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Carers' quality of life and experiences of adult social care support in England

Stacey Rand MA[1] and Juliette Malley MA MPhil[1,2]

[1]Personal Social Services Research Unit (PSSRU), University of Kent, Canterbury, UK and [2]Personal Social Services Research Unit (PSSRU), London School of Economics and Political Science, London, UK

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Correspondence
Stacey Rand
Personal Social Services Research Unit (PSSRU)
Cornwallis Building
University of Kent
Canterbury CT2 7NF, UK
E-mail: s.e.rand@kent.ac.uk

What is known about this topic

- Informal carers provide a significant form of support for people with long-term conditions and older adults.
- Caring can affect the health, quality of life and well-being of carers.
- Carers' policy in England advocates the support of carers through publicly funded services and interventions to sustain their health and well-being.

What this paper adds

- Carers' quality of life is affected by the provision of social care support directed at carers, as well as the provision of support to the care recipient. Both the carers' and care recipients' attitudes towards service use may affect carers' quality of life.
- Despite the recent promotion of policies to support carers in England, we found that barriers to accessing social care support persist.
- Social and community exclusion can adversely affect carers' quality of life, but, outside the workplace, current policy does not seek to address this.

Abstract

Informal carers make a vital contribution to the well-being of the people they care for or look after. Against the policy background in England, the purpose of this study was to explore the views of carers who are in contact with adult social care support services. A qualitative study with 31 carers, who were recruited via local authorities and carers' organisations, was conducted between April and July 2012 to collect data on carers' experiences and perceptions of their quality of life (QoL) with and without adult social care and support for themselves or the person they look after. Through framework analysis, three key themes were identified: (i) definitions of social care services 'for' the carer or 'for' care recipient and social care outcomes; (ii) carers' access to social care services; and (iii) the meaning and value of informal care. We find that carers' QoL is affected by social care support directed at carers and support directed at those they care for, as well as access to services, the experience of stigma in communities, and in how individual needs and preferences are considered when making decisions about care. While there is much to welcome in the direction of policy in England, this study has shown that there are some gaps in thinking around these areas that will need to be addressed if the lives of carers are to be improved.

Keywords: caregivers, carers, carers' services, quality of life, social care, social policy

Introduction

A significant form of support for adults with physical or intellectual disabilities or mental health difficulties is the care provided by friends and relatives (OECD 2011). In England alone, there are five million carers (also known as 'caregivers'), defined as family members, friends or other informal networks who are not formally employed to provide care, such as help with personal care or everyday tasks (Department of Health 2010c). There are substantive differences between countries as to how care is provided, with different emphases on state-provided care and 'informal' care provided by friends or family. In states where either informal or state-provided care is predominant, there tends to be little policy debate. However, within many European countries, where care is provided through a combination of state-funded and informal care, there is an ongoing debate about the best way to support carers (Mestheneos & Triantafillou 2005).

Policy makers in England have stated that their aim is to support carers to continue caring and to recognise the contribution of informal

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carers in the White Paper 'Caring for our Future: Reforming Care and Support' (Department of Health 2012b) and in the National Carers' Strategy (Department of Health 1999, 2010b). The White Paper describes informal carers as 'partners in care' and acknowledges that they may also require social care support in their own right. The White Paper outlines three broad objectives: identifying and supporting carers; enabling carers to have a life alongside caring; and entitling carers to assessments and support (see Table 1). These proposals build on the direction of the National Carers' Strategy to increase the recognition of carers and to support them in maintaining their quality of life (QoL; Department of Health 1999, 2008, 2010b).

Table 1 The policy context for carers in England: 'caring for our future: reforming social care and support' (Department of Health 2012b)

Policy strategy from caring for our future: reforming social care and support (specific proposals)	Description
Carers should be able to have 'a life of their own alongside caring' Explore options of how to support carers to remain in employment	The carers' strategy focuses on carers' ability to have *a life of their own alongside caring* in terms of overall quality of life and well-being. The White Paper specifically highlights the issue of carers in paid employment, which is in line with evidence that combining paid work and informal care is a significant challenge; informal carers in Northern Europe are likely to reduce their working hours (Spiess & Schneider 2003); and a significant minority of carers are at risk from prematurely leaving employment or may not re-enter employment after they stop providing informal care (Mckeown *et al.* 2003, Henz 2004). In England, the Work and Families Act (2006) extended the right to request flexible working to carers and offers some protection to carers' status in the workplace. However, only 27% of carers in employment were aware of their rights to request flexible working. Furthermore, 26% of carers of working age indicated that caring had affected their ability to take up or remain in employment (Department of Health 2010c). The White Paper proposes to explore further options to support carers to remain in the workforce.
Carers should be supported in their role Entitlement to social care services and support, national eligibility criteria for carers	The White Paper addresses the issue of *entitlement and access to social care services* in England. Under the *Carers (Equal Opportunities) Act 2004* local authorities (LAs) must inform carers of their right to an assessment of their needs separate from the assessment of the service user. However, there is no obligation on adult social service departments in LAs to provide carers with support or services based on the needs identified in a carer's assessment. The White Paper sets out to fundamentally change the responsibility of LAs by legislating for an entitlement to public support. 'Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care' (Department of Health 2010a) outlines that the assessment of eligibility for publicly funded care should be driven by the needs of the individual. LAs are encouraged to consider a position where carers assessed to have a critical need should be supported by public services. The White Paper proposes to strengthen this guidance by implementing a nationally set minimum eligibility threshold for carers.
Carers should be supported to maintain their health and well-being Integration of health and social care services	The White Paper recognises that care-giving can have a detrimental impact on *carers' health and well-being*. This is supported by evidence that carers may be at risk of poorer health outcomes than non-carers (Schulz *et al.* 1997, Schulz & Beach 1999, Sorensen *et al.* 2006). The White Paper asserts that carers need tailored support to enable them to maintain their health and well-being. The White Paper proposes to place the responsibility for the identification and support of carers with the English healthcare system, through the National Health Service (NHS) Commissioning Board and Clinical Commissioning Groups. This responsibility currently lies with adult social services within LAs. The 'integration' of the English healthcare (the NHS) and social care (adult social services administered by LAs) systems has been part of the health and social care policy agenda in England for some time (Wistow 2012). The shift in responsibility between agencies for carers appears to be set within the context of the policy vision that services should 'join up around the carer'.

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Recent policy strategy in England has focussed on the individual outcomes of people with long-term conditions and their informal carers, and the use of outcomes as a means of assessing the performance of social care and other public sector services (Department of Health 2006; 2010b; 2012a; 2012c). The Adult Social Care Outcomes Framework (Department of Health 2012a) comprises a number of social care outcome measures that are reported by local authorities (LAs) in England and includes the Adult Social Care Outcomes Toolkit (ASCOT) measure of care recipients' and informal carers' QoL (Fox *et al.* 2010, Malley *et al.* 2012, Netten *et al.* 2012). This measure is a high-level indicator of the aspects of QoL that may be affected by social care support and services. While these high-level measures can tell us what life is like for carers in contact with social care services, it is important to understand how social care services can support carers to maintain their QoL and also the interactions between the outcomes of care recipients and their carers.

In policy and practice in England there persists a distinction between social care services 'for' the care recipients and 'for' the carer, even though this conceptual distinction (Twigg 1989, Oliver & Barnes 1998, Pickard 2004) and the concept of policy and services 'for' carers (Twigg 1989, Oliver & Barnes 1998, Pickard 2004) are ongoing contested issues. Furthermore, there is evidence that support for older people or people with disability can relieve the burden on carers and that both services 'for' the care recipient and those 'for' the carer may improve carers' outcomes (Pickard 2004). The National Carers' Strategy aims to improve the QoL and support available to all carers. Carers are, however, not a homogeneous group. The QoL of carers can be affected by a number of factors other than the direct or indirect effects of social care support; for example, QoL is also affected by educational level, gender and the type of illness or disability experienced by the care recipient (Molloy *et al.* 2005, Kitrungrote & Cohen 2006, Greenwood *et al.* 2008, Schoenmakers *et al.* 2010, Zegwaard *et al.* 2011). There is also evidence that the QoL and health outcomes of carers and care recipients may be linked through shared aspects of the environment or influenced through the social interactions within the carer–care recipient relationship or wider social context (Lyons *et al.* 2002, Ostwald *et al.* 2009a,b, Siminoff *et al.* 2010, Hall *et al.* 2012, Thomson *et al.* 2012). An understanding of these interactions and influences on outcomes of both care recipients and carers would support the interpretation and use of outcome measures to evaluate social care support and policy.

To explore the direction of carers' policy in England, we draw on interviews conducted with carers of adults with physical disabilities, mental health conditions and intellectual disabilities. These interviews were conducted as part of the testing and development of a measure of the effect of social care services on carers' QoL (Rand *et al.* 2012). We discuss the findings in the context of the social care White Paper and the National Carers' Strategy, and conclude by considering the implications for policy and practice.

Methods

Design

A qualitative research method that combined cognitive interviewing (Willis 2005) with open-ended questions was used to collect data. Informal carers of people with long-term conditions were interviewed about their perceptions of the effect of caring and of adult social care services on their QoL.

Participants

Carers were recruited through three LAs in England and two carers' organisations in these locations. The research sites were chosen to represent a cross-section of authorities, and differed in size, location (urban, rural and suburban/rural) and population mix. The LAs sent an invitation letter and information sheet on behalf of the research team to a sample of carers known to them (aged 18 and over) of people with physical disability, mental health conditions and/or an intellectual disability. The carers' organisations sent an invitation to all carers in contact with their services. All of the carers supported someone who received publicly funded social care support and/or were in contact with carers' services. The carers contacted for this study were selected to have current experience of adult social care services because the topics covered by the interviews focused on carers' experiences of social care and its impact on their QoL. The letter included a return slip for carers who wanted to take part. The carer was then contacted by the interviewer to arrange a convenient time and place for the interview.

Data collection

A total of 31 interviews were completed between April and July 2012 by one interviewer. One interview was excluded from the analysis due to the extended length of time since the carer had last contact with the care recipient and social care support services. The interview was conducted in two sec-

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Table 2 Structure of the ASCOT-Carer INT4 questions using the *Occupation* domain as an example (Rand *et al.* 2012)

	Example	Response
Present QoL	Which of the following statements best describes how you spend your time in your present situation?	Four levels
Filter question	Do the support and services that you and [Name of Care Recipient] get from ≪EXAMPLES of social care services based on earlier questions about receipt of social care services≫ help you to spend your time doing things you value and enjoy?	Yes or no
'Expected' QoL in the absence of services	(If filter question = yes): Imagine you and [Name of Care Recipient] didn't have the support and services from ≪EXAMPLES of social care services based on earlier questions≫ that you do now, and no other help stepped in. In that situation, which of the following would best describe how you'd spend your time?	Four levels

ASCOT, Adult Social Care Outcomes Toolkit; QoL, quality of life.

tions. The first section of the interview was devoted to the cognitive testing of survey questions using both 'think aloud' and 'probing' techniques (Willis 2005). The questions were based on the carer QoL measure (Fox *et al.* 2010, Malley *et al.* 2010), which covers seven domains of QoL: Occupation, Control, Social participation, Self-care, Time and space to be yourself, Safety, and Feeling encouraged and supported in your caring role. The interview included additional questions to ask carers whether social care services affect each aspect of their QoL, and to indicate their QoL in the imaginary 'expected' situation that social care support and services would no longer be available (see Table 2). The full findings of the cognitive testing and question development are outlined in a technical report (Rand *et al.* 2012). In the second section of the interview, the carers were asked open-ended questions about the effects of caring on their lives, their experiences of social care services and the effect of this support more generally on their QoL. The interview took place at the carer's home or another convenient location, and lasted between 40 and 70 minutes.

Ethical approval was obtained from the Social Care Research Ethics Committee, and research governance was obtained from all participating LAs. Written informed consent was recorded prior to the interview.

Data analysis

All interviews were audio-recorded with permission, transcribed verbatim and then analysed in NVivo using the framework approach (Richie & Spencer 1994). Although the first part of the interview was designed to test questions for an instrument designed to measure carers' QoL, we draw on data from both parts to gain insight into carers' experience of social support services and their outcomes.

Based on recent policy developments and literature, the a priori concepts identified for the initial data coding were: the domains of carers' QoL, such as Occupation and Social participation; and the effect of social care services on carers' QoL. Two further themes emerged from the data: barriers to accessing social care support; and carers' understanding of the meaning and value of the role of 'carers'. The themes related to different domains of QoL and how social care services affect each QoL domain are excluded from this analysis, as they have been discussed elsewhere in the context of the development of a measure of carer QoL (Holder *et al.* 2009, Fox *et al.* 2010, Rand *et al.* 2012) and will be further developed and reported as part of the ongoing 'Identifying the Impact of Adult Social Care' project.

Findings

The characteristics of the sample of carers are outlined in Table 3. Of the 30 carers included in the analysis, 14 looked after or supported someone with a physical disability, 10 supported someone with a mental health condition or dementia, and six supported someone with an intellectual disability.

Social care services and outcomes: whose services, whose outcomes?

Many of the carers had experience of both services 'for' carers, such as support groups or advocacy, as well as services 'for' the care recipient, such as home care. The carers were able to explain why services for

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Table 3 Demographic characteristics of the participants (N = 30)

	Number
Gender of carer	
Male	5
Female	25
Age of carer	
18–24	1
25–44	0
45–54	6
55–64	8
65–74	9
75 and over	6
Relationship of care recipient to carer	
Spouse/partner	12
Child	11
Parent or grandparent	5
Sibling	2
Co-residency with cared-for person	
Co-resident	23
Not co-resident	7
Client group of the cared-for person	
Physical disability and sensory impairment (sensory impairment)	14 (1)
Mental health (dementia)	10 (5)
Intellectual disability (autism spectrum disorder)	6 (3)
Services and support for carers	
Carers' organisation/group	27
Information and advice	21
Training for carers	5
Carers' counselling or someone to talk to in confidence	2
Support to stay in employment	1
Services and support for care recipient	
Home care/personal assistant	16
Day centre or activities	14
Equipment	14
Residential respite/replacement care or breaks	8
Lifeline alarm	5
Supported living (housing with a support worker on-site)	2
Meals service	2

Local authorities use the following client groups: PDSI, physical disability and sensory impairment; ID, intellectual disability; MH, mental health. We have used the same broad categories here, but have provided a breakdown of significant subgroups within each.

the care recipient did or did not have an effect on a particular domain of QoL, and give an account of the beneficial effect of these services on their QoL; for example:

> [Services for me as a carer are] not as important as [Care Recipient] having care, because they allow me to have the energy to have the social contact. [CR1]

> The support workers would come and they'd talk to me as much as they would talk to [Care Recipient]. They'd feedback the problems and the issues. [CR5]

Some carers also spoke of the impact of services 'for' care recipients on their QoL through their effect on the well-being of the care recipient:

> …if I put him somewhere like [name of respite care service] it would be a service, but he wouldn't enjoy it. I wouldn't enjoy it because I wouldn't feel safe – he would just be a nightmare. So, if we're getting the right services, he's happy and I'm happy. We're all happy bunnies. [CR7]

Another carer spoke of how her perceptions of day care services and whether these met the needs of the care recipient had an effect on her QoL in terms of feeling encouraged and supported:

> If [care recipient] didn't have the daycentres – he will sit in front of the television, and he needs to have stimulation. [At one of the day centres] … it's a smaller group … I think he feels that he's more of an individual there.

In some interviews the carers spoke of the tensions in balancing their own needs with the well-being of the care recipient: for example, some carers reported that the care recipient preferred to live at home without home care support. This choice met the care recipient's needs, but negatively affected the carer's QoL. One carer spoke of how she had less social contact and time for herself than she wanted, which affected her overall QoL, and explained that this was due to the care recipient's negative attitude towards receiving help:

> My husband doesn't accept any help apart from me. I accept help sometimes (from the carers' group) … But we have very little contact or anything with anyone. [CR15]

Carers' access to services

Many of the carers had experienced significant barriers and challenges during enquiries to LA adult social service departments or other organisations. Key themes that emerged from the interviews include difficulties in navigating the system, and experiences of unresponsive or defensive interactions with services. A number of carers spoke of the psychological impact of these experiences, such as feeling helpless or ineffective in finding the help that they need, and anxiety or frustration caused by a lack of transparency in what help may be offered at the end of an assessment or enquiry to adult social services. The carers' experiences of navigating the system of care also had an impact on their self-reported QoL, as well as on their perception of the care recipient's QoL:

> And I was just going round in circles in the end and not getting anywhere at all. Which I felt then affected how I was looking after [Care Recipient]. I felt inadequate 'cause I couldn't look after him. [CR12]

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It nearly drove me crazy, I'll tell you, trying to find help. [CR10]

Despite nationally defined eligibility criteria for care recipients and guidance for the access to care for carers in England (Department of Health 2010a), the themes around barriers to access of social care support reported by carers in these interviewers are similar to those observed 10 years ago by Arksey (see Table 4), who referred to the perceived barriers to service use or accessing support as 'rationing' of care. A number of carers also spoke of their choice to not access or to stop using services that failed to meet the carers' or care recipients' needs or preferences. Two carers spoke of how they felt that home care was an invasion of privacy, and that home care changed the nature of a household from a 'home' to a 'care home'. The carers' attitudes and preferences affected their choices of whether, or how, to access social care support [CR31; CR22]. A number of carers also spoke of how attitudes towards services could act as a barrier to accessing support:

I think what you've got to remember is that many people of my parents' age, the social services only become involved with people who are out of work, unemployed – not professional people. There's this sort of stigma. And so getting any sort of services involved in their care is very difficult. [CR2]

Some carers described how they felt that there was less stigma associated with contact with a carers' organisation compared with contact with adult social services, which then affected their choice as to which organisation to approach for support:

Table 4 Carers' experiences of the rationing of social care support services

Type of rationing (Klein *et al.* 1996, Arksey 2002)	Findings
Rationing by deterrence – access to care is made difficult	We needed to [make adaptations around the home] and again I tried to phone social services and I just couldn't get an appointment so I gave up. [CR15]
	Well it was my experience of being in this caring business if you're not forceful they'll just walk over you, especially now with the money like it is … If you look like you're not going to make an effort or if you don't appeal, they're of the opinion if you don't appeal you didn't want it anyway. [CR31]
Rationing by denial – services are denied to specific individuals or client groups	[Sighs] I have rung the carers' group but I didn't get any support … I rang regarding something in the newsletter but it didn't apply to us because we didn't qualify. [CR14]
Rationing by delay – access to services is discouraged by delaying tactics	There are the promises, but – November and we're now July? How much longer do I have to wait? [CR22]
	They don't do reviews unless something radically changes … I've been in touch to get a reassessment and they said, 'Is there any change?' only that he's got worse, but they don't do reassessments. [CR25]
Rationing by deflection – agencies protect resources by channelling clients to other services	I was given lots of phone numbers and lots of avenues to go down … I couldn't understand why. [CR10]
Rationing by charging – the service user contributes towards the costs of the services they receive	And because the government have cut so much they're charging each individual more and more money for the care they're getting. And whether you can afford it or not, and we can't afford it anymore. [CR19]
Rationing by termination or dilution – services are withdrawn or the quality or quantity of services is reduced	One carer had recently received notice of the withdrawal of a day care (college placement) provided for the care recipient over a number of days per week and spoke of the uncertainty and anxiety that this had caused:
	Because when the rug gets pulled, the rug gets pulled. And they're doing it all the time and they shouldn't be. [CR13]
	Another carer [CR29] spoke of how the care recipient's day care centre had closed and then reopened, but with a more limited range of activities available to clients.

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There's a stigma to social services and I don't want too much contact … I think things like that are better done with the carers' association because I think you've always got the stigma with social services that they're going to cause problems. [CR26]

Although carers' organisations may be part-funded by LAs, some carers perceived them to be completely separate from the LA. The aim of these organisations is to support carers by providing advocacy, social opportunities, information/advice and support groups. The focus on carers enables these organisations to be more responsive to their needs without the associated pressure of accommodating potentially conflicting care recipient needs in the allocation of resources. Some carers spoke positively of the support they received from these services.

If I have a problem that I'm a bit unsure of, I know I can go to them or ring them and they'll make time to have a chat with us. Or if I was feeling a bit low myself, they're always there to help and listen and give us advice. [CR18]

However, the interviews identified a number of barriers to the access of carer services delivered by carers' organisations, including the timing and location of the meetings, which were inconvenient or in locations that were not easily accessible by public transport, and the inability of the support groups, advice or services to meet the carers' specific needs or preferences [CR13; CR15; CR17; CR23; CR24; CR30; CR31].

There is a [carers'] group in [place name] which I went to once, but I wasn't very happy with it … I sat there, nobody talked to me. And they all talked between themselves. And I wasn't brought into the conversation. [CR30]

Recognised, valued, supported: carers as 'expert partners in care'

In the interviews, it was found that carers' own understanding of the nature of their relationship with the care recipient and caring tasks did not always align with the policy objective of recognising carers as 'expert partners in care'. 'Expert carer' is widely understood by carers to mean professional care workers rather than as a term that covers their role (Fox *et al.* 2010); a number of carers had previously worked in health or social care and made clear comparisons between the professional role of paid care worker and informal care:

If you start work at eight o'clock in the morning, you know at two o'clock you can walk out that door. You can forget it all until the next day. Whereas, when you're in this role, you can't walk away. That's the difference – the pressure that it puts on you. [CR21]

There is a further tension in the use of the terminology as, although it recognises and raises the status of carers, it does this at the expense of acknowledging the potential limitations of non-professional care and the carer's needs as a co-client. Some carers spoke of the expectations placed on them as informal carers, particularly if caring had not been a voluntary decision, and how this affected their understanding of the caring and QoL:

You're the victim because you're in a box that you can't get out of. [CR13]

I'm only doing it [caring] because I have to … if you can pull yourself away early on, do it. Because otherwise you'll be trapped like I am. [CR31]

The carers recognised that not everyone is capable of being an informal carer and that particular skills and psychological robustness, alongside emotional or practical support, are required to be able to continue in this role over a period of time.

[We need …] some way of talking to people or getting people to understand that not all families can actually do what I'm doing. [CR2]

Furthermore, the recognition of carers' status as 'co-workers' in policy does not always translate into practice by social and healthcare professionals. While some carers spoke of how they were fully involved and consulted in discussions with professionals, others reported experiences where they had not been recognised or consulted:

Well, I truly believed that I didn't come into the equation at all. I didn't count. I was just a [relative] who was available to do hospital runs or dental runs. [CR10]

There were examples where carers felt that their contribution was not widely recognised:

There are an awful lot of people out there that couldn't give a damn. [CR13]

However, many of the carers spoke about caring as a job:

I'm just one of the carers in this country. I'm just one of the carers that do this job. Because it is a job, you know, no matter how they come about, it's a job. [CR19]

The carers felt that the economic or societal value of informal care is not widely recognised within local communities or even by friends and family. In one case, this lack of recognition led to the carer experiencing hostility from a neighbour:

…because we complained about the noise waking [the care recipient] up at six o'clock in the morning, I then got told

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to get up at six o'clock in the morning the very next day and get myself down the job centre 'cause I might need a job. [CR13]

Other carers also spoke of their frustration that informal care is not perceived as economic activity, and that they are seen as a burden to society ('on benefits').

Discussion

In many European countries, the policy agenda has shifted in favour of publicly funded social care support for carers to support and sustain carers' QoL. While this strategy is primarily driven by a reliance on informal carers within the context of pressure to contain the costs of health and social care (Mestheneos & Triantafillou 2005, Courtin *et al.* 2012), it also recognises the ambiguous position of carers as both 'co-workers', who promote the well-being and independence of the people they care for, and 'co-clients', who are entitled to have the support needed to have a life alongside caring (Twigg 1989), with an emphasis on the latter position and the eligibility of carers for support in their own right. This approach does not, however, explicitly acknowledge the role of choice in whether to provide care or not (Arksey & Glendinning 2007). There is some evidence that the outcomes of carers (Quinn *et al.* 2010) and care recipients (Camden *et al.* 2011) may be affected by the carers' motivations for providing care. Therefore, within the context of the policy agenda of improving carer outcomes (Department of Health 2012c), an important consideration is whether carers, and indeed care recipients, should be supported to choose whether or not to provide or receive informal care.

This study explored carers' experience of social care support and services and how this support, both 'for' the carer and 'for' the care recipient, affects their QoL. The recognition of carers as 'co-clients', who should be able to access the support they need to maintain their well-being through the introduction of a minimum eligibility threshold for publicly funded services, is to be broadly welcomed. The implementation of this policy will, however, need to address, first, the persistent issue of barriers to the access of social care support, and second, how to ensure that publicly funded support is effective in maintaining carers' QoL and well-being. The findings illustrate how social care support for both carers and care recipients continues to be rationed at a number of levels within the care system (see Table 4), despite the introduction of national guidance on eligibility criteria (Department of Health 2010a). Although an entitlement to support for carers and the introduction of national minimum eligibility criteria could potentially address some of the problems around access to support, such policies are only valuable if the issue of funding adult social care support is also adequately addressed. It is unclear whether the proposed additional budget of £175 million per year for carers' support will be sufficient to cover the anticipated increase in carers' assessments and service provision (Joint Committee on the Draft Care & Support Bill 2013), or to maintain LAs' funding commitments to universal access carers' services, such as those provided by carers' organisations, or to provide other social care support services without charging.

Apart from the central issue of eligibility and access to publicly funded support, there is also the question of how to ensure that such support benefits the health and social care outcomes of carers. The findings of this study indicate that carers' QoL may be affected both through direct support for themselves as carers and through the support for the people they care for. The effect of the latter may be due to direct benefits to the carer, such as social contact and support from care staff, or indirect benefits, whereby the carer's QoL is improved through the carer's perception that the care recipient's needs are met. The interviews also highlighted the potential for tensions in the delivery of services in situations where the needs and social care outcomes of care recipients and their carers are in conflict. Services need to find ways to manage such conflicts. A framework for assessing the impact of social care that attempts to combine the outcomes of both carers and care recipients, so that trade-offs between them could be explored, would allow the evaluation of services from the perspective of both parties. Although the current Adult Social Care Outcomes Framework in England (Department of Health 2012a) includes outcomes for both carers and care recipients, it does not, in its current form, capture trade-offs or efficiencies in care recipient–carer outcomes. There has been some research into the measurement of carer outcomes to develop 'societal perspective' in service evaluation (Van Den Berg *et al.* 2004, Bobinac *et al.* 2010), but further research to establish an approach to simultaneously measuring outcomes for carers and care recipients would be extremely valuable.

In addition to the other themes within policy, as supported by the findings of this study, the call for greater recognition of carers' contribution to society in the White Paper is to be broadly welcomed. However, while the White Paper identifies ways to address stigma in the workplace, it is silent about stigma and exclusion in other spheres of life. To improve carers' outcomes more broadly, there should

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be wider recognition of the impact of social exclusion and stigma at a community level, and initiatives to address stigma and exclusion of carers in their communities. Carers' organisations play an important role in promoting the voice of carers and could be partners in informing the public about the value and importance of informal care.

There were also directions in policy strategy that were not salient themes that emerged in the interviews, such as the White Paper's proposal to review the support available for carers in the workplace. While some carers spoke of employment as an aspect of their overall QoL, it was not mentioned by the majority of carers, although this may be due to the nature of the sample (51% of the sample were of retirement age compared to 27% of carers in England; Department of Health 2010c). As a significant minority of carers in England are no longer in the workforce, and it is recognised that contributions to society, such as community involvement and voluntary work, are important to carers' self-perception of QoL, there is a need to support carers to stay engaged in their communities and be able to pursue leisure and social activities. The potential impact of the policy to support carers to remain in employment on carers' health and well-being is also unclear. There is some evidence that carers who are not in employment have better health outcomes than carers in employment (Kitrungrote & Cohen 2006, Greenwood *et al.* 2008), are more likely to report positive experiences of caring and be at less risk of poorer psychological health outcomes (Opree & Kalmijn 2012). If the objective of improving carers' health and well-being is to be achieved, the development of this area of policy should be take into consideration personal choice in whether to combine caring and employment, as well as to avoid further stigmatisation of carers who choose to care full-time.

There are limitations to the evidence drawn on in this study. The study was limited to carers who use publicly funded social care support themselves or who support someone who uses publicly funded social care support. This is appropriate, given the aim of this research to explore carers' experiences of publicly funded social care support and its effect on QoL. However, it should be noted that less than 3% of carers in England receive social care through LA adult social service departments (Department of Health 2010c), and the majority of carers are not in contact with LA adult social service departments or other sources of publicly funded support, such as carer support organisations. The views expressed here should be interpreted with this in mind, and further studies are encouraged to focus on carers who do not receive social care support, especially with regard to the identification and recognition of carers by health and social care professionals, care recipients and carers themselves. Despite these limitations, this study highlights some important messages for policy and practice.

Conclusion

While there is much to welcome in the direction of the carers' strategy and White Paper, this study has shown that there are some gaps in thinking that will need to be addressed if the lives of carers in England are to be improved. Key issues are the choice to care, stigma in communities, barriers to accessing support, the relationship between carers' and service users' QoL, and balancing the needs and preferences of individuals when making decisions around the provision of care. In a climate of cuts to public services, putting carers on an equal footing with care recipients and extending the access to publicly funded services for carers will only increase pressures on social care budgets, and it is unclear whether current funding proposals for carers' services will meet an increased demand. This potential shortfall in funding and the continued financial pressures faced by LAs will be the main challenges to the realisation of the carers' strategy and White Paper's vision to support the well-being and health of informal carers. More information about the relationship between carers' and care recipients' outcomes, as well as the relative value of different types of social care support, would support the case for more targeted investment in services.

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