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## *'Replacement Care' for Working Carers? A Longitudinal Study in England, 2013–15*

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### **Abstract**

*In the context of rising need for long-term care, reconciling unpaid care and carers' employment is becoming an important social issue. In England, there is increasing policy emphasis on paid services for the person cared for, sometimes known as 'replacement care', to support working carers. Previous research has found an association between 'replacement care' and carers' employment. However, more information is needed on potential causal connections between services and carers' employment. This mixed methods study draws on new longitudinal data to examine service receipt and carers' employment in England. Data were collected from carers who were employed in the public sector, using self-completion questionnaires in 2013 and 2015, and qualitative interviews were conducted with a sub-sample of respondents to the 2015 questionnaire. We find that, where the person cared for did not receive at least one 'key service' (home care, personal assistant, day care, meals, short-term breaks), the carer was subsequently more likely to leave employment because of caring, suggesting that the absence of services contributed to the carer leaving work. In the interviews, carers identified specific ways in which services helped them to remain in employment. We conclude that, if a policy objective is to reduce the number of carers leaving employment because of caring, there needs to be greater access to publicly-funded services for disabled and older people who are looked after by unpaid carers.*

### **Keywords**

*Unpaid care; Employment; Paid services; Social services; Replacement care; England*

### **Introduction**

In the context of the ageing of the world's population, and people living longer with disability, the number of people in need of long-term care is expected to grow significantly in all countries (Colombo *et al.* 2011; Scheil-Adlung 2015). Many countries rely on unpaid care provided by family members or

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friends, primarily women. Yet, in Europe and other high- and middle-income countries, there are 'rises in both female labor market participation and the age of retirement' and 'the reconciliation of gainful employment and caregiving ... is therefore becoming an important societal issue' (Schneider *et al.* 2013: 1231). Tensions between work and care can lead unpaid carers to leave employment, resulting in costs to individuals, employers and society (Colombo *et al.* 2011).

In England, it is estimated that approximately 315,000 unpaid carers of working age have left work because of caring and are not in employment, at a cost to the government of at least £1.3 billion a year (Pickard *et al.* 2012). Drawing on these estimates, a government report stated that 'supporting people to combine work and care has now become an economic as well as a social imperative' (HMG and Employers for Carers 2013: 8). Consistent with this, government policy gives high priority to 'enabling those with caring responsibilities to fulfil their ... employment potential' (HMG 2014b: 28).

Policy around reconciling work and care by successive governments in England has primarily emphasized the role of employers in providing flexible working conditions (HMG 1999, 2008) but there is increasingly an emphasis on 'replacement care', or paid services for the person cared for (HMG 2008, 2010). In the Carers' Strategy, there is an emphasis on developing 'social care markets' to meet carers' needs for 'replacement care to enable them to continue to work' (HMG 2010: 16). The Care Act 2014 states that carers' assessments must consider whether the carer wants to work, and introduces a new duty on local authorities to provide support to meet carers' needs, with Explanatory Notes making it clear that support for carers may be met by providing services to the person cared for, for example, by providing 'replacement care' (House of Commons 2014: paragraph 152).

The emphasis on 'replacement care' in government policy in England represents a marked change from previous government policies, which rejected any notion of replacing, or substituting, unpaid care with paid services (Pickard 2001, 2012). In terms of the conceptualization of carers in the service system, an emphasis on 'replacement care' is consistent with a 'superseded carer' model (Twigg 1996). As such, it involves recognition of the 'dual focus of caring', acknowledging that caring takes place in a relationship and that policy should focus on both the disabled or older person *and* the carer. However, it is important to note that recent government policy sees 'replacement care' as taking the form of services provided through 'social care markets' and is consistent with a neo-liberal approach to care provision (HMG 2010, 2014b).

Despite the increasing emphasis on 'replacement care', insufficient information is known about its effectiveness in supporting working carers in England. The international literature on this issue is varied, with some studies showing a positive relationship between care-recipients' use of services and carers' employment and others showing no relationship or a negative relationship (Lilly *et al.* 2007; Pickard *et al.* 2015). Moreover, none of the existing studies relate to England. Research carried out in other countries is not necessarily applicable to England because of differences in labour market conditions, community care arrangements and funding mechanisms. In

England, studies show that access to services by working carers is low for a number of reasons, including poor access to carers' assessments, which are often the gateway to service support; lack of suitable services; fragmentation of services; costs of services; and reluctance to consider services by some people cared for, which in turn is often linked to poor quality of services and charges for services (Yeandle *et al.* 2007; Arksey and Glendinning 2008; Vickerstaff *et al.* 2009; Milne *et al.* 2013). There is also evidence that employed carers in England would like more service support (Phillips *et al.* 2002; Yeandle *et al.* 2007), but this is not in itself evidence that the provision of such support would be effective in supporting carers' employment.

In order to begin to address the gap in evidence relating to the effectiveness of paid services as a means of supporting working carers in England, we carried out a study using large-scale survey data, which showed that unpaid carers are more likely to be in employment if the person cared for receives paid services (Pickard *et al.* 2015). However, the study used cross-sectional data, collected at one point in time. It was not therefore possible to show conclusively whether it is paid services that enable carers to remain in employment or whether carers who are not employed are less likely to use services. In order to examine causation, longitudinal analysis is preferable.

A longitudinal study of the relationship between receipt of services by the person cared for and carers' employment outcomes in England requires new data because existing surveys do not include the necessary information. The *UK Household Longitudinal Study* includes questions on caring and employment but lacks questions on social care services. The *English Longitudinal Study of Ageing* (ELSA) includes questions on services but they can only be linked to the carer when care is co-resident.

The present study utilizes new longitudinal data to examine the relationship between receipt of paid services by the person cared for and unpaid carers' employment outcomes in England. In our mixed methods study, data were collected using self-completion questionnaires in 2013 and 2015, and qualitative interviews were conducted with a sub-sample of respondents completing the 2015 questionnaire. Given the public expenditure costs of carers leaving employment, the study focuses on unpaid carers who leave employment *because of caring*. We focus on public sector employees, who tend to have relatively 'carer-friendly' working conditions, in order to control for this aspect of the working environment as far as possible, allowing us to explore the role of services in supporting working carers. Drawing on the quantitative and qualitative data, we ask the question: what are the potential causal connections between service receipt by the person cared for and carers leaving work because of caring?

## Data and Methods

### Questionnaires

Our study, the Personal Social Services Research Unit (PSSRU), *Overcoming Barriers: Unpaid Care and Employment Longitudinal Study*, began by collecting data from a sample of carers who were employed in the public sector in England.

Data collection began with an online survey, the *Survey of Employees*, to identify employees providing unpaid care. In November 2012 to February 2013, potential participants were sent the survey link by their trade union or employer, with responses being returned directly to the research team. Unpaid carers were identified using the 2011 Census question: 'Do you look after, or give any help or support to family members, friends, neighbours or others because of either long-term physical or mental ill-health/disability, problems related to old age? Do not count anything you do as part of your paid employment' (ONS 2011).

Working carers who opted to take part further, were sent a self-completion questionnaire in February–June 2013, the *Working Carers' Questionnaire*. The baseline questionnaire included questions about socio-demographic characteristics, employment, unpaid care, combining work and care, and services received by the main person cared for. The main person cared for is defined as the person whom the carer spends most time helping and, if the carer spends an equal amount of time helping two or more people, is the care-recipient who lives with them.

In May–July 2015, working carers who completed the baseline questionnaire were sent a further self-completion questionnaire, the *Working Carers' Follow-on Questionnaire*. The follow-on questionnaire included questions about changes in socio-demographic characteristics, employment, unpaid care, combining work and care, and services received by the main person cared for.

Our questionnaires used validated questions from other surveys (for further details, see Brimblecombe *et al.* 2017a). Additional questions were piloted with respondents who did not take part in the main study.

### *Interviews*

At the end of the follow-on questionnaire, respondents were invited to take part in a telephone interview, and 40 interviews were subsequently conducted in June–November 2015. The number of interviews was based on previous research (Phillips *et al.* 2002). Respondents were sampled for the interviews to reflect the age, gender, ethnicity and employment status of those completing the follow-on questionnaire. The semi-structured interviews lasted for approximately one hour, and were designed to collect qualitative information on carers' experiences around changes in their circumstances since 2013, including their employment, care provision, service receipt and reasons for non-receipt. The interview schedule was piloted with respondents who did not take part in the main study.

Ethics approval was obtained from the Social Care Research Ethics Committee. Consent for the questionnaires was assumed from their voluntary self-completion. Consent for the interviews was obtained verbally at the start of the interview.

### *Methods: key definitions*

All carers in our longitudinal sample were employed in 2013. The analysis distinguishes two main employment outcomes in 2015: carers who remained

in employment, and carers who left work because of caring and were not in employment. These outcomes are based on answers to questions about the carer's employment in 2015, as well as to the following question: 'In the last two years, have you left your employment because of the care you have been or were providing?'

The analyses examine potential connections between carers' employment outcomes and receipt of 'key services' by the person cared for. 'Key services' are those that were associated with carers' employment in our earlier cross-sectional analysis: home care, personal assistant, day care, meals-on-wheels or their equivalent and short-term breaks (Pickard *et al.* 2015). 'Day care' refers to a day centre, lunch club, day activities or special school/college. 'Home care' refers primarily to help with personal care. 'Personal assistants' are people employed by individuals with care needs, often in receipt of personal budgets. 'Meals-on-wheels' are meals delivered to individuals at home. Short-term breaks refer to short stays in residential homes or short-break/respite centres.

All analyses focus on carers aged below State Pension age at follow-on, which was 62 years for women and 65 for men in early 2015. The analysis excludes those caring for someone in residential care, because national and international definitions of unpaid care do not necessarily include people caring for someone in those settings (Lilly *et al.* 2007; Maher and Green 2002). The analysis focuses on carers providing care for ten or more hours a week, because it is at this threshold that unpaid care has a negative effect on employment and when carers' employment is 'at risk' (King and Pickard 2013). The focus on carers whose employment is 'at risk' is consistent with our earlier cross-sectional analysis (Pickard *et al.* 2015).

In addition to service receipt, the analysis considers a number of other factors that may affect carers' employment outcomes, which have been identified in previous studies. These include the characteristics of the carer (age, gender, ethnicity, health, education); the carer's work (full or part time, use of 'carer-friendly' benefits, difficulties combining work and care); care provided (hours of care, number of people cared for, locus of care); and the care-recipient (care-recipient's age, relationship to carer) (Young *et al.* 2005; Lilly *et al.* 2007; Schneider *et al.* 2013).

Carer's age is measured by whether or not the carer was 53 or over at baseline because this relates to eligibility for an occupational pension. The majority of respondents worked in local government and could take their pension at age 55, so that those aged 53 in 2013 were eligible for a pension in 2015. Carer's ethnicity distinguishes White (British, Irish and Other White) backgrounds from Black and Minority Ethnic (BME) backgrounds. Use of 'carer-friendly' benefits refers to use of at least one of: short-term/emergency/flexible leave; flexible hours; time off in lieu; compressed hours; job share; working at home; paid overtime; and phone at work. Difficulties combining work and care are indicated by whether the carer's work was interrupted for at least 20 minutes, on two or more occasions, in the last month. Hours of unpaid care refer to hours provided to the main person cared for. Other definitions are given in the results section below (table 2).

*Quantitative analysis*

The quantitative analysis examines the association between receipt of 'key services' by the person cared for at baseline (2013) and carers' employment outcomes at follow-on (2015). The analysis examines whether variations in service receipt at baseline are associated with *subsequent* changes in carers' employment, in particular, leaving work to care. This is important for our examination of potential casual connections between service receipt and carers' employment, because temporal precedence can be regarded as a necessary condition for establishing a causal relationship.

Multivariate analysis is undertaken. Explanatory variables include the care-recipient's receipt of services at baseline, as well as other relevant variables. A *p* value of <0.05 is used as the criterion for significance.

*Qualitative analysis*

The interviews were recorded and transcribed in full, with the permission of the participants. Each transcript was read by two researchers and thematic analysis was undertaken both manually and using a qualitative data software package (NVivo 2012).

The qualitative analysis is informed by the research question: what are the potential causal connections between service receipt and employment outcomes? The approach taken to answering this question is mainly inductive thematic analysis (Braun and Clarke 2006). Key themes examined are: carers' reasons for leaving work; whether services would have helped carers to stay in employment; and ways in which services might have helped. We then identified several sub-themes within each theme. The process was iterative: as the analysis developed and new sub-themes emerged, the thematic framework and data were revisited, and data recoded accordingly. In the analysis, we also explore how the themes related to the factors affecting carers' employment outcomes that are identified in the quantitative analysis.

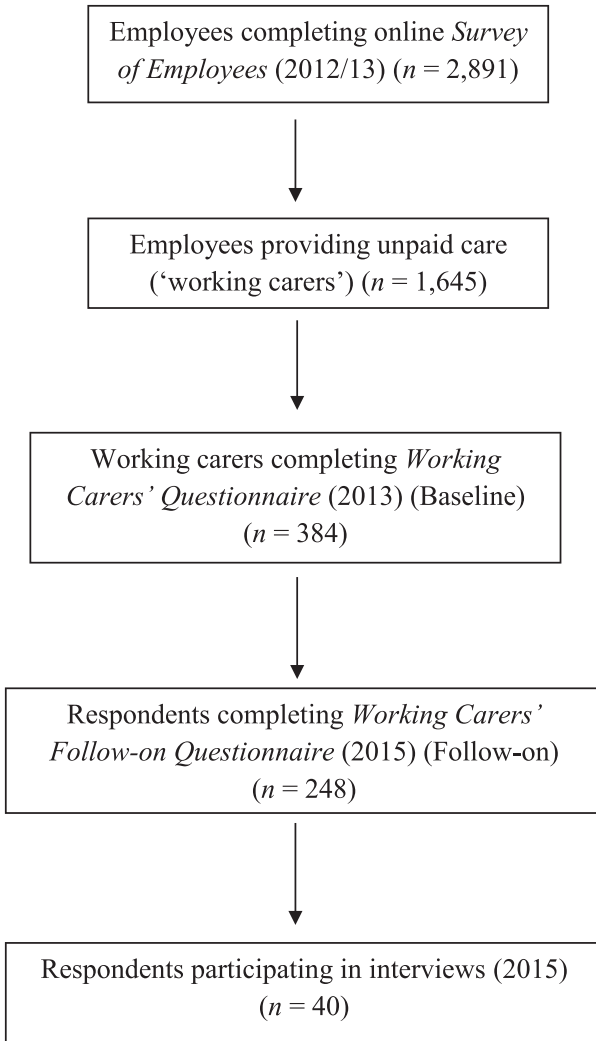
## **Service Receipt and Employment Outcomes: Quantitative Results**

*Sample characteristics*

Nearly 3,000 employees completed the initial *Survey of Employees* in 2012/13, of whom 1,645 provided unpaid care (figure 1). About half opted to take part further and 384 completed the *Working Carers' Questionnaire* in 2013, at baseline (a 50.5 per cent response rate). Two years later, 373 of these respondents were sent the *Working Carers' Follow-on Questionnaire*. The follow-on questionnaire was not sent to 11 people who had completed the questionnaire in 2013 but were no longer caring because, as indicated in a question asked at baseline, the care-recipient had died between the initial survey and the baseline questionnaire. Of the 373 people who were sent the follow-on questionnaire, 248 completed it (a 66.5 per cent response rate).

Figure 1

Flowchart of participants through PSSRU study: longitudinal study sample selection



Of the 248 respondents in our longitudinal sample, 166 were caring for ten or more hours a week for the main person cared for at baseline. Key characteristics of these respondents at baseline, compared to similar working carers in national survey data, are shown in table I. The national data are from the *Survey of Carers in Households* because this survey allows for the



Table 1

Characteristics of working carers providing unpaid care for ten or more hours a week for main person cared for: PSSRU study compared with national data, England

| Characteristics                             |                                  | PSSRU longitudinal study (baseline)    | National survey<br>( <i>Survey of Carers in Households</i> ) |
|---|----------------------------------|--|--|
| <u>Working carers</u>                       |                                  |  |  |
| Gender                                      | % women                          | 83.7 (77.4, 88.5)<br>( <i>n</i> = 166) | 63.1 (59.3, 66.8)<br>( <i>n</i> = 621)                       |
| Age (years)                                 | % < 35                           | 3.7 (1.7, 7.8)                         | 19.9 (17.0, 23.3)  |
|   | % 35–44                          | 14.2 (10.0, 20.4)                      | 21.1 (18.0, 22.4)  |
|   | % 45–54                          | 50.6 (43.0, 58.2)                      | 32.3 (28.8, 36.1)  |
|   | % 55–64                          | 31.5 (24.8, 39.0)                      | 21.9 (18.8, 25.3)  |
|   | % 65 and over                    | 0<br>( <i>n</i> = 162)                 | 4.8 (3.4, 6.8)<br>( <i>n</i> = 622)                          |
| Ethnicity                                   | % BME                            | 9.7 (6.1, 15.2)<br>( <i>n</i> = 165)   | 10.5 (8.3, 13.1)<br>( <i>n</i> = 622)                        |
| Health                                      | % in fair/bad health             | 42.8 (35.5, 50.4)<br>( <i>n</i> = 166) | 32.7 (29.1, 36.5)<br>( <i>n</i> = 609)                       |
| Employment status                           | % full-time                      | 61.6 (53.9–68.7)<br>( <i>n</i> = 164)  | 50.9 (46.9–54.9)<br>( <i>n</i> = 603)                        |
| Unpaid care hours for main person cared for | % caring 20 or more hours a week | 66.4 (58.1, 73.8)<br>( <i>n</i> = 137) | 56.2 (52.3, 60.1)<br>( <i>n</i> = 621)                       |
| <u>Main person cared for</u>                |                                  |  |  |
| Care-recipient's gender                     | % women                          | 59.1 (51.5, 66.4)<br>( <i>n</i> = 164) | 61.9 (58.0, 65.6)<br>( <i>n</i> = 622)                       |
| Care-recipient's age (years)                | % under 16                       | 12.7 (8.5, 18.7)                       | 11.8 (9.5, 14.5)   |
|   | % 16–64                          | 32.7 (26.0, 40.2)                      | 36.4 (32.7, 40.2)  |
|   | % 65 and over                    | 54.5 (46.9, 62.0)<br>( <i>n</i> = 165) | 51.9 (47.9, 55.8)<br>( <i>n</i> = 621)                       |
| Care-recipient's relationship to carer      | % parents/in-law                 | 48.8 (41.3, 56.3)                      | 51.2 (47.3, 55.1)  |
|   | % spouse/partner                 | 17.5 (12.2, 23.7)                      | 20.1 (17.2, 23.5)  |
|   | % son/daughter                   | 26.5 (20.4, 33.7)                      | 19.5 (16.6, 22.8)  |
|   | % other                          | 7.2 (4.2, 12.2)<br>( <i>n</i> = 166)   | 9.2 (7.2, 11.7)<br>( <i>n</i> = 621)                         |

Sources: *Survey of Carers in Households, 2009/2010* (HSCIC 2010); PSSRU Working Carers' Questionnaire, 2013.

Notes: Percentages and 95% confidence intervals.

identification of the main person cared for, using the same definition as in our study. Our sample is in many ways comparable to national data on working carers. The majority in our sample are women and in mid-life, with a minority from BME backgrounds. Approximately half care for a parent/parent-in-law and half for someone aged 65 and over. In our sample, there are, however, higher proportions who are women and aged 45–64 and lower proportions aged under 44 than nationally, which may reflect the

underlying public sector population from which the sample was drawn (Damant and Jenkins 2011).

### *Working carers' employment outcomes*

Excluding those who would have reached State Pension age in two years' time, those caring for someone in a residential home in 2013 and missing data, we have information on the employment rate at follow-on of 151 respondents who were working and caring for ten or more hours a week at baseline. Two years later, 83.4 per cent ( $n = 126$ ) were still in employment. These results are comparable with results using national data. Previous research using the ELSA, which was carried out separately by gender, showed that 85.8 per cent of women caring for ten or more hours a week at baseline remained in employment two years later (King and Pickard 2013). In our study, 84.1 per cent of women caring for ten or more hours a week at baseline (106 out of 126 women respondents) remained in employment two years later.

Not all the carers who left work in our study did so because of caring. Of the 16.6 per cent of carers who had left work at follow-on, 9.9 per cent ( $n = 15$ ) had done so because of caring and 6.6 per cent ( $n = 10$ ) for reasons other than caring. We explore in the qualitative interviews why some carers left work for reasons other than caring. The quantitative analysis below focuses on our main area of interest: carers who left work because of caring.

### *Service receipt and leaving work to care*

Table 2 presents descriptive results on the characteristics at baseline of carers who either remained in employment or left work because of caring ( $n = 141$ ). The patterns shown are generally consistent with the literature on the factors affecting carers' employment (see earlier references). Carers leaving work to care in our sample were, in particular, more likely to be older than younger; women rather than men; and in poor rather than good health. They were also more likely than not to experience difficulties (interruptions) at work due to caring, and to care for longer hours, on a co-resident basis and for more people. Table 2 also shows that working carers looking after care-recipients with no 'key services' at baseline were more likely to leave work to care than those looking after someone with services.

Multivariate logistic regression analysis was used to identify the predictors of leaving work to care in two years' time, based on the characteristics of the sample at baseline. The dependent variable distinguishes remaining in employment (the reference category) and leaving work because of caring.

The multivariate analysis draws on the characteristics at baseline potentially affecting employment outcomes (table 2). Some variables are excluded because of low cell counts or correlations between variables. We exclude ethnicity and use of carer-friendly benefits because empty cells are indicated in table 2. The variable measuring the care-recipient's age is omitted because

Table 2

Characteristics at baseline of working carers providing care for ten or more hours a week to main person cared for, by employment outcomes two years later

| Characteristics at baseline (2013)       |                          | Carers' employment outcomes at follow-on (2015) |   |             |
|--|--------------------------|---|---|-------------|
|  |                          | In employment (working carer)                   | Left work because of caring and not working | Sample Base |
| <u>All</u>                               |                          | 89.4 %  | 10.6 %                                      | 141         |
| <u>Carers</u>                            |                          |   |   |             |
| Carer's age (years)                      | Under 53                 | 94.7%   | 5.3%  | 75          |
|  | 53 and over              | 83.3%   | 16.7%                                       | 66          |
| Carer's gender                           | Men                      | 95.2%   | 4.8%  | 21          |
|  | Women                    | 88.3%   | 11.7%                                       | 120         |
| Carer's ethnicity                        | BME                      | 100.0%  | 0.0%  | 12          |
|  | White                    | 88.3%   | 11.7%                                       | 128         |
| Carer's education                        | Has degree or equivalent | 89.9%   | 10.1%                                       | 69          |
|  | No degree or equivalent  | 88.9%   | 11.1%                                       | 72          |
| Carer's health                           | Good/very good           | 91.3%   | 8.8%  | 80          |
|  | Fair/bad/very bad        | 86.9%   | 13.1%                                       | 61          |
| <u>Carer's work</u>                      |                          |   |   |             |
| Employment status (hours [hrs] a week)   | Part-time (<= 30 hrs)    | 89.8%   | 10.2%                                       | 49          |
|  | Full-time (> 30 hrs)     | 88.8%   | 11.2%                                       | 89          |
| Carer-friendly benefits at work          | Not used benefits        | 100.0%  | 0.0%  | 10          |
|  | Used benefits            | 88.5%   | 11.5%                                       | 130         |
| Caring interrupts work                   | Not frequently           | 93.5%   | 6.5%  | 77          |
|  | Frequently               | 84.7%   | 15.3%                                       | 59          |
| <u>Unpaid care provided</u>              |                          |   |   |             |
| Hours of care a week                     | 10–19                    | 94.9%   | 5.1%  | 59          |
|  | 20 or more               | 85.4%   | 14.6%                                       | 82          |
| Locus of care                            | Not co-resident          | 90.6%   | 9.4%  | 53          |
|  | Co-resident              | 88.6%   | 11.4%                                       | 88          |
| Number of people cared for               | One person               | 92.0%   | 8.0%  | 100         |
|  | Two or more people       | 82.9%   | 17.1%                                       | 41          |
| <u>Main person cared for</u>             |                          |   |   |             |
| Care-recipient's age (years)             | Under 65                 | 91.0%   | 9.0%  | 67          |
|  | 65 and over              | 87.7%   | 12.3%                                       | 73          |
| Care-recipient's relationship to carer   | Parent/in-law            | 91.0%   | 9.0%  | 67          |
|  | Partner/child/other      | 87.8%   | 12.2%                                       | 74          |
| Care-recipient's receipt of key services | Has services             | 98.2%   | 1.8%  | 56          |
|  | No services              | 82.7%   | 17.3%                                       | 81          |

Sources: Working Carers' Questionnaire, 2013; Working Carers' Follow-on Questionnaire, 2015.

Notes: Row percentages and sample base. The total sample base (141) excludes carers who left work for reasons other than caring.

it is correlated with carer's age (Chi-Square = 6.6,  $p = 0.010$ , degrees of freedom [df] = 1). Locus of care and interruptions at work are omitted because they are correlated with provision of care for 20 or more hours a week (respectively, Chi-Square = 39.5,  $p < 0.001$ , df = 1; Chi-Square = 7.0,  $p = 0.008$ , df = 1).

The results of the multivariate analysis show that, controlling for other variables, carers leaving work to care were significantly more likely than those remaining in employment to look after someone who did not receive at least one 'key service' at baseline (table 3). In addition, those aged 53 years and over, those caring for 20 or more hours a week, and those caring for two or more people were more likely to leave work to care than, respectively, younger people, those caring for fewer hours and those caring for one person.

The analysis so far shows that, where the person cared for did not receive services at baseline, the carer was *subsequently* more likely to leave work because of caring, suggesting that the absence of services may have contributed to the carer leaving work. In the interviews, we explored with the carers themselves how services may have helped them to stay in employment.

Table 3

Regression results for factors associated with leaving work to care after two years: working carers providing care for ten or more hours a week to main person cared for at baseline

| Covariates at baseline (2013)           |   | Left work because of caring |             |              |
|---|---|-----------------------------|-------------|--------------|
|   |   | Beta coefficients           | Odds ratios | Significance |
| Care-recipient's service receipt        | Care-recipient did not use services ... relative to care-recipient used services    | 2.616                       | 13.681      | *0.016       |
| Age of carer                            | Carer aged 53 years and over ... relative to carer aged under 53 years              | 1.457                       | 4.295       | *0.032       |
| Hours of care for main person cared for | Care for 20 or more hours a week ... relative to care for less than 20 hours a week | 1.621                       | 5.059       | *0.026       |
| Number of people cared for              | Care for two or more people ... relative to care for one person                     | 1.325                       | 3.761       | *0.040       |
| Constant                                |   | -6.584                      | 0.001       | **<0.001     |
| N                                       |   |                             | 137         |              |

Sources: Working Carers' Questionnaire, 2013; Working Carers' Follow-on Questionnaire, 2015

Notes: Final model. The reference category is 'carers who remained in employment'. The sample number is lower than in table 2 because of missing data ( $n = 4$ ). Other variables entered into the model: carer's gender, education, health and employment status, and relationship of care-recipient to carer. Significance: \* $p < 5\%$ , \*\* $p < 1\%$ .

## Carers' Views on Services and Employment: Qualitative Results

The characteristics of the people we interviewed are shown in table 4. Our analysis focuses on three groups: nine interviewees who left work because of caring; five who left work for other reasons; and 15 carers in employment who cared for ten or more hours a week for someone receiving community care services.

### *Reasons for leaving work: aspects of caring that led carers to leave work*

The aspects of caring that led unpaid carers to leave work are important because it is these aspects that paid services potentially addressed. There were two main sub-themes here: work-related issues and the needs of the people cared for.

The most common reasons for leaving work that were given by people who left work to care were associated with tensions between working and caring. These carers were not 'balancing', or even 'juggling', work and care; they were, as one said, 'struggling' to work and care. There were three main work-related issues. First, carers struggled at work as a result of interruptions.

Table 4  
Characteristics of interview sample

| Characteristics at baseline (unless otherwise indicated)          | Number interviewed          |    |
|---|-----------------------------|----|
| Carer's gender  | Men                         | 8  |
|   | Women                       | 32 |
| Carer's age (years)   | Under 53                    | 15 |
|   | 53 and over                 | 25 |
| Carer's ethnicity   | BME                         | 5  |
|   | White                       | 35 |
| Carer's employment at follow-on                                   | In employment               | 26 |
|   | Left work because of caring | 9  |
|   | Left work for other reasons | 5  |
| Hours of care provided by carer per week to main person cared for | Less than 10                | 8  |
|   | 10–19                       | 14 |
|   | 20 or more                  | 18 |
| Number of people cared for by carer                               | One person                  | 28 |
|   | Two or more people          | 12 |
| If key services received by main person cared for                 | Received                    | 18 |
|   | Not received                | 22 |
| Total   |                             | 40 |

Sources: Working Carers' Questionnaire, 2013; Working Carers' Follow-on Questionnaire, 2015; interviews carried out by research team in 2015.

Notes: Sample numbers.

Some spoke of frequent telephone calls from or to the person cared for while they were at work. One carer went 'back and forwards' between work and home, often going home at lunch-times. Carers who were interrupted at work spoke of being constantly 'anxious' about the person cared for. A second difficulty arose around taking time off work. In several cases, sickness procedures were instigated against carers who had taken time off, which could ultimately have led to dismissal. Difficulties around time off work were often associated with the stress of combining work and care. Several carers experienced work-related stress and had to have time off, but this in turn could lead to more difficulties and stress if the employer then started procedures against them. The third type of difficulty experienced by carers at work was to do with changes in working conditions that made it harder to combine work and care. For example, the carer who went 'back and forwards' during the working day decided to stop work when an office move was proposed that would have made it impossible for her to go home in the day-time.

The second main sub-theme relating to the aspects of caring that led carers to leave work was to do with the needs of the person cared for. Three carers said that they left work because of this, and all cared for more than one person. For example, one carer commented on why she left work as follows:

*'Well, a lot of it was to do with the caring because I wasn't well me self, I was caring for me husband, me dad was dead, I was looking after mum. ... It was getting to the stage, I was absolutely shattered.'* (56-year old woman, left work to care, no services)

#### *Other reasons for leaving work*

Where carers left work but did not say that this was because of caring, their main reasons were primarily financial. Four of the five people we interviewed, who left work for reasons other than caring, gave their ability to take their occupational pension as a key reason for leaving work; two had taken voluntary redundancy, as well as their pension; and the fifth had been made compulsorily redundant. They also gave the following reasons for leaving employment: disillusionment with their jobs in the context of public expenditure cuts and pay freezes; wanting to spend more time with (non-disabled) family members; wanting to spend more time on themselves; and serious physical health problems. Caring was given as part of the reason for leaving work by three people but was never the prime reason and, of these, one said that caring had not impacted on his ability to work and another said that the care-recipient's needs were not the reason for stopping work.

Those who left work because of caring also gave other reasons for leaving employment. Around half said that they left work partly because they qualified for an occupational pension and/or took voluntary redundancy; some spoke of disillusionment with their jobs or pre-existing health conditions; one wanted more time with her (non-disabled) partner; and one wanted more

time for herself. The difference with those who left work for reasons other than caring was that the carers who left work to care *always* gave reasons for leaving work that were related to caring, in addition to any other reasons.

#### *Whether services would have helped, or did help, carers stay in work*

Interviewees were asked what would have made, or did make, a difference to balancing work and care, and were prompted about specific factors if they did not mention them, including services. In this context, the majority of people we interviewed, who left work because of caring, said that services for the person cared for would, or would 'possibly', have helped them stay in work. The most common type of service that would have helped was home care. Several mentioned particular personal care or practical tasks, with which paid carers would have been helpful. As one said:

*'If somebody had been there, like a carer, somebody to come in of a morning, dinner [lunch] time ... I'd have felt a lot ... better within myself at work.'* (56-year old woman, cited earlier)

The working carers we interviewed, who looked after someone receiving services, overwhelmingly thought that services helped them to stay in employment. All but one of the 15 interviewed said that services helped them to combine work and care. Of those that said services helped, most of the care-recipients received home care/personal assistant, and a few received day care, meals-on-wheels or short-term breaks.

#### *How services helped carers to remain in employment*

There were a number of sub-themes relating to the ways in which services helped carers to remain in employment. Services helped partly by addressing issues that could have led carers to leave work to care. As indicated earlier, many carers who left work to care, and lacked services, spoke of anxiety about the person cared for while at work. In contrast, the majority of working carers with services said that services for the care-recipient meant that, for example, they were 'not anxious' while at work.

Another common reason for leaving work to care was associated with issues around taking time off, which could lead to dismissal. One of the working carers we interviewed had experienced this but, in her case, she received services and stayed in employment. In this case, when the carer began caring, her mother did not receive services. Her mother's health deteriorated and the carer started visiting before and after work, but it became too much and she took time off for depression. Her employer then started procedures against her. However, in this instance, the carer contacted social services, which arranged for paid carers to visit her mother every morning and evening. The carer explained that the paid care helped her to work because:

*'... just purely from a time factor, I could not have carried on going before and after work ... And also from a peace of mind factor, because I know they will contact*

*me if they have any concerns.*' (50-year old woman, working carer, with services)

Carers also left work to care because of the care-recipient's needs and, as noted earlier, in every instance, they were caring for more than one person. Other carers, caring for more than one person with services, remained in employment. For example, one carer looked after her severely disabled child and her parent. However, both received services, with the child receiving day care five days a week, while the parent had twice-daily visits from paid carers. Commenting on the importance of these services in enabling her to work, the carer said *'I couldn't without them'*. The services for the main person she cared for, her disabled child, were particularly important and, in this regard, she commented:

*'Without the day-centre, I'd never have been able to work.'* (59-year old woman, working carer, with services)

Services also helped carers to stay in work by providing the type of support that carers who left work to care said they needed. As previously indicated, carers leaving work to care, and lacking services, typically wanted paid carers to visit the care-recipient when they were at work and do practical tasks. Working carers with services often had precisely this type of service. Most working carers with services who we interviewed said that services helped by providing care when the carer was at work and/or by helping with personal care/domestic tasks. One carer, whose father was looked after by a paid carer while he worked, said:

*'It's like a weight off my mind ... I know that [my father] is going to be fed and looked after while I'm at work ... I know he's being taken to the toilet.'* (39-year old man, working carer, with services)

## Discussion and Conclusions

Previous research on unpaid carers, providing care for ten or more hours a week, has shown an association between carers' employment and service receipt by the person cared for, using cross-sectional data (Pickard *et al.* 2015). Our present study takes the analysis forward by using *longitudinal* data, which are preferable for exploring causation. Our results show that, where the care-recipient did not receive at least one 'key service' (home care/personal assistant, day care, meals and/or short-term breaks), the carer was *subsequently* more likely to leave employment because of caring, controlling for covariates. Since temporal precedence can be regarded as a necessary condition for establishing causation, our results suggest that the absence of services contributed to the carer leaving work. Therefore, the association between service receipt by the care-recipient and the carer's employment did not arise because, for example, the carer or care-recipient dispensed with services after the carer left work. The absence of services was not therefore a consequence of the carer leaving work. Rather, it



was more likely that the carer leaving work was a consequence of the absence of services.

Our qualitative interviews allowed us to explore with the carers themselves the potential causal connections between service receipt and employment outcomes. Our qualitative results are consistent with previous research on the reasons why carers leave work, particularly the tensions between working and caring, including 'tiredness and lack of concentration; worry about caring responsibilities at work; and stress ...' (Arksey 2002: 152). However, what our research adds is greater understanding of the mechanisms by which services for the care-recipient may help carers to combine care and work. Services helped carers to remain in employment partly by addressing issues that could have led them to leave work to care, for example, by reducing their anxiety about leaving the person cared for. Services also helped by providing the type of support that carers who left work said they needed, in particular, services provided during their working day and help for the care-recipient with personal care/domestic tasks.

In addition to service receipt, a number of other factors were associated with carers' leaving employment because of caring, including the carer's age, caring for 20 or more hours a week, and caring for more than one person. These results are consistent with previous British studies (Carmichael and Charles 2003; Heitmueller 2007). In our study, there was a correspondence between the factors associated with leaving work to care in the quantitative analysis and the reasons given by carers in the interviews. Qualifying for an occupational pension contributed to the decision of a number of carers to leave work to care, even though their primary reason was to do with caring, and qualifying for a pension is related to the carer's age. A number of carers we interviewed said they left work because of the care-recipient's needs, and all cared for more than one person. Although carers did not talk about leaving work because of caring for 20 or more hours a week, a finding of the quantitative analysis, they did talk about being interrupted at work and, in the quantitative analysis, being interrupted at work was correlated with caring for 20 or more hours a week. The fact that leaving work to care was associated with more intense forms of caring is important. It suggests that carers who said that they had left work because of caring were not making some kind of *post hoc* rationalization about their reasons for leaving work, but were indeed providing more 'burdensome' forms of care.

Not all the carers in our study said that they left work because of caring. Of the working carers who cared for ten or more hours a week in 2013, 10 per cent left work because of caring and seven per cent for other reasons. In the interviews, carers who left work for reasons other than caring said that they left work primarily for financial reasons, and had either taken an occupational pension or been made redundant. Most working carers in our sample were employed in local government, and local government employees in the UK fell by eight per cent between 2013 and 2015 (ONS 2015). It is likely that some of the carers in our sample who left work during this time did so primarily because of reductions in public sector employment. Nevertheless, most of the carers in our sample who left work did so because of caring and, for these

carers, receipt of services by the person cared for significantly affected whether they left work.

Our study has a number of limitations. The study is based on carers working in the public sector and this may raise questions about its applicability to the private sector, where employees in England are less likely to have flexible working arrangements (BIS 2012). However, we deliberately selected employees with 'carer-friendly' working conditions, and our analysis is likely to be applicable to employees with 'carer-friendly' working arrangements, whether in the private or public sectors (a point discussed further below). In addition, most of the respondents were recruited to the study through a trade union. It is possible that union members may have a different view on the value of services than other working carers, and this may potentially affect the generalizability of the results. However, our working carers are in many ways comparable to carers nationally, and many of our findings are similar to previous research, including the finding on the value of services for working carers (Arksey and Glendinning 2008). Lastly, our study is relatively small-scale, and this has restricted our analysis to some extent. For example, our multivariate analysis of carers' employment outcomes did not include ethnicity. Nevertheless, our study represents a unique contribution to research on caring and employment because, as indicated earlier, existing large-scale longitudinal surveys in England do not include information on caring, employment and services for co-resident carers *and* those caring for someone in another household. Our study suggests that such data should be collected in future. The collection of improved large-scale longitudinal data on caring and employment would permit not only the inclusion of data on receipt of services by the person cared for, but also the inclusion of other important variables, such as the carer's type of employment and experience of accessing workplace support and flexibility.

Our results have important implications for policy. The findings support the policies of recent governments in England that emphasize 'replacement care' as a means of supporting carers' employment (HMG 2008, 2010). This is because the results show that unpaid carers looking after someone who does not receive paid services are subsequently more likely to leave work to care. Our study also supports an emphasis on 'replacement care' because it suggests that 'carer-friendly' working conditions are not sufficient on their own to protect carers' employment. Although the carers in our sample had relatively 'carer-friendly' working conditions, one in ten left employment because of caring over the following two years. Alongside a policy emphasis on flexible working, therefore, an emphasis on 'replacement care' is also needed.

Many working carers and the people they care for would welcome greater access to paid services. Previous research in England has found unmet need for services by working carers (Phillips *et al.* 2002; Yeandle *et al.* 2007) and by disabled or older people (Vlachantoni *et al.* 2011). Earlier analysis of our sample at baseline found that there was a high level of perceived unmet need for services by *both* working carers *and* the people they cared for, particularly where unpaid care was provided for ten or more hours a week (Brimblecombe *et al.* 2017a). Analysis of our longitudinal sample at follow-on found that unmet need by working carers remained high two years later, but that many

carers and the people they cared for experienced barriers to receipt of social care services and, as a result, carers were often forced to make accommodations to their working lives (Brimblecombe *et al.* 2017b, forthcoming).

However, although our results support recent government policies emphasizing ‘replacement care’ in England, they raise an important issue around the emphasis on ‘the market’ as a means of meeting the needs of unpaid carers and the people they care for. Most of the people cared for in our study were adults and, with regard to care for adults, the costs of ‘replacement care’ are likely to fall to care-recipients, typically disabled or older people, who may lack the resources to purchase care on ‘the market’ (Lewis and West 2014). It is therefore likely that more *publicly-funded* ‘replacement care’ is also needed.

A key policy implication of our study is that, if an objective of government is to reduce the number of carers leaving employment because of caring, there needs to be greater access to publicly-funded services for disabled and older people who are looked after by unpaid carers. However, at present, access to publicly-funded social care in England is restricted by strict eligibility criteria and means-testing. Implementation of reforms to the funding system, introduced under the Care Act 2014, has been delayed (Carers UK 2015). Moreover, the availability of adult social services is being reduced in England, despite increased demand (Burchardt *et al.* 2015; House of Commons 2017). Reducing the availability of social care services may, however, incur unanticipated costs. As noted earlier, the public expenditure costs of carers leaving employment in England are more than a billion pounds a year (Pickard *et al.* 2012). If restricting access to publicly-funded social care for disabled and older people results in more carers leaving work because of caring, it may therefore result in further public expenditure costs.

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