

**“It’s very weird having other  
people in the space that you think  
is kind of private”: Choice and  
decision making around home  
based health and social care  
services**

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The Policy Research Unit in Quality and Outcomes of person-centred care (QORU) is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics (LSE) funded by the Department of Health.

Our aim is to improve the quality of health and social care of people with long-term conditions through generating high-quality evidence about need, quality and outcomes of person-centred care.

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## Background

The government wants everyone who needs health and social care support to have choice and control over that support, whether at home or in residential care settings. Existing research suggests that good information is key to helping people make choices about their care. Good information should be accessible and up to date. We also know that some people are better able to access information and organise their care than others, depending on different factors such as age, gender and social class. It is apparent that the experience of illness is shared between the person with the illness and their family members, and evidence suggests that informal carers (that is, carers who are unpaid) may not ask for formal care (that is, paid carers), even if they may need it. This is partly due to people wanting to remain independent and not have paid staff in their home.

## Aims

The study aimed to:

- explore how people with long term conditions (LTCs) or their carers make the decision to have formal care in the home
- identify the triggers and barriers to the use of formal home care services
- to identify what information people use when making decisions about formal home care
- contribute to discussions around what is 'good' information

## Methods

We analysed interviews with 235 people who either had Parkinson's disease or autism, or who had survived heart failure or stroke, or were carers for people with Multiple Sclerosis or dementia. The interviews were conducted between 2003 and 2012 and people were asked to talk about their experiences without interruption, and then the interviewer followed up their stories with some further questions.

The data were analysed and three main themes or areas emerged: how people felt about having formal care in the home, how people organised formal care in the home and what sort of information they used to reach their decisions about this (see Table 1 for sample extracts). We then examined these three themes looking specifically at choice. We thought about choice in two ways; the operation of choice, how people choose between different options of service type and provider, and the mechanisms of choice, the factors which help people to make their selection.

## Summary of findings

**Table 1: Sample Extracts**

Theme	Example extract
<b>How people felt about formal home care</b>	I: And is it ok having home help in?  P: Oh yes. We look forward to it. In fact my husband looks forward to it more than me. He didn't want a home help at all, but now he's quite happy. I think he would miss it if he wasn't getting it now. (S24)
<b>How people organised formal care in the home</b>	And one day it took me three quarters of an hour to coax her [wife] into the bath, and I was getting so frustrated and of course it was rubbing off on her and she was getting uptight. So I literally went down the stairs after we had finished and rang Bathability who the psychiatric nurse had mentioned long before, probably eighteen months before. (ALZ50)
<b>What information people used to make decisions about formal home care</b>	It's [um] but sometimes, until these things are mentioned to you, you don't know what's available, really. [um] You have to rely on other people to mention them to you [um] and not knowing anybody else with MS or a similar condition that's had this help from the council we weren't really sure what was aware, weren't really aware, rather, what was available. (MSC19)

As expected, most people expressed a strong desire to remain independent and not have formal care in the home. Various factors influenced this desire including the age, gender, ethnicity and social class of the person, their family situation and the severity of their illness. The decision to use formal care was often an outcome of discussions between various people, including the person who needed the care, family members and health or social care professionals. Sometimes there was disagreement between the person with the LTC and family members. In other cases, the trigger to deciding on the use of formal care could be post-hospitalisation for a stroke, deterioration in health or the needs of an informal carer for help or a break.

We found that people were not offered a choice of different types of formal care, such as personal support or respite care, or a choice of providers of formal care, the company offering the staff. For example, people were offered the option of respite care or, if they refused it, having no support at all. We also found that the service offered was sometimes not fit for purpose or was not good quality. For example, some carers of people with dementia wanted someone to take their relative out for a walk or to sit with them, but they were only offered cooking and cleaning support. In other cases, the respite provision offered catered for an older age group than the recipient, or did not have appropriately trained staff. Many private care providers also had a high staff turnover, which meant different care workers entering people's homes to provide the care. Some people who paid for their formal care with their own money (self-funders) were able to organise more effective care, drawing on their networks of friends and neighbours, and a few people used direct payments to buy care.

People's ability to choose was also affected by a lack of appropriate information. People were not aware of what services or support were available, or what they were entitled to. They did not understand the way in which health and social care were organised, or who was responsible for what. They described how professionals failed to make their roles clear and how there was a lack of joined up services. People said that they had expected to be given the relevant information from health or social care professionals, but actually obtained this through various sources including other people with the same condition, support groups, professionals and the internet. People varied in how much information they wanted at different points in their illness with some wanting a map of what to expect and others preferring not to know what lay ahead.

Some people were able to obtain the relevant information and organise their support, particularly those who paid for their care themselves.

## **Discussion and Conclusions**

- Making the decision to have formal home care can involve the person needing the care, their family or friends, health and social care professionals. It can be a difficult decision to make, partly because having formal care in the home can be unsettling and disruptive.
- Some people were better able to organise effective formal care and this appears to relate to their social class and ability to pay for the care themselves. This suggests a lack of fairness around access to appropriate information and organising formal home care.

- People were unable to make a choice about formal care because they were not offered options to choose from. This means that the government's aim, for people to have choice in health and social care, is not happening. People were often only offered one service, or nothing, or a service that was either inappropriate, insufficient or of poor quality.
- Increasing use of direct payments may facilitate a more effective mechanism of choice but choice only becomes meaningful if there are available and relevant options of services to choose between. This is reliant, in part, on the restrictions placed by local authorities on the use of direct payments.
- The ability to make choices about formal care was also affected by a lack of 'good' information. The information people needed to understand what they were entitled to and how to organise that support was not readily available. This was complicated by a lack of joined up services between health and social care.
- People need to be given a range of types of formal care, and of providers of good quality formal care, to choose from. They also need to be given clear, accessible, timely information detailing these choices and their entitlement to them.
- We do not know whether people, particularly informal carers, would accept earlier that they needed formal care in the home if there were more service options, good information and better integration of health and social care. Of course, the current changes to who is entitled to support in England will also lead to a postponement in the use of services by those who do not have the resources to self-fund and this further undermines the principle of choice.
- Further work is needed to explore whether people and providers treat health and social care provision in the home differently. It could be that health care provision focuses on the person with the LTC while social care focuses more on the household.