

# What can the experiences of informal carers contribute to an understanding of inequalities in care?

Nicola Brimblecombe, Derek King, Madeleine Stevens, Martin Knapp; Personal Social Services Research Unit, London School of Economics and Political Science (LSE)

[n.s.brimblecombe@lse.ac.uk](mailto:n.s.brimblecombe@lse.ac.uk)

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## Background

Changes in the provision of care, and fiscal austerity in many countries, has resulted in many disabled and older people not having their support needs met, with a marked pattern of inequality of access (Broese van Groenou *et al.*, 2006; Garcia-Gomez *et al.*, 2015; Burchardt *et al.*, 2016; Age UK 2017; Institute of Fiscal Studies, 2017; Kroger *et al.*, 2019). Lack of services is a major contributor (Forder & Fernández, 2010; Vlachantoni, *et al.*, 2011; Humphries *et al.*, 2016). In England, for example, there have been substantial and ongoing cuts to adult social care budgets since 2009/10 (Forder & Fernández, 2010; Burchardt *et al.*, 2016) with a simultaneous reduction in the numbers of adults receiving state-funded care services (Burchardt *et al.*, 2016; Humphries *et al.*, 2016). Need, meanwhile, remains high. Greater unmet need is associated with health condition, ethnicity, age, income, area deprivation, and funding source (Vlachantoni, 2013; Brown & Sondaal, 2016; Humphries *et al.*, 2016; Kroger *et al.*, 2019). There are suggestions it might also be associated with funding source (public versus private) (Baxter & Glendinning, 2014; Humphries *et al.*, 2016). In addition, there are differences in how unmet need is experienced and how it impacts (Ipsos Mori, 2017). In a situation where there is reduced availability of publicly-funded formal care services, constrained financial or other resources may limit access to alternatives such as self-funded or informal support.

Unmet need for services has the potential to affect informal carers as well as disabled and older people with support needs. Providing care can impact negatively on employment, physical and mental health, wellbeing and social participation, leading to sometimes high individual and societal costs (Brimblecombe *et al.*, 2018). There are socio-demographic inequalities in who provides informal care and who needs care and an association between provision of care and income, social class, educational level, ethnicity and gender (Young *et al.*, 2006).

Brimblecombe, King, Stevens, Knapp (May 2019) What can the experiences of informal carers contribute to an understanding of inequalities in care?

Current legislation in England stipulates that assessment of a carer's needs must consider the option of those needs being met by providing services to the person they care for, so-called 'replacement' or 'substitution' care (Care Act 2014). In a series of mixed-methods studies we set out to explore the association between formal care services and carers outcomes. The first, longitudinal study focussed on working-aged informal carers and the most recent on young adult carers. Working-aged carers predominantly provide care for older people, usually their parent or parent-in-law. Young adult carers provide care to working age adults, for whom care need is increasing markedly (Bottery *et al.*, 2019) and who make up the just over half of the European population with potential care needs (Burchardt *et al.*, 2018).

There are a number of different ways of conceptualising unmet need and inequality in care. One well-used definition is based on the extent to which needs for help with Activities of Daily Living (ADLs) and/or Instrumental Activities of Daily Living (IADLs) are met (Brown & Sondaal, 2016; Ipsos Mori, 2017; Kroger *et al.*, 2019). Definitions vary from no help to insufficient help. In the English context, the definition used in the 2014 Care Act, and therefore in practice, includes no care, insufficient care and care provided by unpaid carer being intensive and with potential for impact on carer wellbeing. Another perspective on unmet need is one which considers needs of both disabled or older person and informal carers. The rights-based approach takes an even broader perspective. For example, the World Health Organization defines long-term care as '*the activities undertaken by others to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity*' (World Health Organization, 2015, p.127).

## Data and Methods

### Survey and interviews: working age carers

Our target population for the survey was informal carers living in England who were in paid employment at baseline (2013). Carers were identified through an online screening survey. We sent self-completion questionnaires to carers identified in that survey in 2013 and 2015. This included questions on socio-demographic characteristics, employment, provision of care, and service receipt. In 2013 the person receiving support from the informal carer was also sent a questionnaire. Questionnaires used validated questions from other surveys.

In 2013, when data from both informants was collected, the sample size was 384 working carers and, within that, 165 care-recipient/carer dyads. For the following analysis we used data from 150 of those dyads, excluding dyads where there was no information on need for services from both carer and care-recipient. The majority of the sample were aged between 45 and 64, and were providing care for

Brimblecombe, King, Stevens, Knapp (May 2019) What can the experiences of informal carers contribute to an understanding of inequalities in care?

a parent or parent-in-law. In 2015, we conducted in-depth telephone interview, and a sub-sample of 40 informal carers who had completed the questionnaire in 2013 and 2015. The sample was selected to reflect the age, gender, ethnicity and employment status of those completing the follow-on questionnaire, and included different caring and employment situations.

### Survey and interviews: young adult carers

Our target population was young people aged 16 to 25 living in England who provided informal care to an adult. Participants were recruited through a wider range of for a and methods. In total, 188 young people aged 16 to 25 with caring responsibilities completed the survey. We then carried out semi-structured interviews with a subset of 14 young people who had completed our survey and who indicated they were willing to take part in further research. We aimed to carry out interviews with carers where formal social care services were and were not being received, and with those who perceived a need for more services as well those who did not.

### Quantitative analysis

We used chi-squared tests of association to explore the extent of unmet need for services and any groups differences. Carers were asked whether or not the person they support has the right amount of support or services and, if not, what services they need from a list: home care, personal assistant, cleaner, daycare, lunch club, meals on wheels, supported employment, special school or college, after school club or holiday club, community transport services, equipment, short break, residential home and other services not already specified. In the working age carers study, care-recipients were asked the same question about services for themselves. Based on the literature, we explored group differences by type of disability, hours of informal care per week, carer's gender, ethnicity, and kin relationship of carer to care- recipient. For young adult carers, we did not explore kin relationship because the sample explicitly excluded those caring for children e.g. disabled siblings and because the vast majority of the sample cared for a parent.

### Qualitative analysis

Interviews with carers were recorded and transcribed in full, with the permission of participants. Each transcript was read by two researchers and analysis was undertaken using a qualitative data software package. The qualitative analysis was mainly deductive, driven by the research questions. The approach taken was thematic analysis. Codes were gathered into themes and themes were re-examined and recoded to reflect emerging interpretations of the data. In presenting the results below, we use pseudonyms and have further anonymised the results by removing potentially identifying information.

Brimblecombe, King, Stevens, Knapp (May 2019) What can the experiences of informal carers contribute to an understanding of inequalities in care?

## Results

### Extent of unmet need and group differences

#### *Working age carers*

As can be seen in table 1, perceived unmet need for services is high with nearly half of care-recipients (47%) and two thirds of carers (66%) perceiving a need for more services (table 1). The table also shows the factors significantly associated with perceived unmet need for services. These were level/type of disability; level of informal care provision; and kin relationship. A higher proportion of those with at least one difficulty with ADLs had unmet needs compared to those with no difficulties with ADLs. A higher proportion of those receiving 10 hours or more a week unpaid care from the working carer reported having unmet need. A significantly higher proportion of those caring for parent or parents-in-law had unmet needs, compared to those caring for someone else. Carer's gender and carer/care-recipient's ethnicity were not significantly associated with perceived unmet need for services.

TABLE 1

#### *Young adult carers*

Table 2 shows that type of ill-health/disability was significantly associated with young adult carers perceiving unmet need for services for the person they support. A higher proportion of those caring for someone with a mental health condition compared to a physical health condition reported unmet needs for services. Care hours were not significantly associated with unmet need but care type was, with a higher proportion reporting unmet need when personal (ADL) care was being provided. Female carers were more likely to report unmet need than male carers. Carer's ethnicity was not associated with perceived unmet need

TABLE 2

### Experiences of unmet need for care

Unmet need for services had an impact on carers as these examples show:

*'They did this assessment...and the social worker came and she said 'well we're offering you eight hours' and I just, I went hysterical. I went absolutely hysterical. I was screaming.... I couldn't believe it, in my wildest nightmares, I couldn't believe they'd go from fifty-five hours to eight. I couldn't, I just ... it was unbelievable. Even now, I'm gob-smacked. I got to the point and I just said 'I can't do it. I cannot do it...., I cannot not sleep, I can't never have a night's sleep'.... So [social worker] went away and then a couple of days later ... by this time I was in the worst depression, and you know, I had been going through a really bad time. Everyone wanted to put me on tablets....and I'm saying 'no, ...I'm not*

Brimblecombe, King, Stevens, Knapp (May 2019) What can the experiences of informal carers contribute to an understanding of inequalities in care?

*depressed because I'm depressed, I'm depressed because I can't fix this situation. And giving me tablets isn't going to fix this situation'. You know, so it was really a horrendous time...'* (Abby, working age carer).

*'My mum not having support, it made me constantly worry. Because even now, when I know she's bad, I'm like, am I going to come home to find my mum's in hospital or worse?...Because it used to be that she could be left in the house on her own, but now she can't.'* (Isabel, young adult carer)

*'It's been so hard to get her services over the years... just to get her into mental health services....It's so stressful, just getting the help or the fact she's not getting the help she needs'* (Cleo, young adult carer)

And, as can be seen from the following examples, on care-recipients too:

*'It's causing me a lot of stress if I'm honest. I feel really – I feel actually quite ill because the thought of – I mean yeah I can take him and do it, but the thought of in September having to send him on his own [to a new college] I don't even know if I can – I don't even know if I can do that, I – I'll have a go, I'll, you know, I'll try. [Son shouting in background]. He's saying no!'* (Sue, working age carer)

Interviewer: *'You said that the home care was withdrawn and then she'd got a lot worse ...'*

Carer: *'Yeah. Oh, I mean that was really, really sad and so frustrating. It should never have happened....but you know, that looks as if it's gone forever now, doesn't it?... I feel it is. Because if – you know – they're talking about [council name] have got to find another twenty million in cuts – where's it all going to come from?...So, it's not going to get better is it?... I mean they're closing so many homes, it's frightening....'* (Margaret, working age carer)

C. *'We agreed a time for him to come in the morning [so carer could go to work] [but]...they were coming later and later and later... so obviously my dad was already trying to get up, trying to wander, he was wandering around the house...there were days when they'd come, they'd sort of ask him if he wanted to get ready...to get up or get washed or dressed, he'd say no so of course then they'd just leave him.... then he was left for...four or five hours 'til lunchtime, so he'd be wandering around the house in just his bed clothes, he wouldn't have had breakfast or anything like that. ...The foods that he was being given would just be left in front of him.... Well my dad with dementia he didn't know how to peel an orange or peel a banana or anything like that, so every day I used to come home at lunchtime and he had – he literally hadn't eaten.'* (Steve, working age carer)

*'Well, she used to have a psychologist – like a team – she used to go every week for a psychology appointment over two years, and then they just stopped it because of funding, and it was detrimental to my mum's health and it took her downhill so much.'* (Jane, young adult carer)

Brimblecombe, King, Stevens, Knapp (May 2019) What can the experiences of informal carers contribute to an understanding of inequalities in care?

There was a recognition that this could also be difficult for careworkers:

C: *It's not necessarily the carers themselves – their fault, but they've probably got, you know, ten people to get up in the morning or whatever and... they've been allocated three quarters of an hour to get that person up, washed, dressed, fed, and – and everything and, you know, three quarters of an hour is not – it's not sufficient.* (Steve, working age carer)

## Summary

### High levels of unmet need

We found perceived unmet need for services was high for disabled and older people and young adult and mid-life informal carers. Other research has also found high levels of unmet needs, in this case with help needed with ADL and/or IADL tasks (e.g. Vlachantoni *et al.* 2011; Garcia-Gomez *et al.*, 2014; Brown & Sondaal, 2016; Burchardt *et al.*, 2016; Humphries *et al.*, 2016; Ipsos Mori, 2017; Kroger *et al.*, 2019). We found that there was greater unmet need for people with personal care needs, again consistent with some other research (e.g. Maplethorpe *et al.*, 2014), although other research finds the opposite (e.g. Kroger *et al.*, 2019).

As can be seen from the interviews, unmet need for services, and indeed for care, affected both carer and person with support needs. Not being able to provide enough, or the right type of services may also impact on paid careworkers. Our research took place in a context of high staff turnover, staff shortages, and issues with pay, training, workload and other working conditions (SCIE, 2013; NAO, 2018). Careworkers' working conditions can have a direct impact on service quality, as well as on careworkers themselves (CQC, 2010).

### What can the experiences of informal carers contribute to an understanding of inequalities in care?

The experiences of informal carers can contribute to an understanding of inequalities in care in a number of ways. Firstly, even when informal carers are providing some, and often high levels of care, care needs were in many cases still unmet. This was especially the case for personal care needs which, as Bonsang and colleagues found, in many cases requires trained professional help (Bonsang, 2009). Given many carer's other commitments, geographical proximity, capacity and so on, this level of unmet need is perhaps unsurprising. It is nevertheless important to recognise because of the assumptions inherent in some policy and practice that people receiving help from an informal carer do not have unmet needs. Secondly, unmet need can affect both carer and care-recipient. For the disabled or older person not having their needs met can have a number of implications, and in some cases may mean that they have to 'lead more restricted lives' (Burchardt *et al.*, 2015, p.53). Informal

Brimblecombe, King, Stevens, Knapp (May 2019) What can the experiences of informal carers contribute to an understanding of inequalities in care?

carers may have to fill gaps in formal provision with the potential for impact on their employment, education, health and wellbeing (Brimblecombe *et al.*, 2018). For both carer and care-recipients, experiencing unmet need and trying to get needs met can be very stressful (Brimblecombe *et al.*, 2017; Brimblecombe *et al.*, in submission). Thirdly, and relatedly, there were sometimes differences of opinion between carers about how needs should be met which raises broader questions about whose needs are or should be met and how; which should take priority in cases of conflict of needs; and if needs are considered to be met if they are met solely by an informal care but at some cost to their wellbeing, employment and so on. Care provided by low-paid careworkers under stressful working conditions may meet service users' needs (to varying extent), but there may be negative impacts on careworkers' mental health and self-esteem (e.g. Stanley *et al.*, 2007; Coffey *et al.*, 2009). There are socio-economic, gender and geographic inequalities in who receives informal and formal care and who provides that care (Young *et al.*, 2006). In understanding inequalities in care it is therefore important to take into account carers' perspectives, careworkers' perspectives and the perspectives of disabled and older people with care needs.

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Brimblecombe, King, Stevens, Knapp (May 2019) What can the experiences of informal carers contribute to an understanding of inequalities in care?

## Tables

Table 1. Factors associated with perceived unmet need for services (working age carers and the person they care for)

	% of carers who say that the person they care for needs more services	% of care- recipients who say they need more services
N=150	66.0% (99)	47.3% (71)
Care-recipient has difficulty with one or more ADLs	73.1*	54.6*
Care-recipient does not have difficulty with ADLs	47.4*	28.9*
Informal care provision of less than 10 hours a week	61.5	25.6*
Informal care provision of 10 or more hours a week	68.5	55.6*
Male	56.5	34.8
Female	67.7	49.6
Ethnicity: White	66.9	44.6
Ethnicity: Black and Minority Ethnic	67.2	65.0
Care-recipient is parent/in-law of carer	73.0*	43.8
Care-recipient is other relative or friend	55.7*	52.5

Source: Adapted from Brimblecombe, N., Pickard, L., King, D. & Knapp, M. (2016) 'Perceptions of unmet needs for community social care services in England: A comparison of working carers and the people they care for'. *Health and Social Care in the Community*, online version doi: 10.1111/hsc.12323

\*=p<0.05

Table 2. Factors associated with perceived unmet need for services (young adult carers)

N=135	% of carers who say that the person they care for needs more services 60.0% (89)
Care-recipient has a mental health condition	68.5*
Care-recipient has a physical condition only	51.7*
Personal care provision	68.8*
Other types of care provision	48.2*
Informal care provision of less than 10 hours a week	63.0
Informal care provision of 10 or more hours a week	59.3
Male	38.7*
Female	65.6*
Ethnicity: White	57.7
Ethnicity: Black and Minority Ethnic	65.4

Source: Analysis of PSSRU, LSE Survey of young adult carers, 2018

\*=p<0.05