU and the AAU settings which patients viewed positively. Although journeys could involve long days and repeat visits, at each stage of their care staff made efforts to keep patients and their carers informed about what was happening and what the next steps were, and to involve them in discussions about delivering the care that fitted the patient. Many of the patients were able to be part of the decision-making process around the treatment they received, and this sometimes meant them rejecting suggestions of help offered. Some patients, especially when they were acutely unwell, did not always expect to participate in decision-making. These patients were content to rely upon the decision-making of the professionals to do what was best for them in an environment where they felt cared for.

Recommendations for the future

Our research is an indication of the feasibility of conducting research in acute care settings and that participating in ethnographic research, even during periods of acute illness, can be acceptable to patients. This offers the possibility of designing other studies where the experiences and perspectives of patients can contribute to an understanding of whether, and how, acute services work for them.

This study also shows ethnography as a means of drawing older people living with frailty, including cognitive frailty into research. Thus future research around care provision and new platforms of care for older people with frailty should consider building in a qualitative, ethnographic component.