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Special Issue

Developing the knowledge base about carers and personalisation: contributions made by an exploration of carers' perspectives on personal budgets and the carer–service user relationship

Mary Larkin BA (Hons) MSocSci PhD

Division of Social Work and Health Studies, Faculty of Health and Life Sciences, De Montfort University, Leicester, UK

Correspondence
Mary Larkin
Faculty of Health and
Social Care,
The Open University,
Walton Hall,
Milton Keynes,
MK7 6AA UK
E-mail: Mary.Larkin@open.ac.uk

What is known about this topic

- The mainstreaming of personalisation and more specifically, personal budgets, is set to continue.
- Although carers are central to the successful implementation of personalisation, knowledge about carers and personalisation is emergent.
- There is a clear need for more knowledge about personalisation and carers.

What this paper adds

- Services and support accessed through personal budgets can be used to effect an improved carer–service user relationship.
- Carers need to have confidence in the quality of the care for personal budgets to be effective.
- Sources of stress for carers are local authorities' processes, the paperwork associated with personal budgets, recruitment and staff management.

Abstract

This qualitative study aimed to explore an under-researched issue within the emerging body of research about carers and personalisation – the carer–service user relationship. It was carried out across 11 English local authorities between 2011 and 2012 and focused on the impact of a change in the service user's social care arrangements to a personal budget on this relationship. Using purposive sampling and explicit inclusion criteria, data were gathered through semi-structured in-depth interviews with 23 carers in long-term dyadic relationships with an adult in receipt of social care who had changed to a personal budget. The interviews explored carers' perceptions of the carer–service user relationship before and after the advent of the personal budget and changes that had occurred. The findings were thematically analysed and reflect the fact that in addition to the effects of the move to a personal budget on the carer–service user relationship, the interviewees talked at length about a range of other effects of this move. Just over half of those interviewed felt that the personal budget had enhanced the carer–service user relationship. The other effects were both positive and negative. Three quarters reported positive outcomes, such as feeling happier, healthier and having more control over their lives. Although two thirds experienced negative feelings about having less involvement in the service user's care, these feelings eased over time and if they had confidence in the quality of the care. Over half found administering the personal budget stressful. Further analysis of these findings showed the study contributes not only to existing knowledge about the carer–service user relationship within personalisation but also to knowledge about the effects of personalisation on carers more generally. It therefore simultaneously develops the emergent knowledge base about carers and personalisation. Recommendations based on this analysis are made about future practice and research.

Keywords: carers, carer–service user relationship, personal budgets, personalisation, self-directed support

Introduction

Carers are at the heart of the caring process, and their importance to the successful implementation of personalisation is consistently acknowledged (Newbronner *et al.* 2011, SCIE 2012, Welch *et al.* 2012). Personalisation policies are being progressively mainstreamed, and while there has been a commensurate increase in research evaluating their advantages and disadvantages, there has been less research about carers and personalisation than about other groups (Dickinson & Glasby 2010, Larkin & Dickinson 2011, Slasberg *et al.* 2012, Woolham & Benton 2012, Glendinning *et al.* 2013). Furthermore, the majority of the findings about carers and personalisation have emerged from studies into the various forms of self-directed support, such as direct payments, individual budgets and personal budgets. Although these are the technical levers to bring about personalised services, their visibility has meant that they are often mistakenly conflated with personalisation in its broader sense (Larkin & Dickinson 2011). The fact that the focus of studies has been on the technical levers only limits their contribution to knowledge in relation to carers and personalisation. Other features of studies carried out to date also restrict the extent they develop this body of knowledge. Most notable is the way they are often carried out within a particular local authority, and, because few have focused exclusively on carers, findings about carers tend to be incidental to or only part of a main study (Larkin & Dickinson 2011, Jones *et al.* 2012, Moran *et al.* 2012, Mitchell *et al.* 2013).

Nonetheless, these studies constitute a nascent knowledge base about the outcomes of personalisation for carers. Examples of positive outcomes are that carers are more likely to be undertaking activities of their choice, have more time for themselves and other family members, have a social life, feel in control of their daily lives, have a higher quality of life, enjoy caring and have a better relationship with the person for whom they care. In addition, carers' health and well-being are either less likely to be adversely affected by caring or more likely to improve with self-directed support. However, such outcomes vary with the nature of the needs of the person they are supporting, the amount and quality of the information available to carers and the ways in which different local authorities implement self-directed support (Hatton & Waters 2011, Office for Public Management 2011, Carers Trust 2012, Forder *et al.* 2012, Jones *et al.* 2012, Moran *et al.* 2012, Hatton *et al.* 2013).

Among the less positive outcomes is the stress carers can experience because of self-directed support.

Examples of the sources of stress are the self-directed support processes, tensions around specifications on what resources can be used for and tailoring individual support in a flexible and creative way. While the administrative and managerial tasks associated with self-directed support can also be burdensome for carers, particularly at the beginning of the process of setting up personal budgets, those carers with previous experience (paid and unpaid) of these tasks cope better (Rosenthal *et al.* 2007, Grootegoed *et al.* 2010, Callaghan *et al.* 2011, Routledge & Lewis 2011). Other findings indicate that carers have to cope with several changes in their caring role, which they may find challenging. These changes include the service user making more decisions about their own care and, because personal budgets can be used to pay the carer for the care he/she provides (or at least some of it), entering into a contractual relationship with the service user (Rosenthal *et al.* 2007, Glendinning *et al.* 2009, Duncan-Turnbull 2010). With reference to the latter, there is also evidence that when carers become a paid personal assistant to the relative they care for, they still bear the burdens of caring, which in turn adversely impacts other aspects of their lives, such as their social and working lives (Breda *et al.* 2006). For example, a recent study showed that personal budgets do not improve carers' opportunities to undertake paid employment (Hatton *et al.* 2013).

Parallel demographic and policy developments attest the importance of progressing understandings of the impact of personalisation on carers. The long-term demographic shift towards an ageing population and continuing improvements in the longevity of children and adults with lifelong disabilities mean that the number of carers will increase. Indeed, three in five adults in the UK will become a carer at some point in their lives (Buckner & Yeandle 2011, Carers UK 2013). Personal budgets for service users and their carers, involving a needs-based sum of money being directly paid or managed by the Local Authority, are now a mandatory part of all care plans. Other policy developments have introduced personal health budgets for people receiving NHS Continuing Healthcare. Consequently, more of those who are carers will directly experience a personal budget of some sort, either as a result of the person they care for being in receipt of one or in their own right (Department of Health 2012, HM Government 2012, Carers UK 2013). Personalisation will therefore impact the lives of the growing number of people in our society who will become carers. Simultaneously, policies are reflecting a commitment to improving the outcomes of personalisation for *all* carers (ADASS 2009, Department of

Health 2010a,b, Moran *et al.* 2012). Such a progressive impact, together with requirements to address carers' needs, points to an ongoing need for *more* knowledge about personalisation and carers.

While this study addressed this need for further knowledge about personalisation and carers, its specific aim was to contribute to the emerging knowledge base about carers and personalisation by exploring a hitherto under-researched key issue. As previously mentioned, existing studies have provided some insights into changes in the caring role that occur as a result of personalisation, which affect the nature of the relationship between service users and those who care for them. There has been a growing recognition of, and interest in, the importance of this mutually dependent relationship with the delivery, quality and experience of care in general and within a personalised approach to service delivery (Shakespeare 2000, Barnes 2006, Dalley *et al.* 2012, Nelis *et al.* 2012). Thus, changes in this relationship and the implications of these changes for carers are an aspect of the impact of personalisation on carers, which requires further exploration to ensure the successful implementation of this agenda within health and social care. Hence, this study was designed to develop better understandings of how a change in the service user's social care arrangements to a personal budget affects the carer–service user relationship.

Methods

A qualitative design comprising semi-structured in-depth interviews with carers selected through a process of purposive sampling and the application of explicit inclusion criteria was adopted. The study was carried out by the Carers Federation and De Montfort University between 2011 and 2012. Ethical approval was obtained from both organisations and their requirements were adhered to throughout the study.

Sampling and data collection

Semi-structured in-depth interviews were carried out with 23 carers drawn from 11 English local authorities (8 County Councils, 2 City Councils and 1 London Borough). The recruitment criteria were:

- the carers were in a long-term dyadic relationship with an adult service user whose social care funding had changed to a personal budget and
- the personal budget was paid directly to the service user.

Dyadic relationships can be defined as binding (this includes legally binding), usually continuous associations between two individuals. Such relationships involve commitment and the individuals con-

cerned are also often related (Spruytte *et al.* 2002, Nelis *et al.* 2012). As most caring is embedded in a dyadic relationship (Larkin & Milne 2014), the exclusion of carers in other types of relationships increased both the representativeness of the sample of carers who participated in the study and the generalisability of the findings. The decision to only include carers of those whose social care arrangements had changed to a personal budget was taken because the mainstreaming of this form of self-directed support meant that the findings would be highly relevant to current and future developments within personalisation. The reason for the focus on personal budgets directly paid to the service user as opposed to Local Authority managed personal budgets was that these are more likely to impact on the carer–service relationship (Moran *et al.* 2012, Hatton *et al.* 2013) Thus, this form of personal budget optimised the opportunity to explore how this relationship is affected by a change in the service user's social care arrangements to a personal budget.

Carers Federation staff recruited the interviewees by sending an information leaflet about the study to carers' centres and carers' organisations in England known for their work around personalisation. In addition to outlining the study, the leaflet set out the eligibility criteria, invited those interested in taking part to contact the researchers and informed participants of their right to confidentiality and to withdraw at any point.

The semi-structured interview schedule was piloted with the first four carers to make contact and then refined to maximise carers' responsiveness. The final version of the interview schedule focused on carers' perceptions of the nature of their relationship with the service user before and after the advent of the service user's personal budget, current level of satisfaction with this relationship, adjusting to the personal budget, support available to them and any changes in stress and happiness levels. The effects of the move to a personal budget on their activities, role and other relationships were also explored.

After the pilot, interviews with 25 carers, all of whom had volunteered to take part in the study upon receipt of the information leaflet, were conducted. Written consent was obtained from each one at the beginning of their interview. The interviews were digitally recorded and lasted between 60 and 90 minutes. Transcription was carried out before analysis and involved anonymising each transcript, including the use of fictional personal and place names.

Although all of the interviewees were in a long-term dyadic relationship, it transpired during the course of the interviews that two of them did not meet the second of the inclusion criteria. Therefore, these interviews were not analysed.

Data analysis

The transcribed interviews were thematically analysed using inductive coding (Boyzatis 1998, Braun & Clarke 2006). Iterative readings of the transcripts were undertaken and initial data-driven codes generated. Given the sample size, during this recursive and systematic process, coding was performed manually with text highlight colours. Thematic maps were used to identify how different codes combined to form themes and the relationships between codes, themes and different levels of themes. This resulted in the identification of key themes and sub-themes within them. These were then reviewed by revisiting the coded data extracts for each theme to ensure that the data within each of them and their sub-themes cohered meaningfully. Where themes did not capture the contours of the coded data, they were reworked or discarded as appropriate. The penultimate stage involved assessing the validity of the thematic map in relation to the whole data set, making further refinements to the themes and revising the titles of the themes so that they were all conceptually meaningful, clear and concise. Finally, a summary of each main theme and its sub-themes was produced to capture the overall 'story' that had emerged from the data.

The last stage of the data analysis involved triangulation of the summaries of the themes in two forums; one was a group of carers who had direct or indirect experience of personal budgets and another was at a meeting of a Local Authority Carers Lead Officers Network. These forums were used to confirm and develop interpretation of the data to gain a deeper understanding of its relationship with knowledge about carers and personalisation (Devine & Heath 2009, Perri 6 & Bellamy 2012).

Findings

The key characteristics of the sample are set out in Table 1. This shows that the interviewees' dyadic relationships were either partner relationships (married, civilly partnered or cohabiting) or parent–adult child relationships.

During the interviews, in addition to talking about the impact of the personal budget on their relationship with the service user, the carers volunteered much information about the impact of personal budgets on their lives more generally. This was reflected in the findings; while the study showed that a service user's personal budget could enhance the carer–service user relationship, it also provided insights into a range of positive and negative effects of service users' personal budgets on carers.

Table 1 Carer characteristics

	n
Type of dyadic relationship	
Partner relationship	18
Parent–adult child relationship	5*
Age	
30–45	6
46–64	8
65+	9
Gender	
Female	16
Male	7

*One of these carers cared for twin daughters with Down's syndrome.

Enhanced personal relationship

Although there was no evidence that any of the carers and service users in partner relationships had been in crisis, several of these carers reported that their relationships were 'strained' and over half of them felt that the change to a personal budget had effected improvements. This sentiment was expressed by Molly when she said that while it had not got to:

…the point where Richard and I have discussed separating or divorce … but it is our silver wedding next year and we are renewing our vows, so it is a really positive thing and I think the personal budget has got a lot to do with that.

Many different reasons were put forward for the improvements which had taken place. One male spousal carer admitted that he used to be 'dominating' and now that his wife had more control, their relationship had 'improved, because she's much happier in being able to take a greater part in running the home'.

Others said that they were more 'relaxed' and 'less snappy' with each other. Another reason given was that they had more control over their lives as a couple; Edith whose husband had multiple sclerosis (MS) said:

We have no control over the MS and that is accepted, but we have got control of how we live our life and that was a massive issue beforehand.

Interestingly, none of the four carers who were now employed by the service user felt that this contractual arrangement had changed their relationship. Instead, they focused on how they liked the flexibility to choose how much caring they did.

Carers also attributed their enhanced relationship with the person they cared for to the fact that they used the personal budget to access services, which

enabled them to undertake activities 'individually and together'. The opportunity for greater independence through 'appropriate support' meant that they could have 'a break' from each other. As Cathy explained:

Both of us like to be by ourselves and we couldn't be on our own at all before and now we can be to some extent and that improves our relationship.

The exception was the carer who missed the time she used to spend with her husband in their pre-personal budget days; she said:

I used to love taking him out and going out with him, but we don't have time for that now very much.

While having more independence was valued, those in partner relationships specifically valued the way they could now share activities and commented that this played an important role in enhancing their relationships; it was described as 'opening up our vista' and there were comments such as 'we can be a couple again' and 'I've got my husband back'. Examples of shared activities were pursuing interests and socialising together. For instance, John explained how he and his wife Joan were now:

...able to go out together and eat. Although I have to feed Joan, it doesn't stop us going out and enjoying our lives and restaurants together, and going out with friends and so forth. All these things have become more evident I feel with the personal budget.

Similarly, Robert talked about how:

The (personal) budget ... encouraged us to get out and about and do things ... like our cycling ... we go out and meet other people.

Three commented on the fact that there had been no or little change in quality of the relationship because of the age of the service user as well as or in addition to their illness or disability. For example, one of the older carers said:

It hasn't changed an awful lot because of Keith's age and condition.

The significance of the service users' disability was poignantly highlighted by one of the younger carers; she said that the personal budget had not brought about a changed relationship with her husband as his disabilities meant that:

There is not really a relationship; I'm here, and he's comfortable with what's happening. And while he's happy I just toddle along.

Furthermore, the point was made that a service user's condition can result in the carer–service user relationship 'changing all the while' and hence

enhancement through a personal budget may only be temporary.

Positive outcomes for carers

Personal budgets had resulted in positive outcomes for over three quarters of the carers. In general, they felt happier, mainly because they had 'more freedom'. Comments included 'it's freed my life up' and 'before I had to it all, everything, I felt much more trapped and almost resented it and I don't anymore'. Increased freedom meant that they had more time to themselves and could pursue their own interests. One parent carer had picked up interests he had dropped because of the demands of caring for his son:

I used to go to the football with my brother and a couple of other guys a few years ago, and I'd stopped doing that because it was getting more difficult. And he offered me this year the opportunity of a season ticket, and my wife was saying 'of course you can do it, we've got carers' and I'm not only going, but enjoying it. I play golf a couple of times a week too.

Some had started to pursue new interests. An example was June who had taken on an advisory role with a charity, which she described as:

...life changing I suppose in the sense that I have been invited to do things that I never thought I would be asked to do ... being interviewed for national news, sitting on advisory boards ... that wouldn't have happened if we had not been given the opportunity of having Eric's personal budget.

However, a third said their increased happiness levels were due to the fact that the person they cared for was also happier. This sentiment was summed up by the carer who said 'Well, if he's happy, I'm happy. It rubs off, doesn't it?'

The carers who talked about the positive effects of personal budgets on their lives also said that they were feeling healthier; having more free time enabled them to 'do some exercise' and 'keep fit'. Many commented on the fact that they were healthier because they felt less 'stressed'; arrangements made through the personal budget had 'taken stress off' them and afforded them more 'opportunities to relax'. As Jude explained, employing a personal assistant for her partner in the evening meant that she could:

Just completely relax for an hour, because I know I'm not going to get called, to do anything, or get anything, or move anything. I know for that 1 hour he's not going to say 'Jude'.

Negative outcomes for carers

As demonstrated, reduced caring responsibilities contributed to the positive effects of personal budgets on

both the carer–service user relationship and on carers' lives more generally. However, two thirds of those interviewed experienced negative feelings about being less involved in the service user's care provision. They not only talked about feelings of being 'pushed out' and 'redundant' but were also anxious about the replacement care accessed through the service user's personal budget. Indeed, the extent to which carers reduced their caring responsibilities was often dependent on their confidence in that care. The parent carers talked about the importance of having 'people whom you trust' because:

…they are taking your most precious thing out you need to be absolutely sure that they are going to treat the young person properly.

Both partner and parent carers made comments such as 'I've got to feel confident' and 'it makes a terrific difference' if 'I know I have got a carer that I can rely on'. In some cases, personal assistants had 'become friends of the family almost', which was 'an incredible help'. When carers lacked confidence in the standard of care, it was hard for them to 'let go' and relinquish caring duties. An example is Derek; although paid carers were supposed to wash his wife's hair, he found himself doing this for her because he 'didn't trust these guys'. Others felt that their role could not be done by someone else because they would 'not know what to look out for' and that 'learning the job' can 'take a long time'. Furthermore, there were situations where a lack of expertise about the service user's needs could be a safety threat. Such situations led to carers being even more reluctant to 'take time out' from caring. As Maureen explained, her partner will:

…do things that'll be a danger to him, and sometimes people aren't aware that he's going to do them. Like taking the lawn mower to pieces, he could cut himself if he goes down to the shed, and they don't follow him…, so it's difficult for me to leave him with people….

Although most of the carers reported that over time they gradually felt 'a bit more relaxed' about having less involvement, their concerns inevitably shaped the opportunities personal budgets afforded to improve various aspects of their lives.

Another negative outcome for carers was the administration of the service user's personal budget. Over half felt that personal budgets were stressful to administer. Reference was frequently made to the lengthy and 'complicated procedures' that had to be worked through to set up a personal budget. While the day-to-day administration of personal budgets was very time consuming, the paperwork,

recruitment and staff management were seen as particularly problematic. With respect to staffing, several difficulties were identified. The first was:

…finding the right people … you really do get all sorts of people, with limited training and not necessarily the attributes of being a carer.

Once they had overcome this hurdle, there was the issue of managing the staff and their relationship with them. Some focused on the demands of teaching staff about the care required when the service user had complex needs, how uncomfortable they felt having other people in the house and of the need to set 'boundaries'. Others found dealing with underperforming staff very challenging. An example was Harry. He said that the carers they now employed:

Will use any excuse to get out of anything, they really will, so we are really not happy with these guys at all.

And he found it upsetting that his wife 'dreads them coming in'. Keeping good staff also caused carers much anxiety. Concerns expressed included:

We've always had problems with carers, the one we've got at the moment we get on really well with, and I'd be sorry if she left 'and' I don't want to lose the one person I found after months and months of looking.

A major source of stress was the problems they had experienced with their local authorities. Inadequacies in the level and nature of support provided by their local authority were reported by half of those interviewed. The following illustrates these points:

We contacted our local council and said that I would like to get an assessment. It took a long time for them to assign us a social worker and then we went through three social workers because they were leaving the department, retiring or other things they were doing instead … the first person who came out was phenomenally useless. I think it finally got signed off by the duty care worker because the worker she had been assigned last had moved departments again.

Others talked about lack of information and disputes with their local authorities. The fact that one carer said 'the pressure I was under resulted in me virtually having a nervous breakdown' illustrates the extent of the stress experienced. Changes and the ever-present threat of reductions in funding also caused carers 'constant worry' and led to them being 'frightened to death'.

Some of the aforementioned difficulties had eased with time and several commented that their previous employment expertise and age helped them to cope. For example, those who had managerial or commercial backgrounds were least likely to report difficulties

Table 2 Summary of findings in relation to existing knowledge on the carer–service user relationship within personalisation

Existing knowledge validated	Knowledge refuted	New knowledge added
Improved relationship with the person for whom they care (Hatton & Waters 2011, Office for Public Management 2011, Jones *et al.* 2012, Moran *et al.* 2012)		Improvements in the carer–service user relationship can be effected by using personal budgets to access support, which enables both parties to undertake activities individually and together
Service users' needs can limit improvement in relationship (Glendinning *et al.* 2009, Hatton & Waters 2011, Office for Public Management 2011)		
	Contractual relationship with the service user was challenging and does not necessarily reduce the level of care provided (Breda *et al.* 2006)	A contractual relationship can provide flexibility on the amount of caring provided

with administering a personal budget. A typical comment from these carers was:

I've worked in the commercial world myself. So I have some inkling in what to do … I don't find the admin too difficult.

Nonetheless, just under half used other services to support them with managing the personal budget, such as carers groups, Third Sector Organisations and broker services.

Discussion

Further analysis of the findings in relation to existing studies showed that they validated, refuted and extended existing knowledge about the carer–service user relationship within personalisation and about the effects of personalisation on carers. With reference to the carer–service user relationship, although the study confirmed that personal budgets can improve this relationship and that service users' needs can limit improvements, ways in which personal budgets can be used to effect improvements were identified. In relation to knowledge about personalisation and carers more generally, the study endorses evidence that personalisation can have positive outcomes for carers in terms of their control over their daily lives, quality of life, health and well-being. It also highlights the importance of carers having confidence in the quality of the care accessed through personal budgets. While validating existing findings about the stress of administering personal budgets (particularly at first) and the value of previous employment experience, it shows that the most problematic issues are paperwork, recruitment and staff management and that many carers need additional support. Other sources of stress that emerged are issues with local authorities and worry about the effects of continuing budget cuts.

Summaries of how the findings relate specifically to previous research are set out in Tables 2 and 3. Tabular, as opposed to discursive, presentation has been adopted for the purposes of clarity and ease of future reference as the body of knowledge about carers and personalisation develops.

This study addressed some of the limitations of existing studies about carers and personalisation, in that it focused on carers' perspectives and was carried out in several different local authorities. The inclusion of carers of service users in receipt of a personal budget only is a further strength, in that it contemporises the study in the context of the move to personal budgets as the main form of self-directed support. However, other aspects of the sampling imposed limitations on the generalisability of the findings and their conclusiveness. For instance, a larger sample size that was stratified in terms of the national profile of carers or the nature of the service users' disability could have provided more comprehensive data. This in turn could then have been used to develop firm conclusions.

Nonetheless, by confirming and extending existing knowledge, this small study enhances the emerging evidence base about the impact of personalisation on carers. In so doing, it simultaneously suggests the following recommendations for practice to improve the outcomes of personalisation, for both carers and service users:

- *Support planning to include advice on the use of personal budgets to create the right environment to maintain and strengthen the carer–service user relationship*
  The carer–service user relationship could be better sustained if support planning addresses using personal budgets to access good quality services, which create opportunities for service users and carers to have some independence as well as to pursue interests and socialise together.

Table 3 Summary of findings in relation to existing knowledge of the effects of personalisation on carers

Existing knowledge validated	New knowledge added
Stress associated with self-directed support processes (Hatton & Waters 2011, Carers Trust 2012, Moran *et al.* 2012, Hatton *et al.* 2013)	Issues with local authorities, specifically Worry about effects of continuing budget cuts
More in control of their time and their daily lives (Hatton & Waters 2011, Jones *et al.* 2012, Moran *et al.* 2012)	
Better quality of life (Hatton & Waters 2011, Jones *et al.* 2012, Moran *et al.* 2012) Improved health and well-being (Hatton & Waters 2011, Forder *et al.* 2012, Moran *et al.* 2012)	
	Carers have concerns about being less involved in providing care themselves. However, these feelings ease with time and if they have confidence in the quality of the care
Managerial and administrative responsibilities are burdensome, especially in the early stages, but previous employment experience helps (Rosenthal *et al.* 2007, Grootegoed *et al.* 2010, Callaghan *et al.* 2011, Routledge & Lewis 2011)	Paper work, recruitment and staff management were the most problematic Many need additional support

- *More support and training for carers with paperwork, and employment and management of staff*
  In addition to providing information about where carers can get help with paperwork, and the employment and management of staff, consideration needs to be given to developing more support and training for carers around the areas of management and administration of personal budgets that cause them the greatest problems.
- *Review self-directed support processes*
  Streamlining local authority self-directed support processes for carers is essential, particularly as the number of carers of those in receipt of personal budgets increases. Moreover, as the demands on shrinking health and social care budgets continue to increase (Appleby 2013), it is important that carers' fears about reductions in funding are addressed and innovative practice at a local level is identified when decisions are being made about meeting people's needs (Brookes *et al.* 2013).

The analysis of the findings also highlights areas for further research. For example, other ways of strengthening the carer–service user relationship to enhance the experience and quality of care. In addition, building resilience into this relationship so that it can sustain the delivery of care in the face of the demands placed on it throughout the caring trajectory. Apart from empirical research, this study points to the need for regular and more formalised scoping of the existing research on carers and personalisation to secure the best outcomes for carers within personalisation. Not only is an up-to-date and rigorous overview of the existing evidence base invaluable for the development of effective practice but it is also beneficial in terms of designing future research that makes productive contributions to knowledge.

Conclusion

This is the first study to focus solely on the carer–service user relationship and although it was small scale, it develops the evidence base about carers and personalisation. This emerging evidence base is important at a national level and is also transferable as personalisation increasingly becomes a reality internationally. In addition, the study draws attention to significant issues which need to be considered in debates about the future development of this evidence base. One such issue is the need to look beyond the more easily recognisable models of self-directed support within personalised approaches to service delivery to gain a comprehensive understanding of carers' experiences within personalised systems. Furthermore, given that carers are essential to the delivery of health and social care *and* there will be a growing dependence on a limited 'pool' of carers, there is an urgent need to identify ways of ensuring that the current financial climate does not reduce the potential of personalisation to lead to tangible improvements for carers.

Acknowledgements

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