



Ageing Well Dying Well

**Patients' and family caregivers'
experiences of integrated care
at the end of life**

We wanted to find out what research had already been done about the experience of integrated care for older people at end of life in community settings



What is known about this topic

- Increasing numbers of older people require care in community settings at the end of life
- Older people experience more long-term conditions and have multiple and complex health and social care needs
- National and international policies promote integrated health and social care services that put people and communities at the centre of care

What this project adds

- Family caregivers are essential in providing care and support, but often find it bewildering and stressful
- Despite policy imperatives, there remain significant challenges in communication between professionals
- The views of patients and carers need to be considered in service planning, and providers need to be flexible and responsive to their needs

Introduction

The numbers of people aged 65 and over are increasing and many older people live with long-term conditions such as heart failure, lung disease, cancer, dementia and frailty, that reduce their independence and quality of life. As a result of these long-term conditions there is more need for end of life care services for frail, older people.

Integrated care is promoted in many countries as a way of improving the delivery of health and social care and putting patients at the centre of care. An important goal of integrated care is to try and keep people out of hospital and instead treat them in community settings such as care homes or at home. However family carers and patients often find that they struggle to understand the health and care system and feel that their needs are not always recognised by health and care services.

This project wanted to find out what research had already been done on family carer experiences of integrated care for older people at the end of life in community settings.



What did we do?

The project was done in 4 stages

Stage 1. Discussions with stakeholders

We talked to service users and staff to find out what their views and experiences were. We asked them ‘what are the important issues when we think about providing support and care for older people as they come to the end of their lives?’ We talked to staff such as care home managers, hospital ward managers, community nurses, community palliative care staff from a hospice, senior nurses from a hospital frailty team, and a geriatrician. To make sure we understood what service users thought, we interviewed a carer who had recently lost a parent and we also talked to two patient advocates. We included the results of two reviews of end-of-life care within the South Asian and Caribbean communities. These discussions were summarised into a list of 15 topics.

Stage 2. Workshop

We invited all of our interviewees to an on-line workshop to discuss the 15 topics and decide which were the most important. Nineteen people took part on the day, including staff from local health and social care organisations, an independent patient advocate and a bereaved carer.

Our bereaved carer gave a moving talk about her experience and then each of the 15 topics were presented in turn. After discussion everyone was invited to select their ‘top 5’ topics. We used Mentimeter, which is an on-line voting software. Once we had a Top 5 list, we asked everyone to rank the topics in order of importance. Using this approach the highest priority topic was ‘Fragmentation of care’, followed in order by communication issues between professionals and families, interprofessional communication, impact on immediate carers and family, and advance care planning.

Stage 3. Further discussion

After the workshop the project team realised that if the review focussed on ‘how fragmentation of care for older patients in community settings in the last year of life affect patients’ and family caregivers’ experiences’, it would automatically include the top 5 priorities.

Stage 3. Looking at the research

We used online databases to search for published research projects about end of life care in the community that talked about patient or carer experience. We looked for research projects that included patients aged over 65 and were published in English after 2001. We found 19 studies.



What did we find?

The review showed that family caregivers are essential in providing care and support. However they often find dealing with health and care services bewildering and stressful because of the number of different teams involved and the lack of 24-hour care, particularly at night and weekends.

At the end of life people need health and social care services to provide adequate support, good communication, and continuity of care. Family carers want to be able to care for their loved ones without becoming confused or exhausted. Good communication and positive relationships between service users and healthcare staff are extremely important.

The views of patients and carers need to be taken into account in service planning, and providers need to be flexible and responsive to patient and family carers' needs.

Thankyou!

We would like to thank all of the people who gave their time and shared their knowledge and experiences with this project.

We have written a research paper and it is currently being reviewed by the journal Health and Social Care in the Community. We are hopeful that it will be published soon.

The project team plans to continue to work together and apply for funding to do more research in this area.

If you would like to know more about this project please contact [Mary Turner](mailto:m.turner@hud.ac.uk) (m.turner@hud.ac.uk) or [Christine Smith](mailto:christinesmithconsultancy@gmail.com) (christinesmithconsultancy@gmail.com)

