



“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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October 2012



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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This is an independent report commissioned and funded by the Policy Research Programme in the Department of Health. The views expressed are not necessarily those of the Department.

Introduction

This study explores how people with long term conditions (LTCs) and their carers decide to use and organise formal care within the home through a secondary analysis of 230 in-depth interviews. Within this report, we use the term ‘formal care’ to refer to personal support, non-physical care and emotional/psychological support, as defined in the Home Care Standards Act (2000), as well as to health care services provided in the home and the use of day centres, respite and short term breaks.

Background

Personalisation, according to the Department of Health (DH), means that every person who receives support, whether provided by statutory services or self-funded, will have choice and control over the shape of that support in all care settings. The Association of Directors of Adult Social Services estimates that 35% of eligible users and carers in England were using personal budgets by April 2011 but that there are variations across age and type of condition. In a third of these cases, the recipient had taken their budget as a direct payment and in the remaining; the local authority was managing the personal budget (Samuel, 2011). There is concern that self-funders, who account for an estimated 35% of the social care market (Department of Health, 2008), remain largely unsupported by local councils and receive limited information, advice and support (Hudson and Henwood, 2009).

A brief review of existing research suggests a tendency to focus on health *or* social care in studies, rather than engaging with these as overlapping types of formal care. People with LTCs may need both health and social care support within the home setting and there is a lack of joined up health and social care provision (Caring for our Future, 2012). Social care interventions often focus on the technical efficiency of the informal care network, while health care interventions focus more on making the individual better able to maintain or restore function to the individual (Netten and Davies, 1990). Much research about formal care services focuses on the experiences of older people, underlining demographic changes in the UK and other advanced industrial countries, although it is argued that there are similarities between caring for older people and for those with LTCs (Tullett and Neno, 2008).

Choice

Choice is an organising principle of health and social care policy in the UK, although the operation and mechanics of choice warrants attention. Users have arguably become consumers within an economic framework of 'rational choice' which maximises utility and relates to conceptions of autonomy, inclusion, rights and citizenship (Botti and Iyengar, 2006). The emphasis on choice has led to a widening of what is considered to be appropriate formal care provision beyond the traditional focus on personal care in the UK (ibid). It is now accepted that people can choose to include a diverse range of services or activities to create person centred care and support, although whether this is the case is less clear in practice.

'Good' information is presented as a precondition to choice in academic and policy arenas. Information should be accessible, up to date and accurate (Arksey and Glendinning, 2007), and tailored to individual need both in terms of content and presentation (Fasolo et al, 2010). A recent scoping review on access to information about social care services found that a range of information available through a single source is important to social care service users (Baxter et al, 2006), while a review of the use of quality information in decision

making about health and social care services found that word of mouth is a key source of information (Turnpenny and Beadle-Brown, 2012). In practice, people tend to draw on a range of information sources (ibid). A report into the health and social care experiences of people with long term neurological conditions found a lack of information about care options and patchy, uncoordinated services (Winchcombe, 2012). In addition to 'good' information, there obviously has to be a choice of good quality services and support available. Meaningful choice involves the option to choose between different types of provision or support and a range of providers rather than a choice between one service or nothing (Dowding, 1992, Arksey and Glendinning, ibid).

It is important to remember that access to information is not equitable with some people better placed, in terms of financial and social capital, to gain and make sense of information than others (Clarke et al, 2007). Demographic factors, such a socio-economic class, and access to social networks, constrain or enable peoples' ability to exercise choice and some people are likely to be able to attain better outcomes than the 'resource poor' (Arksey and Glendinning, 2007). We argue discussions around choice, particularly among policy makers, seem to be overly focused on the principle of choice without fully exploring how choice works in practice.

The 'informal' carer

The beliefs and perceived needs of informal carers need to be taken into consideration by care providers as the 'sharing' of the illness experience between patient and informal carer is evident in studies of people's experiences of LTCs (Hynes et al, 2012, Clark et al, 2007). It is well documented that informal carers provide care because of a sense of obligation and duty, but also because morally, they perceive it to be the right thing to do although they may not perceive themselves as 'carers' (Twigg, 1994). Many people frame the care they provide as reciprocation for the love they have received over time (Lewis, 1998). The way in which informal carers perceive themselves and their role has implications for the type of information produced around the use of formal care. Little is known about the decision making processes of those without informal care-givers (Baxter et al, 2006)

Egdell (2012) argues that care decisions are the result of a complex interplay of social, moral, emotional and cultural factors, to which we add economic and political factors. Moreover, the social networks of people can influence their willingness to seek formal or informal help (Pattyn et al, 2011). Tensions around power and the relationship between care providers and family caregivers exist, as family caregivers encounter both barriers and facilitators at an individual and system level (Gantert et al, 2009, Neufeld et al, 2008). Care recipients can also resist formal care. For example, people with dementia who live alone can often refuse to use either home care or day services even when informal carers are not able to care adequately for them (Durand et al, 2009).

Evidence suggests that informal carers do not readily ask for formal care even when they need it (van Exel et al, 2008). The importance of informing caregivers of the relevant

advantages and quality principles of using health and social care home services is arguably central to reducing the number of caregivers who think they do not need help (Graessel et al, 2011). Although, again, we caution that sufficient availability of good quality care is needed.

The home

The desire to remain at home, through periods of ill health is well documented in existing research (Ryan et al, 2009, McGarry, 2009, Harrefors, et al, 2009, Schofield et al, 2006) and home care is seen as a critical benchmark in healthcare provision. This is not without challenge, however, as research highlights the unacknowledged tensions and strains created by this emphasis on care in the home (Exley and Allen, 2007). The home is “imbued with a legacy of powerful notions of family, privacy and control” (England and Dyck, 2011, p217) and with the shift from institutional to community based care has become a negotiated space between the private and the institutional (Milligan, 2009). Whilst the health and social care needs of patients may override the private space of the home, informal carers may resent this intrusion and the reordering of their domestic space into a paid workplace (England and Dyck, 2011). This calls into question the distinction between ‘caring for’ and ‘caring about’ which becomes less certain within a domestic environment. Whilst regulations constrain and limit the caring practices of formal home care staff, the location of the caring work within the family home can be troubling (Angus et al, 2005). The home is not just a physical space but also the social and emotional relationships therein (Exley and Allan (ibid, p2317). For Dyck et al (2005) the home space (and the bodies within) remains paradoxical; private and public, individual and social. We suggest the home, once formal care is introduced, may become a more liminal space that is neither public or private, or individual or social.

Overall, there has been little focus in existing research on the decision making process leading to the use of formal care in the home. Baxter’s et al’s (2006) scoping review found little evidence of accessibility of information about short term breaks, respite and day centres. We know that barriers to the take up of formal care in the home include not wanting additional help, the negative experiences of others and inappropriate and insufficient services (Gott et al, 2007). We do not know what makes people decide to use formal care, how they go about organising formal care and what information sources and resources they use, or would like to use. Here we re-analyse a sample of 230 interviews with carers and patients with LTCs in order to;

1. Explore the decision making process undertaken by people with LTCs and their carers in arranging home based care and support, with a focus on the operation and mechanics of choice.
2. Identify the factors, triggers and barriers to the use of home based care and support.
3. Identify the information resources and sources people use in making these decisions.
4. Contribute to discussions around what constitutes ‘good information’.

Methods

The qualitative data used in this project were gathered as national, purposively sampled interview collections which aimed for maximum variation. The interviews were collected by experienced qualitative social scientists working with the Health Experiences Research Group in Oxford between 2003 and 2012. All interviews were tape recorded, transcribed, checked by the interview participant and copyrighted for a number of non-commercial purposes, including secondary analysis and publication.

The projects shared a research question (What are the experiences and information and support needs of people with X?) and a common interview method that started with an appropriate variation on an open ended question intended to invite a narrative response (for example, 'could you tell me all about your experiences from when you first thought there might be a problem?'). When the person had completed their account, a semi-structured section of the interview, including questions and prompts about any issues of interest that may not have been fully discussed in the narrative, was conducted. All participants were asked if they have anything they would like to tell other people who are starting out on the same journey and if there was anything they would like to pass on to NHS staff at all levels, who might learn from the participant's experiences. These questions often add rich, informative data about how services and communication could be improved (Ziebland and McPherson 2006)

Secondary Analysis

Six modules were selected for analysis and involved carers of people with Multiple Sclerosis (MSC), dementia (ALZ), stroke (S), autism (AUA), heart failure (HF) or Parkinson's disease (PD). Full details of the demographic details of the participants can be found in Table 1, Appendix A.

Secondary analysis means analysing data that was collected for a different purpose and, as a method, remains indistinct and sometimes contested (see, for example, Hammersley 2010). The relatively unstructured, open-ended nature of the interview method helps to identify the participants' own concerns, meanings and priorities (rather than being linked to a highly focussed research interest) and makes the interviews particularly fruitful for secondary data analysis (Thorne 1994). Most of the researchers who generated the data were available to clarify any unclear sections and the availability of the data in both video and audio form allowed for further clarification. What was more problematic for this study was that the data were collected with an emphasis on health rather than social care. In many of the interviews, this led to an under-exploration of the organisation of home care. For example, the following extracts illustrate the vagueness around social care provision and funding in some of the interviews;

I went to see the doctor and they registered me eventually as disabled and now, I get my Incapacity Benefit and different things to help me out. And they just told me to make the most of my life. (PD44)

And then there came a stage when she couldn't do very much. She couldn't do much in the kitchen and much in the house. And we got in touch with the powers that be, and at that stage it was planned that we could have some carers to come in (ALZ40).

The lack of clarity around formal care is due to both a lack of engagement with the issue of home care by the researchers, and the participants' poor recollection of how home care was organised, and I return to this in Section 3.

The analysis combines supplementary analysis (a closer analysis of sections of the data not originally considered in depth) with amplified analysis (the use of several data sets) (Heaton (2004)). A thematic approach was taken and the data were open coded initially. A tree structure was produced after twenty interviews had been coded. Some codes were subsumed into other codes whilst others were put aside. With each new condition, new codes were added and the earlier transcripts were re-read for any examples of data relevant to new codes. A visual mapping technique was used to explore the data within these codes and make linkages and connections across the data (Ziebland and McPherson, 2006). The core themes were orientations to the use of formal home care, the organisation of formal home care and information. These three themes were further analysed using two dimensions of choice; operation and mechanics.

Public involvement

Two interviews (S14 and AL04) were read by two members of the public/people with LTCs who were recruited through the Public Involvement Implementation Group that was set up to advise the QORU¹. They independently noted sections of the data that fitted into the codebook. Their interpretations were checked by the researcher (SR) to make sure that areas had not been missed out or misinterpreted. The second coders identified some extracts that had been missed during the initial coding, particularly extracts relating to 'perceptions of need'.

Findings

Choice and decision making

Some people clearly detailed the point at which the decision to seek formal care was made. This often related to the needs of the informal carer who reached a point at which they could no longer care unsupported. In some cases, professionals recognised a need for support before patients or carers were willing to acknowledge they were struggling.

As far as professionals go, I suppose I've had all I could expect and hope for really without having my hand held all the time. And I don't think anybody wants, I think we all resent being taken over by professionals, perhaps not consciously but we feel

1 QORU is a DH funded Quality and Outcomes of Person-Centred Care Policy Research Unit

we want to deal with our own lives ourselves and keep it at that, somewhere at the beginning of our minds, and initially. [...] Maybe not everybody, but while we're coping and before we admit that things are as bad as they are, perhaps even to ourselves, you get that feeling. (ALZ46)

Sometimes the trigger was the need for the carer to have more help with caring, rather than a break from caring. For example, one carer described the stage at which his wife, who had MS, started to use a wheelchair and he was no longer able to help her get undressed as the point at which he needed help. Another carer said that the trigger was when he could no longer get his wife out of bed and she refused to let him wash her.

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)

Apart from a very small minority who received direct payments (DP) and some self-funders, people did not articulate a sense of a principle of choice. Most participants with state funded support did not talk about a choice of services. The decision they often faced was whether or not to accept formal support, rather than a choice between type of provision or providers. Self-funders were more likely to discuss choice, although this choice was not always meaningful without relevant information to help them choose between care providers. For example, one woman caring for her mother with dementia was given a list of providers by social services and said;

I picked one more or less willy-nilly and I had established that it was probably the largest in this county or at least in this town and was used a great deal by Social Services and I thought well if they're using it to that extent then it must be fine. (ALZ15)

The principle of choice could, of course, be undermined by people's health status. When deterioration in health is sudden and acute, as is often the case with strokes, people are not able to exercise choice. Most participants who experienced strokes often returned home after sometimes lengthy stays in hospital and had a care package in place. Home assessments were carried out, usually by occupational therapists, to assess what sort of adjustments, equipment and formal care patients needed.

Most participants expressed strong normative beliefs about autonomy and independence. They preferred to make small changes to their lives, such as doing less, in order to maintain independence. This resistance to formal care extended to not having adaptations or aids in the home and this was sometimes related to a belief that the introduction of aids or adaptations would lead to deterioration in health.

I: *Do you use any aids around the house to help you with things?*

P: No, no I don't. I try [laugh], I suppose I try not too actually. I, I suppose I try and sort of steer away from that because you want to, you want to maintain as much normality in your life as you possibly can. You don't want to feel like you're being beaten by this disease that's affecting you. And my whole sort of strategy is to fight, fight. (PD06)

At the same time, there was often an acceptance and expectation that family members would care for the patient if at all possible. Patients and carers described layers of moral responsibility, reciprocity, kinship obligations and love in their discussions around the provision of care. For example;

I don't, I don't, I don't think I, I even thought of anybody else looking after her to be quite honest. I mean I, I met her when we were 14 and we'd been together all our lives more or less, so I wasn't going to part with her to somebody else! No, no way. (ALZ08)

While staying at home was clearly preferred by most participants, the lack of good quality, appropriate care meant that the experience was challenging. Some linked the quality of carers to the wages paid and a lack of regulation and training around practice. They talked about the importance of care work on the one hand and the low regard it holds in society. Alongside this was the recognition by many people that 'choice' was theoretical rather than practical, as one daughter described how;

Instead of sitting on my mother's sofa talking to me and her about having a little team of carers and how it would be the same ones and allowing us to put forward what we wanted of this team, they should have said 'Well actually that's, you know that's in an ideal world and I'm afraid we're not in a position to do that, at the moment.' But they didn't they said 'Oh yes, well hopefully that's what we'll try and do.' And looking back on it I can see that they were never actually going to achieve it really. (ALZ15)

Some carers, whilst forced to accept formal care because of the health status of the person they cared for, did not like it. The needs of the patient meant that private space became more institutional, and this was troubling for some. For example;

It was this total invasion of any privacy that I might have, the whole of the downstairs of the house was fair game for them. They had total right to go anywhere they wished downstairs. We'd had the downstairs cloakroom changed into a wet room and they'd be in and out of the kitchen. I found that I had got two places to go; either upstairs or in the garden. They were the only two places, and if, as they did, the carers called upstairs, I would not answer them because I felt that if I was upstairs, that it was my right to say 'You do what you have to do, but it doesn't have to involve me.' (MSC17)

The operation of choice

Interaction

This analysis found that the use of formal (and informal care) was the outcome of negotiation between patients, family members and health and social care professionals which, in turn, were influenced by demographic factors. The complexity around this was very apparent. Some level of consensus around the use of informal or formal care was needed and it was clear that household or family members did not always agree. This was particularly common in the dementia interviews where the informal carer decided that formal support was needed but this was disputed by the patient.

And we encountered enormous problems because I think it's a generational thing, my mother found it extremely difficult to accept help. If I did it, it was fine but if anybody else came in then that meant we were exposing ourselves to other people knowing that my father had deficiencies and that was a big problem, because I established the fact that actually there, there was a lot of help available. And we even got to the point where we would book it, I would arrange it for my mother, to be helped for my father, and my mother would actually ring up and cancel it. And I think because of that my father actually went into a full nursing home um, really very much sooner than he really need have done. (ALZ21)

One carer described how his wife, who had dementia, was very resistant to formal care, but he listened to advice from professionals and close family and decided it would help. Another carer said that his GP noticed he was stressed and wasn't coping so put him in contact with the Community Psychiatric Nurse (CPN) who started the process of organising care.

I think if there's one issue where they've [social care professionals] been slightly ahead of me, it's in terms of the provision of respite care, both daily care and more, longer periods of care. I think I felt that, I resisted their advice that maybe the time had come for me to have a little bit of respite and I kept saying "Oh no, it's, it's not time yet, I don't want that." [Um], so in that sense, they were ahead of me, I think and I think they were probably right and I was wrong in, in saying we'd reached a certain point where that kind of provision [for my wife] was needed. (ALZ07)

Many patients and carers felt that their identity, particularly relating to gender, was threatened by their change in health or caring status. Some men expressed shame in giving up work and no longer being "the breadwinner" or the "strong person in the family". Another woman described how she was fiercely independent and found it "frustrating and demoralising" that she could no longer run her home without help. Some women described how their partner expected them to provide care, even though they were growing much older, and some men thought that formal carers would provide better care for their partners than they could. As one carer said, his wife would have "found it very alien" if he had cared for her when she developed dementia. Instead she respected the carers who came in daily.

I: *And do you get any help from social services?*

P: *They, they ask him whether he wants to have a help, home help, you know, because my husband refused to have a help from, because he's, he's that sort of character. He's always wanted me to do everything for him, you know. So it was hard. (S51)*

Some people openly accepted the use of formal care and did not expect to cope alone. This did not mean they were offered a choice of care provision, but that they accepted the need for formal support. They could no longer do particular tasks and, as one carer of a husband with dementia commented, she had “*no intention of soldiering on alone.*”

Well I suppose I never had any difficulty with the decision as to going into respite or going away for a day or an afternoon or a few hours really, because I needed the break. There was no doubt about that. (ALZ33)

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)*

A few people preferred to have formal care rather than expect family members because of a concern about the impact of caring on their relationship. A few people said they wished they'd learned to accept formal care earlier.

Meaningful choice presupposes the availability of different options so that people can choose between x and y, rather than having x or nothing. It also presupposes the availability of valid options. That is, good quality options that meet their needs. Most people were not offered choice of service options and so the operation of choice was compromised. They were often offered a service such as personal care, day centre or respite care. For example;

I wasn't sure whether it was the right thing to do or not but not being there and not being able to see what was going on, I had to accept some help that was being offered. The nurse was offering me the day care centre and we did it. (ALZ09)

She [social worker] could only offer respite care and right or wrong I thought that was wrong for my husband and events later proved that I was right. So I, I couldn't take it up because he, he was so adamant he wouldn't go and so although I think she could have, this was all that she could offer anyway, but she offered it. You know, we got all that there was offered. There may have been other things but I don't know what they were and nothing coming our way. There was no help for anyone coming to the house. (ALZ25)

The service offered was not always appropriate for the participant, or for their carer. For example, several people with autism said they wanted to live independently but wanted someone to call on to answer questions or help them “*to not do bloke shopping or cleaning*”

as they struggled to keep their homes in order and organise their lives. This type of support was not available to them. Several carers talked about day or respite centres that catered for a much older age group or had inflexible provision. One woman described the inflexibility of day centre provision where her husband, who used to enjoy art but could no longer hold a brush properly, was expected to do art on a Wednesday;

Why was he given artwork to do? Because art was on that day for everybody. So here you come to the notion of the person centred care; start with and celebrate what they can do, go along with what they want to do, even if it's something daft like going round the garden picking up all the stones, if that's what he wants to do. (ALZ16)

...during all the time [name] was here the help that I wanted was company and for things for him to do. And all they would offer me was washing and ironing and cooking and cleaning. And I could do that. I'm the generation that isn't overwhelmed by domestic things. I went to work, I didn't particularly want to do them, I paid a cleaner. But I can, I don't mind doing them and it didn't matter, but I wanted him to have company, I wanted him to have stimulus and that could never be provided in any way. (ALZ42)

Quality of available care

There was much criticism of the quality of formal care offered, particularly by private agencies with high staff turnover, inflexible rules and a lack of staff training. Several participants talked about the lack of 'caring' they, or their relative, experienced through formal care. This again compromised the operation of choice as good quality care was not available.

The other thing is they keep changing, about every three years we've noticed they keep changing all the care workers so you never have the continuity [um] of having the same care worker. Since my husband has deteriorated I've had seven care workers. (MSC03)

Before [my husband] went into the nursing home, I'd had live-in carers through an agency and it had been a disaster. I was promised a rota of three or four so that they would get to know [my husband] and he would get to know them. In the end we had a procession of fourteen different people over six months. (ALZ16)

A few people contrasted the 'emergency' care they, or their partner, received on returning home from hospital, who were highly qualified health staff with the 'general' carers who came afterwards;

But then, when you get general carers who follow on and these are the ones you're paying for, they become, they're just normal people untrained, with a love of people and but they'd, slap happy and [er] I just thought, "I have to get to grips with this."

Because it always didn't look clean enough after they'd left and I said to Charles, "Well, what do you think?" And he said, "I'm fed up because I get up at six waiting for them and they don't get here until eleven and then I, they turn up at four to put me to bed." He said, "I don't want them." (MSC37)

The high turnover of staff was problematic as it involved additional work for the patient or informal carer, who had to constantly train staff, and also created issues around dignity as having different formal carers doing personal care could be distressing. Some self-funders were able to operate a more consumer orientated approach to the organisation of support and talked about 'getting rid' of poor quality staff. Self-funders, and a couple of participants receiving direct payments, also demonstrated a more assertive (and effective) approach to organising care. For example;

We're able to talk things through. [um] If we're not happy with a particular carer, we normally first of all just have a word with them and say, "Well, look, we're not happy that you've done that. Can you make sure that that is done in the future because that's what should be done." Because they may not be aware of it. So we, we, do that. Then if it persists, well, then we can, we've got a channel whereby we can go through and say, "Look, we're not happy with this" and they will look into it and take it further. It's very rare that we have to do it. We have had to do it in the past because carers are human beings like [um] all of us are. So [um] sometimes they don't quite do what they should do and we just have to make sure that [um] it's put right. Because there is the company's reputation and my wife's safety as well, and we've got to make sure that she's [um] cared for correctly. (MSC20)

The quantity of care also compromised the operation of choice. Care packages could change with cuts in funding, if people moved to a different area or through the care providers putting pressure on the time staff could spend providing care. Many people talked about services that had been reduced, had waiting lists or were closed altogether. For example;

Like for instance they used to come in the evening for one hour and the idea of that was to help [wife] get washed, changed into her night gear and go to bed. When we had the meetings they says 'Well, if [wife]'s not gonna be ready in thirty minutes to go to bed then she's not gonna go to bed so really we ought to cut the time back to half an hour.' So my reply was 'So if she isn't in bed in five or ten minutes then you can cut it down to a quarter of an hour.' Being sarcastic you see, that's what it amounts to. They said 'No, no, but we could be looking after somebody else.' But they were supposed to be looking after [wife] for that hour. (ALZ08)

The more recent data contained some discussion around the use of direct payments and showed that a few people found being able to organise their care a positive experience. They could try different services before creating a care package that fitted with their needs. Other people did not want to use direct payments, preferring instead to have their care organised for them.

Things like direct payments though are a godsend because they mean that you can choose your care. So you can employ a personal assistant. You can attend day centres or organised activities. It kind of like gives you the freedom to go around somebody who suits and can meet your needs. (AUA04)

We chose not to do that, purely and simply because we didn't want the burden of sorting it all out and then, if anything goes wrong, if they're sick or ill, what do you actually do? We preferred to... we took the choice to stop inside the [um] cushion of the wider thing so if the carer goes ill somebody else sorts that out. So it must have some good things for some people, but it didn't suit us. So we chose to stop within the system. (MSC03)

Some self-funders also described good care arrangements although the level of choice they had was not always clear. The type of care organised by self-funders centred on cleaning, cooking, companionship and gardening rather than personal care. A few people created care packages using neighbours, friends and family members, who provided care on a rota basis, sometimes voluntarily or for a small cost.

Because the ability to appoint your own carers so that you can tailor-make the care, not just for [my husband] but for me and for the whole situation in which we find ourselves has made all the difference between success and failure at this particular end of the illness. (ALZ16)

Mechanics of choice

The mechanics of choice, as mentioned in the methods section, were not always apparent in the accounts. This was partly due to the lack of focus on social care issues in the interviews but also reflects the lack of understanding and awareness participants had of the structure of health and social care organisations.

For most patients and carers, the world of health and social care was a new and complex landscape to navigate. The structure and organisation of the various institutions and professionals involved in organising formal care was ambiguous and service options and entitlement lacked definition and clarity. This ambiguity and incoherence was underlined by frequent statements that started with “*I didn't know...*” or “*Nobody told me that...*”

But the bit that seemed, that I get annoyed about is everything we've, we've done has really had to be things that we've had to find out ourselves. Nobody's ever offered any help or said, “This is what you're entitled to or this is what you can apply for”. There doesn't seem to be any central point where you can get general advice. (S19)

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)

Many patients and carers said they had expected to be told about relevant support and services, and did not realise or think that it should be their responsibility to seek out information. This expectation often led to a delay in the organisation of support. One woman cared for her husband with dementia for years before a social worker became involved and told her about the community psychiatrist. Several people said they did not know who should be responsible for providing relevant information but that someone should. For example;

But certainly nobody told me. I don't know whose job it would have been to tell me, I don't sort of suddenly think, 'Oh they should have told me', I don't, I don't believe this mysterious they, one has to take responsibility but it would have been nice to know from somewhere that this, there was somebody I could have spoken to, perhaps a little earlier than, you know two days before he says 'OK, he's got to go in'. But maybe that's what they do, I don't know. (ALZ25)

Often people found out about support by chance, through informal networks of support which included lay people or professionals unconnected to their care. As one carer said, "I've really, really found it useful to be in the slipstream of somebody else who is just that little bit further down the journey." For example;

And, and, and the other thing I found, we had no, we had no financial help at all. [...] And it wasn't until a friend of ours said, [um] who, who actually was in the RAF, who did something in the RAF, [um] they, they said, "You know, you really could get Attendance Allowance. Have you ever tried for that?" So we did. (MSC10)

I know someone down the road who's got MS, you know, and I chat to him and in actual fact, he [um] he was the one that suggested we go to his hospital because he thought it was good and that's how we found the MS nurse. (MSC11)

When support services were in contact with people, ambiguity could remain about entitlement to support and services. For example, a social worker told one patient that he was entitled to benefits but provided no additional information. Another carer recalled how the social worker encouraged him to ask his 84 year old mother in law, who lived in sheltered accommodation, to help care for his wife with MS for longer periods during the week while he was at work. Many people also described not knowing who the professionals were, in terms of their professional roles or remit.

And then the psychiatrist said to me we need a case conference because I phoned the CPN and I said 'Look I can't cope, you know this I've got to do something, I just can't cope.' So we saw the psychiatrist which we were due to see her anyway and she said 'We need a case conference, we need to something about this.' So we had CPN oh and my social worker whom I thought was a social worker turns out to be welfare

assistant, not a social worker and she said 'I think I need to, to put you over to a qualified social worker.' (ALZ23)

The lack of clarity over entitlements, roles and structures may reflect the complex involvement of different health and social care providers in peoples' lives, and the lack of coherent provision geographically. Some patients and carers explicitly raised a lack of coordinated and person-centred care in their accounts. As one carer said, there was a definite "lack of joined-upness" between services. Limited communication between services led to gaps in knowledge and understanding of service provision and entitlement, and concerns were raised about the homogenous treatment of people with the same condition, particularly when a condition had a variable trajectory.

But no, we felt really the doctor could have cooperated with us a lot more. Again, it was part of the problem, you know, the social worker was working in her little field, the doctor was working in her little field. And we the family weren't getting the information. And again it's all very fine patient, patient confidentiality, but um, if the doctor had cooperated with us more again, we could have supported my mother more. Again, she might have been able to stay in that flat a bit longer. (ALZ04)

However, when you get into the bureaucracy-and it's not the care worker, it's not the [um] social worker that I...they're tied by this bureaucracy, meeting targets etc.- what you actually get there is you're not treated as an individual in that respect. MS affects you individually. Everybody's different with it. Yet they try and put you into a box. And we argue, we're not in a box. What's right for you might be wrong for me. (MSC03)

And incidentally I have four [um] care [um] plans. One for Social Services, one for NHS, [um] one for Crossroads and one for the, [um] the district nurses. So four of them, all of them saying all roughly the same thing. But they all, you know, why, why we don't have one I just don't know. (MSC30)

Some people described how services denied responsibility for them and tried to pass them over to another service. One young autistic woman found her care deteriorated rapidly when she was passed from learning disability services to mental health services. Others expressed frustration at the difficulties they experienced trying to organise care and, again, the lack of transparency around costs and entitlements.

One of the things I found difficult was this transition from the Health Service to the Social Service. I didn't understand it and no-one really explained it to me and you have to push for explanations about these kinds of things. And it's such a grey area you slide into, isn't it? You don't suddenly open a door and go from one room into the other. It's like walking through a thick cobweb sometimes and when you move from the Health Service to the Social Services. When I started to understand the system then I thought 'Well this is ridiculous because, why aren't we told this, why aren't we given a booklet pointing out the transition from NHS to Social Services'. A

gradual one with bits and pieces here and there, what will happen first, what will happen second, what you'll have to pay for now which you didn't before and why you'll have to pay for it and who you'll have to pay. And, none of this was explained properly at all. (ALZ46)

It was apparent from the data that some people were better able to find their way through the system and organise formal care than others. This appears to relate to people's socio-economic class and some participants were clearly more resource rich than others. For example, [MSC30], a retired RAF officer, stated;

Well, I, I, my approach to caring is now, after many years, it, it's a job. [um] A job which has to be done. We know it's a job that has to be done, because I, I, [um] I write to Social Services each year and I say, "I want four weeks' respite each year. These are the dates I'm going to take." I don't ask them, I tell them that this is what I'm going to do. And they h-, have never yet come back and said, "No, that's not a good idea." They accept, because of course [um] now in these days I have also had a, a carer's assessment. So I think you have to take control of these things and tell, tell them what you need. [MSC30]

But if there was more help out there because the onus is on the person with MS or the carer. If I wasn't here, my partner would not have filled in forms. He'd have just said, 'To hell with it.' And there are lots of people with MS who haven't got husbands, wives, girlfriends or whatever. [Um] So it is exceedingly difficult. We need more help and the worse a person gets the more help we need. But, unfortunately, you don't get it. If you don't actually scream and shout and stamp your feet, people just ignore you. (MSC09)

Self-funders and some people with personal budgets were able to create appropriate support and care to meet their needs. Sometimes this self-funded or supplemented package included a combination of paid staff plus friends or neighbours who provided support at no cost. For example;

No, because they offered. The one particular one I'm thinking of the lady that came to clean for my mother and I just said to her, I said 'Don't tell me straight away, think about this, would you ever feel prepared to come and just be a companion to my mother for the same rate of pay?' She said 'I'd love to, love to.' And because it was on a business footing. And then another friend, she was a friend of a friend actually, the vicar's wife, we did that on a business footing and she went in twice a week, so that's three days, and those were on business footings so I didn't feel I was imposing on them. This was all, we did the weekends and so we'd got five days. [...] And the last one was a friend of mine and again she wouldn't accept money. She said 'No.' And so I used to give her at Christmas a lovely big bunch of flowers, Jersey flowers, in fact I used to send it to them all from my mother at Christmas and their birthdays, and now and again I would give her something and say 'Give it to your favourite

charity,' which she would have done, she wouldn't have kept it because she was a great one for helping others and not [um], so she just, the two of them were friends and they didn't want it on a business footing so no I didn't. (ALZ11)

In some respects, self-funders had more choice as they could employ people without the layers of bureaucracy associated with direct payments and personal budgets. A patient with Parkinson's disease said that, after discussion with the social worker, he found his cleaner on "the open market" because the social worker said that it would be cheaper. One man, who cared for his wife with dementia, said that having an excellent care manager was crucial. His wife's care manager did a lot of organising, ringing round various departments and provided very good personal assistants. The council invoiced him for the care.

We started off by having social services. They set the [um] procedures up, made sure it was working okay and then they passed it on to a local company, who come in. [...] we have to pay for all that ourselves. (MSC17)

That same lady still comes in on a Thursday at 9 o'clock and stays through to 3 o'clock. She doesn't now work for Crossroads. She's decided to go independent, so I employ her independently. [um] So I have to employ her so that I can now go off [laugh] and play golf. So I fix myself a, again a period each week where I can now go off and play golf. That costs money. It costs about £70 every Thursday. It's not cheap. But it's what you have to do. (MSC30)

Other self-funders described how social workers "didn't come near them". They found there was a distance and lack of interest in them and they felt unsupported in organising and choosing care for themselves or their relatives. One woman described how it took two months for a social worker to decide not to do an assessment of her mother with dementia and, instead, sent a list of care agency numbers.

I felt that their attitudes were patronising, I felt that [um] they would send in something like an occupational therapist, we got the bathroom done and then they'd say, 'Well, you need to improve the access at the front of your house.' Yes, we probably do. And they'd give us all this stuff that had to be done. I'd say, 'so, what help is there to get all this?' 'Oh, you have to do it yourself.' And I found them just dismissive of, really, the issues. Everything on the surface may seem fine, and I know we're luckier than many, but there was a complete lack of awareness of what it was, from my point of view, what it was like to actually live alongside somebody who was experiencing difficulties. (MSC17)

But it wasn't, when we actually needed practical help [coughs] it was quite difficult to get. There's a lot of, sort of, soft help, emotional support like the carers group and people to talk to and there, there seems to be an awful lot of that but not a lot, we had a terrible time with practical help when we needed it. (MSC18)

The use of direct payments could also be hindered by a lack of information. The following participant, who ended up with comprehensive support and care, described how;

Yes, I was first given direct payments about three years ago and it went completely wrong. It wasn't really explained to me properly. I didn't know what I could do with it, and what I couldn't do with it. And in the end I went back to having commissioned services because it was just easier for me to manage. And then once I'd kind of like exhausted all the, you know, council run services. I had to go back to direct payments. I actually went on the internet and just Googled like autism and learning disability in the area where I lived. And I came up with about three or four independent day services. (AUA04)

'Good' information was not readily available to most people. They had to actively seek out information which was not always clear or comprehensive, creating uncertainty about available service provision and entitlement. Many patients and carers said that different information was needed, both in terms of content and quantity, and for different stages of their illness. This shifting need for information could relate to the resistance to formal care discussed earlier, but also to the health status and well-being of the patient or the informal carer. Some people may not absorb information when they are still trying to come to terms with the diagnosis, when they are very ill or when their caring responsibilities are extensive. The following extracts illustrate the importance of a person-centred approach to information and the layers of social and cultural perceptions around 'needing help';

We had an occupational therapist who was allocated to us very early on; it was indeed she that came to make the initial visit and said 'These are all the services that you can tap into.' I only half listened to what she was saying at that stage. And once, after about nine months when I began to think I needed this woman to really help me through certain things, that's been good. But I guess that's just how it goes. That is does take time before you begin to understand that you need to look outwards towards other supports. I suppose we're the kind of people maybe, like yourself, if you've been used to sort out your own problems without going to outside agencies, and it was a matter of pride that one could do this, but that was kind of misguided. (ALZ07)

No, no there was no plan whatsoever. And [um] yeah that would have been, that would have nice actually to sort of, to know that there was [um] that support if I needed it. And you know, these are the things you have access to and, and, [um] and this is what's going to happen when, when such and such happens and, It's very difficult to, to know because everyone is different and this is why, this is the, this is why I think it's important to, to listen to the patient, to listen what the patient wants and to ask the right questions to ensure that, you know, you know what the, the patient wants. [um] Because only then can you make the right decisions for them or, or, or discuss the decisions with them so, so the right ones are taken. (PD06)

Some people wanted a map of the future so they know what they could expect. They wanted to know what support and services they were entitled to and the different stages of the disease progression. They wanted to be prepared rather than face unexpected issues.

Others only wanted to know the bare minimum about their disease trajectory and their potential future care needs. They did not want to think about the future and were better able to cope with information on a need-to-know basis;

What I found was that each problem that came up, it wasn't until the problem was there that somebody would explain it. But by that time you were in the problem, whereas if it could be taught a little better then it would be a great help I think. (ALZ08)

[Um], I can't think, in many ways you don't want too much information. I mean if, if I'd know when [my husband] started to be ill what life was going to be like for the next ten years I don't think it would have done anything for my state of life at the time. I think you need to get the information as and when you need it and having too much too early is almost worse than not having any. (ALZ39)

At, at the point when you come out of hospital out of rehab, you need a lot of information for the patient and for the carer and [eh] [PAUSE 3 SECS] it, it would be, it would be overwhelming to have it all at once but then you need it all at once because it, it [em] you need to know it's, it's there even if you don't access it straight away. (S22/23)

People described drawing on various sources of information including other patients or carers, professionals (social workers, GPs, community psychiatric nurses, district nurses, consultants, Occupational Therapists [OTs]), organisations (Carer's Centres, condition specific charities, such as the MS Society or Alzheimer Society, Citizen Advice Bureau's), and the internet. Overall, people valued professionals who provided relevant information and demonstrated coordinated care. People were generally very positive about their experiences with OTs and found them very knowledgeable and helpful. Specialist nurses were also highly valued for their support and information, and one person recommended the MS navigator at his local social services department. The information people wanted was sometimes about dealing with particular issues that arose, such as managing personal care, toileting and incontinence. Others wanted to know about more generic issues such as financial or legal support. A key concern for many patients and carers was an emergency contact, in case anything went wrong.

I think all people should have access to a multidisciplinary team. I think [um] people should have the ability to, to draw on other people's experiences [um] because actually that is what people with Parkinson's want to, want to hear. [um] We don't necessarily want to hear the science. We want to hear how other people cope with it. And I think the internet is a huge, huge bonus for that. (PD06)

This concern often related to the level of informal care provided, especially as people got older. As one woman, who was 70, said; "My biggest worry is always being ill. And I think most carers have the same problem". A few people highlighted how reassuring it was to have the contact details for a specialist nurse who they could ring at any time.

I've been allocated a heart failure nurse about 6 or 7 months ago and that was a tremendous help to my case. It's very good to have her number here on my phone. And I told her, I said "I'm really happy to have your number stored in my phone and I know there's someone that I can call at any time". Although I didn't call her but you know, knowing there is someone there that you can call at any time of the day in case of need. That's very important, very important. (HF34)

People liked different forms of information; leaflets, face to face contact, the internet or telephone. Some found telephone helplines reassuring while others preferred face to face contact, either with professionals or with other people who shared their experiences. A few people said a list of names, contact details and a brief description of people's role and responsibilities would be invaluable. Information that was clear and accessible was important to people as the following extract illustrates:

And it's something I've pushed and pushed and pushed for is that these things should be more easily explained. I know they're in booklet form, perhaps everyone won't be able to cope with a booklet, where they should be taken to one side and explained, have it all explained to them properly what the differences are. There's difference of cost. The Health Service everything's free and suddenly everything isn't free because it's Social Services, some things have to be paid for. There are usually things you can cope with paying for but it comes as quite a surprise and people don't understand this and it's very bewildering to a lot of older people that suddenly they have to pay for things. (ALZ46)

Finally, the way in which information was communicated by professionals was noted, with good communication skills being valued. For example,

The CPN we've had from the very beginning and he is excellent. He's very good with me, I know he's very, very busy but when I've had problems he's been on the ball immediately. [...] And he's very good at information sharing. [...] He seems to accept that it's a two way learning process. He doesn't come over all professional on me. He respects my views and my way of thinking and I find that, you know, as a professional myself, I really find that quite helpful. (ALZ22)

Discussion

Our focus on the principle, operation and mechanism of choice has helped to unpack the process of organising formal home care. Different types of decision making are apparent; autonomous, collaborative, delegated or carried out at a crisis point. Decisions are often an outcome of negotiation between various people (e.g. the patient, informal carers, relatives, social and health care professionals, charity workers and support groups and so on) and underlies the point that choice is not an individualised activity but happens within a wider social arena (Arksey and Glendinning, 2007). It is also mediated by social class, gender, ethnicity, age, geographical location and health status. The centrality of the home as a

private space is also a factor. It is not just a physical space but a set of social and emotional relationships and a network of production of wellbeing for all network members (Netten and Davies, 1990). This network has its own way of producing wellbeing that influences decisions around the use of formal home care (although the network is not always harmonious).

The first decision is whether or not additional help, whether formal or informal, is needed and it is clear that people want to maintain their independence for as long as possible. We identified different orientations towards support and who should provide it among family members, and a blurring between the provision of 'informal support' and adjustments in the organisation of domestic tasks between family members, particularly couples. Many people do not have the option of informal support and need formal home care. Those people with informal carers can also need formal support, sometimes to supplement or substitute informal care. Formal care can provide a break for the informal carer, support the informal carer to care or release the informal carer from caring duties.

In principle, patients and informal carers should have a choice between different types of support, such as short term breaks, personal assistance, cleaning, companionship, and from different providers. This did not happen in practice for most participants. The choices people were offered were often compromised or invalid leaving the principle of choice illusory. Most people were presented with a negative choice; the choice of one service option which they could accept or reject rather than a choice of service type and provider. Service options often turned out to be invalid; not fit for purpose, provided in sufficient quantity or not what people wanted. For example, some care provision did not have staff trained to care for patients with dementia, some formal care staff lacked relevant training in providing personal care, and care provision was inflexible, limited by budgets or experienced as intrusive by patients and/or informal carers.

Inefficient mechanics of choice also constrain the operation of choice. Information often had to be sought after rather than given to patients or informal carers by health and social care professionals. The type of information patients and informal carers wanted varied across time and at critical stages. There was often a lack of clear communication between participants and professionals. Negotiating the landscape of health and social care provision was not straightforward and participants struggled to understand the structure and organisation of health and social care support. The lack of good information, that is, information covering structure and process as well as support options, meant that participants were unaware of available support and their entitlement to it. This was particularly the case moving between health and social care as there was a lack of transparency about the two, with no joined up information. As one participant described, negotiating health and social care was like "*walking through a thick cobweb*".

Further work is needed to explore how health and social care provision is treated by people and providers. It could be that health care provision focuses on the individual rather than on the household, and that people are more accepting about the use of health related formal

care in the home, although our data does not allow us to explore this. What is clear is that health and social care need to integrate effectively. What is striking is the overlap between the recently published NICE quality standards for patient experience within the NHS and the concerns that emerged through this analysis. Many of the core domains of these guidelines are identical to the concerns raised by participants; the importance of courtesy and good communication, clarity around professionals' roles, active involvement in decision making and so on. These domains are not new to us and yet clearly remain challenging to incorporate into practice.

The operation and mechanics of choice both involve interaction and we saw how some people were encouraged to use formal care by professionals concerned with the impact of caring on carers, and how informal carers and family members encouraged care recipients to accept formal care. In addition, informal social networks were an important source of information. Within this interactional space, participants demonstrated different levels of passivity to their health and social care needs. Some appeared better able to make effective demands of the system, while others remained less engaged and involved in the process. Some self-funders too were able to create appropriate support and care, while others were unable to access relevant information or interact with social services. This suggests unequal access to appropriate information and support within a personalisation agenda which needs attention.

Conclusion

The extension of choice and control for service users is a core feature of government policy and yet the accounts analysed here suggest that the principle of choice is often illusory in practice. Both the operation and mechanics of choice are compromised through a lack of good quality options to choose between and by unclear pathways to access them. Until people are provided with valid health and social care support options from a range of providers and have access to clear information about these choices and their entitlements to them, the personalisation agenda rings hollow.

Accepting and incorporating changes to the domestic organisation of households can be challenging and we discussed earlier how informal carers may need, but not readily ask for support (van Exel et al, 2008). What we do not know is the relationship between the choice not to have support and the quality of information provided about available services. That is, if there was a greater diversity of options, more extensive and accessible information and a better integration of health and social care, would patients and informal carers be less likely to resist or postpone their use of formal care in the home? The current increases in eligibility criteria in England many lead to a forced postponement in the use of services by those who do not have the resources to self-fund and undermine the principle of choice even further. The gap between policy prescriptions and practice may widen in the current UK context.

The passivity around choice and decision making apparent in many of the accounts is possibly an outcome of compromised dimensions to choice but is also influenced by demographic factors, such as age and gender. The passivity could also relate to the timing of the data collection, some of which was collected before the introduction of direct payments and personalised budgets. Some people found their ability to organise their own care packages through the use of direct payments was a positive development, although this was a very small number of participants. The small number of participants discussing the positive use of personalised budgets leads us to be cautious in dismissing the broader findings as artefact. We suggest that the passivity also relates to the location of care in the home which, with the introduction of home care, is transformed into a liminal space. While most people clearly want to remain at home, the introduction of services into what is considered to be a private space can be unsettling and disruptive.

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Appendix A

Table 1: Demographic table

Module	Stroke	Heart Failure	Autism	Parkinson's Disease	MS (carers)	Dementia (carers)	Total
Fieldwork date	2006 2011	2003	2007 2010	2008	2011- 2012	2004	
No. of interviews	45	40	40	41	35	29	230
No. of participants	48	40	41	41	36	29	235
Age at interview							
16-24			15		1		16
25-34	3		9		1		13
35-44	3	2	7	4	7		23
45-54	7	7	4	7	7	6	38
55-64	9	8	1	16	11	7	52
65-74	10	10	1	10	7	1	39
75+	11	13	1	4	2	5	36
Not specified	5		3			10	18
Gender							
Male	23	25	27	23	16	14	128
female	25	15	14	18	20	15	107
Ethnicity							
White British	42	31	40	39	29		181
Black British	1	1	1		3		6

Module	Stroke	Heart Failure	Autism	Parkinson's Disease	MS (carers)	Dementia (carers)	Total
Fieldwork date	2006 2011	2003	2007 2010	2008	2011- 2012	2004	
SE Asian				1			1
Other	5	2		1	4		11
Not specified		7				29	36
<i>Marital status</i>							
single	3	2	30	1	3	1	40
Married	23	32	6	30	23	24	138
Divorced/separated	6			4	3	1	14
Widowed	10	6		3	1		20
With partner			3	3	6	2	14
Not specified	7		2				9