

Adrift in foreign land: Study highlights failings when older people transferred between health and social care services

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A major study of the experiences of older people moving between health and care services published today highlights significant problems in the quality of the service they received. The researchers from the University of Birmingham's Health Services Management Centre found that too often older people were excluded from decisions and carers in particular felt undervalued by statutory providers. This is despite patient and carer involvement being a central aim of current NHS reforms, championed by the phrase "Nothing about me, without me".

Unique elements of the study:

- 22 [older people](#), including people with [dementia](#) as, acted as 'co-researchers' on the study, working in partnership with [academics](#) on the design, conduct and analysis of the research
- The research explored the views and experiences of 4 different groups of older people, including older people with dementia and older people from minority ethnic backgrounds
- The research team and co-researchers have been working with [service providers](#) and commissioners in the four [case study](#) sites to implement the recommendations and improve local services

Older people told researchers that they wanted to be seen as a human being with needs and [feelings](#), not just as a problem to be solved.

However, many people felt that they were not always treated with dignity and respect, which is regarded as the foundation for good care. The problems highlighted included:

- A lack of information about the services on offer
- Difficulties getting a clear [diagnosis](#) of dementia
- Patients not being kept informed about important developments in their care
- Very little advance notification and preparation for discharge from hospital
- Unreliable home and [social care](#) arrangements

Despite these problems, the researchers also heard about services and professionals that provided personalised, compassionate and proactive care. One participant described herself as "proud and patriotic" after receiving a service designed to support patients and their families to make the transition from hospital back home.

The national study was carried out between November 2008 and October 2011 in four case study sites in England, allowing the research team to examine the experiences of four very different groups.

- Older people with dementia
- Older people from minority [ethnic backgrounds](#)
- Older people living in rural areas
- Older people living in a younger city

The study was funded by the National Institute for Health Research Health Services and Delivery Research (NIHR HS&DR) programme. The researchers took the unique approach of working with 22 older people, including a number with dementia as 'co-researchers'. These co-

researchers were involved in designing, carrying out and analysing the research alongside University academics. Academics and co-researchers interviewed a total of 75 older people about their recent experience of care transitions. Participants included both patients and carers.

The research revealed a range of issues common to all the groups that they regarded as crucial to good care:

Feeling orientated in a 'foreign land'

The research showed that transitions are a common, and often a permanent, feature of older people's lives. Participants' experiences of transition were frequently accompanied by a sense of disorientation. While professionals could help to ease this sense of disorientation with clear communication and sharing of information, this didn't always happen, leaving older people anxious about what was happening to them and what the future held.

Being recognised and valued as a person

Common to all of the groups of older people was a wish for services to recognise and value them as a person. The research showed that too often older people were not involved in decisions about their care, and older carers in particular felt undervalued and excluded by support services and health professionals.

Importance of family, friends and community

Family, friends and neighbours played a huge role in helping participants to live independently at home and participate in social activities, in so doing reducing the risk of loneliness and isolation that older people can experience. This was not always taken into account by

those planning care.

Services not taking a planned and proactive approach

Transitions are unsettling experiences for older people because they create change and uncertainty. Aside from isolated examples, the research found little evidence of health and social care services taking a planned and proactive approach to the care and support of older people. Far more common were experiences of stumbling across services, having to seek them out, or even in some cases needing to 'fight' for them.

Jo Ellins who led the research explains: "Our findings demonstrate major shortcomings in services for older people in making the difficult transitions between health and social care. Whilst getting this right is not an easy thing to do, given the complexity of individuals' needs one of the most striking findings was that even the smallest gestures by providers to connect with somebody as an human being – such as a smile or a hug – could make a significant difference to their sense of dignity and their experience overall.

One of the reasons we wanted to engage older people and their carers as co-researchers was to get honest and frank accounts of what those experiences are truly like."

Provided by University of Birmingham

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