

Understanding and improving transitions of older people: a user and carer centred approach

Executive Summary

Jo Ellins¹, Jon Glasby¹, Denise Tanner², Shirley McIver¹, Deborah Davidson¹, Rosemary Littlechild², Iain Snelling¹, Robin Miller¹, Kelly Hall¹, Katie Spence¹ and the *Care Transitions Project* co-researchers.³

¹ Health Services Management Centre, University of Birmingham

² Institute of Applied Social Studies, University of Birmingham

³ Solihull, Leicester, Gloucestershire, Manchester

Published September 2012


***National Institute for
Health Research***

This project is funded by
the Service Delivery and
Organisation Programme

© Queen's Printer and Controller of HMSO 2012. This work was produced by Glasby *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health.

Address for correspondence:

Dr. Jo Ellins
Health Services Management Centre
University of Birmingham
Park House
40 Edgbaston Park Road
Birmingham B15 2RT
Email: J.L.Ellins@bham.ac.uk

Conflicts of interest:

The authors have no financial or other competing interest that might have biased this work.

This report should be referenced as follows:

Ellins J, Glasby J, Tanner D, McIver S, Davidson D, Littlechild R, Snelling I, Miller R, Hall K, Spence K and the Care Transitions Project co-researchers. Understanding and improving transitions of older people: a user and carer centred approach. Final report. NIHR Service Delivery and Organisation programme; 2012.

Relationship statement:

This document is an output from a research project that was commissioned by the NIHR Service Delivery and Organisation (SDO) Programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. From January 2012, the NIHR SDO programme merged with the NIHR Health Services Research programme to establish the new NIHR Health Services and Delivery Research (NIHR HS&DR) programme. Should you have any queries please contact Hsdrinfo@southampton.ac.uk

Copyright information:

This report may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NETSCC, HS&DR.

National Institute for Health Research
Evaluation, Trials and Studies Coordinating Centre
University of Southampton
Alpha House, Enterprise Road
Southampton SO16 7NS

© Queen's Printer and Controller of HMSO 2012. This work was produced by Glasby *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health.

Disclaimer:

This report presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and not necessarily those of the NHS, the NIHR or the Department of Health.

Criteria for inclusion

Reports are published if (1) they have resulted from work for the SDO programme including those submitted post the merge to the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors. The research in this report was commissioned by the SDO programme as project number 08/1809/228. The contractual start date was in November 2008. The final report began editorial review in November 2011 and was accepted for publication in September 2012. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The SDO editorial team have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report documentation. However, they do not accept liability for damages or losses arising from material published in this report.

Executive Summary

Background

Older people – especially those with complex and ongoing needs – often move across service boundaries. Poorly planned and coordinated transitions can be detrimental to older people’s health and well-being, and are a source of major disagreement between service commissioners and providers. Despite positive changes following the 2001 National Service Framework for Older People, transition between services is still one of the most problematic areas of policy and practice.

The contribution that older people can make as co-researchers is increasingly recognised. Rather than being passive suppliers of information, as in traditional research approaches, co-researchers have a role in shaping the research agenda and co-producing its outcomes. This approach opens up the possibility for older people to explore and define their own experiences: doing research ‘with’, rather than research ‘about’.

Aims

The aim of this study was not just to understand older people’s experiences of care transitions, but also to conduct the research in a way that would help to embed the findings in health and social care policy and practice.

Specifically, it aimed to:

- Explore older people’s experiences of moving across service boundaries, examining access to services, and information, advice and support needs
- Identify how the needs of particular groups of older people may differ from each other, and the different needs of service users and carers
- Investigate these issues over time, to illuminate how previous transitions impact on current and future needs
- Draw out policy and practice implications for the way in which services prepare and support older people and their carers for care transitions
- Support, and share the learning from, implementation of project findings in four health and social care communities.

Methods

This study was carried out in two phases across four case study sites in England. Each site focused on the transitional experiences of a different group of older people:

1. Who have dementia
2. From ethnic minority communities
3. Living in rural areas
4. Living in an area with a proportionally small older population.

Phase 1 (research) involved in-depth narrative interviews with older service users and carers; participants were followed up approximately six months after their initial interview to explore whether and how care needs following transition had changed and were met over time. In Phase 2 (implementation), the research team fed back the research outcomes to the four sites, and worked with key stakeholders to use the findings to reflect on and develop local practice.

In each site a group of older people were recruited as co-researchers, working with an academic researcher to plan and carry out the research as well as contributing to the implementation phase activities. A broader local infrastructure for the study was also established, with a statutory and voluntary sector lead partner agency in each area that worked with the research team to build and sustain local engagement. Partner agencies selected a specific transition to be the focus of the study in their area; this helped to establish local ownership from an early stage, and ensured that the research linked with existing local initiatives and priorities. Two transitions were selected: entry into and moving between dementia services (site 1) and going into and leaving hospital (sites 2-4). An evaluation of the participatory approach was also carried out involving qualitative interviews and focus groups with key stakeholders involved in the study.

Results

1. Research phase

This study explored the experiences of different groups of older people, in different locations and circumstances, during different types of health and social care transition. Despite this considerable variation in the topic of investigation, the needs, preferences and expectations which older people had in common were far greater than those on which they differed.

Experiences of transition were frequently accompanied by a sense of disorientation and feelings of fear, worry and uncertainty. Rather than being discrete events, as they are sometimes seen by service providers,

transitions were often continuous so adaptation to new circumstances had to be ongoing. In these situations, people sought to make sense of what was happening to them, in order to cope with and adjust to their experience. They wanted to be seen as a human being, rather than a problem to be solved. Even small gestures by providers to connect with somebody as a person could make a significant difference to their sense of dignity and their overall experience.

Good communication by service providers assisted sense-making activities and helped people to feel safe and connected in an otherwise 'foreign land'. However, many participants faced difficulties trying to access even basic information about their health and services, and notification and preparation for transitions such as discharge from hospital was generally poor. Experiences of stumbling across services, having to seek them out, or even in some cases needing to fight for them were common.

The importance of home and social support in older peoples' lives cannot be overstated. Participants often did not feel comfortable coming forward to seek help from formal services at an early stage, and often found it easier to ask for help from family and friends. Getting to know people in service provision roles over a period of time enabled older people to develop meaningful relationships, and make it more likely that support could be provided flexibly and responsively on an ongoing basis. But the reality for many fell short of this, and poor continuity in care and support arrangements was a frequently mentioned problem.

2. Implementation phase

The implementation phase commenced with local events to feedback the research findings to local services and stakeholders. Older people co-designed these events and read out extracts from participant interviews to illustrate key themes from the experiences shared during interviews. This had a powerful effect: rather than being treated as disaggregated data, services were able to see and connect with the findings as real-life experiences; this helped to generate momentum for change.

Stakeholders across the case study sites said that there were 'no surprises' in the research findings: the issues which the research identified had existed and been known about for many years. Because of this, a wish not to duplicate efforts and consideration of the difficult financial context, local stakeholders embedded implementation into existing work programmes and initiatives. While this approach felt justified, it conflated the findings with a much broader range of plans and activities, and this may have served to lose focus. The exception to this was in Manchester, where a project to guide the development of a person-centred single assessment process emerged from the findings and feedback event.

Engaging the statutory sector was essential to ensuring that change occurred, but this proved difficult at a time of substantial policy and

organisational change. Furthermore, our approach did not produce the kind of instrumental data that local services may prefer and a challenge arose in seeking to translate complex lived experiences into tangible service improvements. An important lesson from this study is that gathering experiences in the form of stories enhances their power and richness, but may demand even more careful and creative thinking to turn 'raw data' into concrete actions.

3. Evaluation of the participatory approach

The main motivation for co-researchers to participate in this study was the desire to improve services, often resulting from their own experiences as service users and carers. Co-researcher involvement was felt by all stakeholders to have had a positive impact on the study, especially in terms of data collection and local dissemination of findings. There was general agreement that having older researchers involved in the interviews put participants at ease and that it was helpful for the person interviewing to share some characteristics with the interviewee. Factors that helped the co-research model included time for academics and co-researchers to develop relationships and trust, and the provision of training and support.

Conclusion

Care transitions involve far more than a move across services or settings. Participants in this study experienced transitions on a number of different levels: 1) physical, including bodily changes as well as use of services; 2) psychological, with changes in their identity or sense of self; and 3) social, with changes in their relationships with partners, family and friends. These different transitions often happened simultaneously and if circumstances made coping difficult in one type of transition then it was likely to have an effect on others. Whilst the physical aspects of transition are often a priority for service providers, the importance of the psychological and social aspects was frequently overlooked.

The way older people are treated by professionals and staff has a considerable impact on their overall experience. Most of the suggestions participants made for improving services called for 'micro-changes' in the care environment and in interpersonal relationships. There was little suggestion that what was needed was new or different services; easier and earlier access to existing services emerged as a far greater priority. While these micro-changes may not cost large amounts of money, they do require committed and sustained effort to challenge existing ways of working that may be deeply ingrained in organisational and professional cultures.