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Informal caring in England and Wales – Stability and transition between 2001 and 2011



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ABSTRACT

Informal caring is of significant and increasing importance in the context of an ageing population, growing pressures on public finances, and increasing life expectancy at older ages. A growing body of research has examined the characteristics associated with informal care provision, as well as the impact of caring for the carer's physical and mental health, and their economic activity. However, only a relatively small body of literature has focused on the study of 'repeat' or continuous caring over time, and the factors associated with such trajectories. In 2001, for the first time, the United Kingdom census asked about provision of informal care, enabling identification of the prevalence of informal caregiving at a national level. This paper follows up informal carers from the 2001 Census in order to examine their characteristics and circumstances 10 years later using a nationally representative 1% sample of linked census data for England and Wales, the *Office for National Statistics Longitudinal Study*. The analysis classifies the range of possible combinations of caring and non-caring roles between 2001 and 2011, focusing on the characteristics of those who were providing care at one, or both, time points. Among other results, the analysis identified that, among those who were carers in 2001, caring again in, or continuing to care until, 2011 was associated with being female, aged between 45 and 54 years in 2011, looking after the home, and providing care for 50 hours or more per week in 2001. Such results contribute to our understanding of a particular group of informal carers and provide a more nuanced picture of informal care provision at different stages of the life course.

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1. Introduction

The 2011 Census showed that approximately 10% of the population of England and Wales provided some form of unpaid or informal care, i.e. "look[ed] after, or [gave] 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" (ONS, 2013a). Inclusion of the informal carer question in the 2001 and 2011 UK Censuses reflects the importance of informal caring as a social policy issue (Blackwell, Akinwale, Antonatos, & Haskey, 2005). Increasing public policy recognition of the significance of informal care provision in the last few years (Commission on Funding of Care and Support, 2011; Department of Health, 2012) has

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been matched with expanding academic research examining different aspects of care provision, such as the relationship of carers with the labour market and the impact of caring in the short- and long-term (Berecki-Gisolf, Lucke, Hockey, & Dobson, 2008; Carmichael, Charles, & Hulme, 2010; Dini, 2010). Research on the characteristics of informal carers has consistently shown that women are more likely to provide care than men in most age groups (Glaser, Grundy, & Lynch, 2003; Shaw & Dorling, 2004) but that in later life, men's care provision towards their spouse is more prevalent (Arber, 2006; Dahlberg, Demack, & Bambra, 2007; Del Bono, Sala, & Hancock, 2009). Being married is strongly associated with caring across the life course (Robards, Evandrou, Falkingham, & Vlachantoni, 2012). Researchers have also linked the activity of caring to adverse outcomes for the carer in terms of physical health (O'Reilly, Connolly, Rosato, & Patterson, 2008; Young, Grundy, & Kalogirou, 2005), mental health (Taylor, Ezell, Kuchibhatla, Østbye, & Clipp, 2008) and participation in the labour market (Dini, 2010; Lilly, Laporte, & Coyte, 2010). However, such links are not straightforward (Brown & Brown, 2014) and depend on the particular characteristics of the caring activity such as the number of hours of care provided, the relationship to the person cared for and the health status of the person cared for (Vlachantoni, Evandrou, Falkingham, & Robards, 2013).

Existing studies of 'caring trajectories' have often focused on relatively short periods (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003) and much less is known about the characteristics of individuals who provide care over a prolonged time period or the propensity to repeatedly provide care over a longer time period. Demographic changes point to the increasing importance of older carers for the future supply of informal care, particularly in relation to increasing life expectancy at older ages which can result in longer co-residential living arrangements and therefore prolonged informal caring roles associated with health problems at older ages (Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000). Therefore, this study contributes to the part of the literature which aims to understand patterns of transition in and out of caring activity over time, and the factors associated with such transitions over a 10-year period. Overcoming challenges related to low cell counts or the lack of a representative dataset, the study uses the Office for National Statistics (ONS) Longitudinal Study (LS), a nationally representative 1% sample of linked census data for England and Wales. The study utilises longitudinal data to follow up on informal carers from 2001 to examine how many were providing care 10 years later and what factors were associated with such care, including the hours of care provision at both points in time.

2. Previous research on informal care provision: characteristics, impact and trajectories

A large body of literature has focused on the study of informal care provision at one point in time, shedding light on the demographic, socio-economic and health characteristics of informal carers, as well as the characteristics of their caring activity, such as the number of hours of care

and relationship to the person they care for (ONS, 2013a; Young & Grundy, 2008; Young et al., 2005).

Recent results from the 2011 Census for England and Wales have highlighted that just over two-thirds of informal carers are aged between 35 and 64 years and provide up to 20 h of care per week (ONS, 2013a). The number of hours of care provided typically increases with age, and research has linked specific demographic characteristics, such as being a woman and being married, with a higher likelihood of being an informal carer (Arber & Ginn, 1995; ONS, 2013b; Shaw & Dorling, 2004). This gender differential is reversed in later life, when men are more likely to be spousal carers and to provide a high number of hours of care per week (Del Bono et al., 2009). Both male and female carers bear indirect costs from informal caring whereby they earn less when in work and are less likely to be in paid work than non-carers (Carmichael & Charles, 2003). Research has also aimed to understand the health status of carers, producing sometimes contradictory results (Brown & Brown, 2014; Doran, Drever, & Whitehead, 2003; Ross, Lloyd, Weinhardt, & Cheshire, 2008; Young et al., 2005). However, such evidence of the informal carers' 'profile' is often derived from cross-sectional research, which cannot capture the direction of causality between informal care provision and specific characteristics.

A relatively small number of researchers have investigated informal care provision over time, often in order to understand the impact of caring on the carer's economic activity, morbidity and mortality. For example, O'Reilly et al. (2008) examined carers' mortality risk over time, showing a lower mortality risk for caregivers than non-caregivers, but an increasing risk with the number of hours spent providing care. In a similar vein, research in the US (Rahrig Jenkins, Kabeto, & Langa, 2009) and in the UK (Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010) has argued that overall, caregivers tend to report better health than non-caregivers, although other health-related impacts (e.g. stress, mental health) may be identified among caregivers. Research on the health impact of informal care provision has produced complex results depending on the relationship between the care provider and the care recipient, the health status of both parties at baseline, the particular nature of the caring activity such as the tasks included in the care provision, as well as other roles combined simultaneously with that of a caregiver (Glaser, Evandrou, & Tomassini, 2005; Keene & Prokos, 2008; Schulz & Beach, 1999). Finally, evidence has been found of the impact of health status on one's chances of providing informal care, pointing to a 'healthy carer selection effect' (Young & Grundy, 2008).

Similar complexity underscores the study of the impact of care provision on the carer's economic activity. One side of this debate has provided evidence that taking up caring results in reduced labour market participation in the form of reduced hours, rather than participation per se (Berecki-Gisolf et al., 2008). The other side of the debate points to the importance of including the number of hours informal care provided in the equation, and argues that once such a factor is taken into account, the negative impact of caring on economic activity is viewed at the level of labour

market participation, rather than the reduction of hours worked or on wages (Lilly et al., 2010). However, Heitmueller (2007) noted that not accounting for endogeneity in the relationship between informal care and labour market participation can significantly overestimate the impact of the former on the latter. A less studied part of this literature refers to the opposite direction of this relationship, that is the impact of paid employment on one's willingness to supply informal care, and here the evidence highlights that employment participation and earnings both impact negatively on such willingness (Carmichael et al., 2010). Such findings are instrumental in improving our understanding of what is essentially a diverse group of individuals, often combining caring with other demanding roles and activities over their life course.

In order to fully estimate the role of informal caring and its increasingly important part of the life course for increasing numbers of people (ONS, 2013a; Pickard et al., 2000) some studies have used longitudinal data and analyses to more fully understand informal caring over longer timeframes (Jette, Tennstedt, & Branch, 1992). Such analyses are increasingly necessary given increasing durations of co-residential living at older ages in relation to increasing healthy life expectancy, particularly among men, and a social policy system in the UK which is based on the ability to pay for informal care. Lawton, Moss, Hoffman, and Perkinson (2000) studied 634 women aged 65 years and over for a period of 4 years, and distinguishing between non-carers, new carers, and 'veteran' carers (who had cared for at least 12 months), found that veteran carers tended to be older, were the least likely to be married and the most likely to report poor physical and mental health, compared to all other groups. Tooth and Mishra (2014) used data from the Australian Longitudinal Study on Women's Health to understand ongoing, starting, transitional and never caring patterns across two cohorts of women. They found that socio-economic factors were the most frequently associated with caring trajectories compared to demographic and health factors, but their effect was diverse; for instance financial hardship and reduced labour force participation was associated with continuing caring, but not with starting or transitional caring. An earlier study by McCann, Hebert, Bienias, Morris, and Evans (2004) observed individuals at baseline and three years later, and found that physically healthier individuals were significantly more likely to become caregivers and to continue caregiving, while declining mental health was associated with continuing caregiving. Finally, focusing on spousal caring, Burton et al. (2003) studied 428 individuals at baseline and five years later, and found that the 'risk' of becoming a caregiver was higher among individuals who were older, had a lower income and higher levels of health-risk behaviour prior to taking up the caregiver role.

Within this body of research, some studies have investigated the health impact of such trajectories, albeit with longitudinal data which present 'gaps' in time. Burton et al. (2003) showed that transitioning to heavier caregiving was associated with depression, poorer self-reported health and health-risk behaviours. Using data following the same respondents at two time points (1992 and 1996), Cannuscio et al. (2002) found that women who had started

caregiving experienced a mental health decline, compared to women who were non-caregivers or former caregivers. Similarly poor results in terms of emotional health, as well as physical health and their engagement in the labour market, were indicated in the study by Lee and Gramotnev (2007) of more than 9,000 Australian middle-aged women who had continued, started or stopped caring over the space of 3 years.

In summary, while cross-sectional analyses have identified the prevalence of informal caring and the key characteristics of carers, they have not provided insights on the repetition or continuation of informal caring over prolonged time periods. The limited longitudinal analyses that have been carried out have generally focussed more on the health and mortality of informal carers than the repetition of informal caring or the provision of informal care over a prolonged time period. Most of these studies have been from the US or from Australia and within the UK context there is little known about the repetition of informal caring over a prolonged time period and the characteristics associated with this. Crucially, there are many factors which may be associated with such repetition including reducing or stopping work to assume a caring role (Henz, 2004), which may run counter to the extended working lives agenda, and the increase in life expectancy at older ages leading to longer co-residence at older ages and the increasing likelihood of informal caring and longer durations and repetition of care.

Against this background, this study uses longitudinal data to follow up on informal carers from 2001 to see how many were providing care 10 years later. The key aim of the study is to understand 'what became of carers in 2001, 10 years later', addressing the following research questions:

- i. Between 2001 and 2011, what proportion of individuals in England and Wales were:
 - (a) caring in both 2001 and 2011,
 - (b) caring in 2001 and not caring in 2011,
 - (c) not caring in 2001 and caring in 2011,
 - (d) not caring in both 2001 and 2011.
- ii. How is the number of hours of caring associated with transitions in/out of caring between 2001 and 2011?
- iii. How does the propensity to be a 'repeat carer' vary by age and gender?
- iv. For those providing care in 2001 what are the main predictors of also caring in 2011?

3. Data and method

The data for this study comes from the ONS LS, a study containing linked census and vital events data on a 1% sample of the population of England and Wales (Hattersley & Creeser, 1995). We select ONS LS members aged 16–74 years in 2001 and resident at both the 2001 and 2011 Censuses ($N = 317,752$). The sample therefore encompasses the key informal carer age groups of as identified in cross-sectional analyses of the aggregate census data (ONS, 2013a). In addition, this age group avoids issues arising from edit rules which impacted on the

caring question as part of the post census processing of data among non-respondents under 16 and over 74 years at the 2001 Census (Buxton & Smith, 2010). For the latter analyses this enables the use of the caring intensity variable from 2001 as a predictor of caring at 2011.

To answer the first, second and third research questions on transitions between caring roles, we use a sample of ONS LS members at both 2001 and 2011 to study how many were caring at each census. The question on the census form specifically asked; ‘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?’ (and asked respondents not to include care provision as part of paid employment or childcare). Table 1 identifies the broad caring transition groups considered. Using 2011 data, for the first time, it is possible to quantify the number of carers (and non-carers) falling into each type and the proportion of carers from 2001 also caring in 2011. Three caring intensity response options were included on the census form; low (1–19 h), medium (20–49 h) and high (50 or more hours of care per week) also allowing the identification of transitions in hours of caring between the two dates. Selecting the carers at 2001 (groups ‘a’ and ‘b’ in Table 1) the analysis identifies the number of carers in low, medium and high intensity caring groups at 2001 and their caring intensity at 2011.

In order to answer research question four on the characteristics of those carers from 2001 who were caring 10 years later, we use a sample of only those ONS LS members caring at 2001 to specify binary logistic regression models where the outcome is caring at 2011. The sample is selected based on being recorded in the ONS LS at the 2001 and 2011 Censuses and being a carer at the 2001 Census. To distinguish between light and heavy informal caring at 2001 and 2011 we repeat our model for two samples of informal carers. These are (i) informal carers providing care of any duration at 2001 (with an outcome which is provision of informal care of any duration at 2011); and (ii) informal carers providing 20 h or more care per week in 2001 (with an outcome which is provision of 20 h or more care per week in 2011). This enables the identification of the characteristics associated with caring for any duration and the comparison with the characteristics of ‘repeat intensive’ caregivers at 2001 and 2011 (i.e. caring for 20 hours or more per week). Using variables predominantly from the 2001 Census we examine the characteristics of ONS LS members in 2001 associated with caring at 2011. Our model includes demographic (sex, age, ethnicity, marital status change)

and socioeconomic variables associated with informal caring (housing tenure, economic activity, highest educational qualification) along with variables on the intensity of care provided at 2001, self-reported health status and long-term limiting illness. All variables are measured at 2001 except for marital status, where we use a change in one’s marital status to understand the role of transitions in the odds of informal caring again at 2011. The use of 2001 Census variables is beneficial in relation to the estimation of characteristics which might be associated with the future repetition of informal caring among the population of England and Wales. Individuals living in a communal establishment were excluded from the analysis using the housing tenure variable. Analyses were completed in STATA 11. Predicted probabilities were calculated from the final model for men and women using the ‘margins’ command in STATA, in order to illustrate the probability of caring at 2011 based on the number of hours having cared for at the 2001 Census; the most insightful and policy relevant variable considered in the analyses. Linkage of ONS LS members between the 2001 and 2011 Censuses was high for all age groups, particularly those constituting the key age group of informal carers (ONS, 2015).

4. Results

By way of background, Table 2 presents the numbers and percentages of individuals providing informal care by the number of hours per week, in both 2001 and 2011. Over the 10 year period, the overall prevalence of caring increased slightly from 10% in 2001 to 10.3% in 2011. However the most notable shift was a change in the profile of hours of care provided, with a marked increase in the proportion of the population providing intensive care of more than 20 h a week, rising to 3.8% compared with 3.2% in 2001. Note that although there were more people aged over the age of 65 years at the 2011 Census there has also been an increase in the population at younger ages (because of higher fertility and migration between 2001 and 2011) which led to the same percentage (16%) of the population aged 65 years and over at 2011 as in 2001 (ONS, 2012). This may relate to the relatively modest change in informal caring between 2001 and 2011.

4.1. Dynamics of caring 2001–2011

Table 3 shows the number and percentage of ONS LS members in each of the caring groups for all ONS LS members at the 2001 and 2011 Censuses. Of the total sample, 75.8% were not caring at either time point, while 4.8% were caring in both 2001 and 2011. Individuals not caring in 2001, but caring in 2011 composed 10.6% of the sample, compared to 8.8% who were caring in 2001 but not in 2011. The results suggest that there is a relatively small group of informal carers who provided care at both census dates while there were more people who initiated caring between the two census dates than ending a caring role.

In line with existing research, Table 4 shows key gender differences in informal caring in England and Wales in both 2001 and 2011. The table shows a higher percentage of

Table 1
Changes in caring status between 2001 and 2011.

	2011	
	Carer	Non-carer
<i>2001</i>		
Carer	(a) Caring at 2001 and 2011	(b) Caring at 2001, not caring at 2011
Non-carer	(c) Not caring at 2001, caring at 2011	(d) Not caring at 2001 and 2011

Table 2
Number of informal carers in England and Wales by caring intensity, 2001 and 2011.

Caring intensity	2001 Census		2011 Census	
	N	%	N	%
No care provided	46,824,111	90.0	50,275,666	89.7
1–19 hours per week	3,555,822	6.8	3,665,072	6.5
20–49 hours per week	573,647	1.1	775,189	1.4
50+ hours per week	1,088,336	2.1	1,359,985	2.4
Total	52,041,916	100	56,075,912	100

Source: Aggregate England and Wales informal caring numbers are from 2001 Census table 'KS008' and 2011 Census table 'KS301EW', percentages are from 'ONS (2013a)'.

women caring in both 2001 and 2011 (5.7% of women compared to 3.9% of men), as well as a higher percentage of women who were not caring in 2001 but were caring in 2011 (11.6% of women compared to 9.5% of men), and who were caring in 2001 but not 10 years later (9.7% of women compared to 7.7% of men). In contrast, a higher percentage of men were not caring in 2001 and 2011 (78.9% of men compared to 73% of women). At this aggregate level, such results point to women's overall likelihood of being informal carers compared to men, although further disaggregation is required to understand such dynamics by age group and the number of hours of care provided per week.

Fig. 1 disaggregates the results for individuals who provide care by age group (as measured in 2001), in order to better understand men's and women's informal caring patterns over the life course. Key gender differentials emerge. The likelihood of providing care in both 2001 and 2011 (group a), was highest amongst women aged 45–54 in 2001 (peaking at over 9%), whilst amongst men it peaked at 6% for those aged 45–64 years. The likelihood of not caring in 2001 but caring in 2011 (group c), rises steeply with age and peaks at ages 35–44 (in 2001) for women and 45–54 for men; interestingly at older ages this caring pattern is then found more frequently amongst men than women, conforming with the results of previous research that women are more likely than men to provide care up to their 60s, at which point men's likelihood increases and predominates. Finally, among those who were providing in care in 2001 but who were not caring in 2011 (group b), the 'peak' for both men and women came later, in their late 50s to early 60s; possibly reflecting the fact that in the intervening decade the person (spouse or parent) they were providing care for may have died.

Table 3
Number and percentage of ONS LS members by informal caring status at 2001 and 2011.

	2011	
	Carer	Non-carer
2001		
Carer	4.8% N = 15,214	8.8% N = 27,840
Non-carer	10.6% N = 33,719	75.8% N = 240,979

Source: Authors' own analysis of ONS LS. (Total sample at 2001 and 2011 Censuses, ONS LS members aged 16–74 years in 2001 = 317,752).

4.2. Among carers in 2001 how many were caring again at 2011? How does this vary by intensity?

Table 5 presents selected results from Table 3 further decomposed to show change in the number of hours caring 2001–2011. The key focus of this study is on ONS LS members who were caring in 2001 and the proportion also caring in 2011. Over one-third, 35.3%, of those providing informal care in 2001 (43,054), were also caring in 2011 (15,214). Almost half of these 'double informal carers' (46.1%) reported providing 1–19 h of informal care in both 2001 and 2011, whilst around one in six (16.8%) reported providing more than 50 h of care per week at both points in time. Over a fifth (21.3%) of this group of 'double carers' had increased their hours over the decade and in total, 28% of all carers at both 2001 and 2011 were providing 20 h or more of care at both time points, highlighting the intensity of care provision amongst this group.

4.3. Among carers in 2001 what factors are associated with caring again?

The next part of the analysis is focused on carers in 2001 in order to understand the factors associated with providing care again 10 years later. The analytical sample consisted of ONS LS members providing any level of informal care and aged 16–74 years in 2001 and with complete information on all explanatory variables (N = 42,915). Table 6 shows the sample distribution and the results from the final binary logistic regression model. Focusing on the sample distribution (i.e. the characteristics of carers in 2001), the results are compatible with other cross-sectional profiles of informal carers in the literature. Approximately 60% of the carers were women and 40% were men, and 29% were concentrated in the 45–54 years age group. In terms of care intensity, just over 70% were providing 1–19 h of care per week, followed by 11% who were providing 20–49 h of care and 19% providing 50 h or more of care per week. With reference to marital status, 59% were married at both time points, while almost 90% belonged to the White British ethnic group. Just over a third of the sample owned their home outright in 2001 (34%), with about one-third owning with a mortgage and 14% living in socially-rented accommodation (i.e. from a Local Authority or Housing Association). Although these results are not age-standardised, approximately 58% reported 'good' health, with 32% reporting 'fair' health and about 10% reporting 'bad' health. Around a fifth of the

Table 4

Number and percentage of ONS LS members in 2001 and 2011 by caring status and gender.

Description	N		%	
	Male	Female	Male	Female
(a) Caring in 2001 and 2011	5863	9531	3.9	5.7
(b) Caring in 2001, not caring in 2011	11,653	16,187	7.7	9.7
(c) Not caring in 2001, caring in 2011	14,265	19,454	9.5	11.6
(d) Not caring in 2001 and 2011	118,931	122,048	78.9	73.0
Total	150,712	167,220	100	100

Source: Authors' own analysis of ONS LS members aged 16–74 years in 2001.

sample (21%) reported a limiting long-term illness at 2001. With reference to education, 30% of the sample had no academic/professional qualification, with 19% belonging to the highest educational group. Finally, 17% of carers were retired, while a third (34%) were employed full-time and 16% were employed part-time.

Results from the model where the outcome is informal caring of any duration at 2011 show that (compared to women) men who were caring in 2001 have lower odds of caring in 2011 (OR 0.86). Individuals aged 35–44 years in 2001 (reference group) were the most likely to also be caring in 2011 compared to all other age groups, followed by those aged 45–54 (OR 0.93) and those aged 20–34 years (OR 0.73). It is possible that women's higher likelihood of being carers in mid-life may be driving these results, while the lower odds ratio for the oldest group (65–74) may be affected by men's higher likelihood of caring in later life as well as increasing frailty over time. In addition, the highest risk of being a 'repeat' informal carer among the 35–44 years age group may relate to being within a 'sandwich generation' caring for older parents or children with an illness at one time point or the other. Other demographic factors were also important. Being married at both time

points was significantly associated with being a carer also in 2011 (compared to other categories), possibly reflecting spousal caring, with all other groups of marital status being less likely to be 'repeat carers' in 2011. Those married in 2001 and widowed in 2011 show the lowest odds (OR 0.16) of 'repeat caring', possibly due to one's caring role ending because of the death of a spouse between 2001 and 2011. In terms of ethnicity, Bangladeshi and Chinese/other Asian ethnic groups were less likely than the White British group to be caring in 2011 as well (OR 0.54 and 0.60 respectively).

The inclusion of care intensity in 2001 allows us to better understand care trajectories over individuals' life courses. The results show that, controlling for the full range of characteristics in the model, those who were providing between 1 and 19 h or 20 and 49 h care per week in 2001 show lower odds of caring in 2011 compared to those providing 50 h or more of care per week (OR 0.40 and 0.63 respectively).

The relationship between informal care provision and the carer's health status is complex, and such complexity is reflected in the results of this analysis as well as the wider literature. Carers reporting 'fair' health in 2001 did not

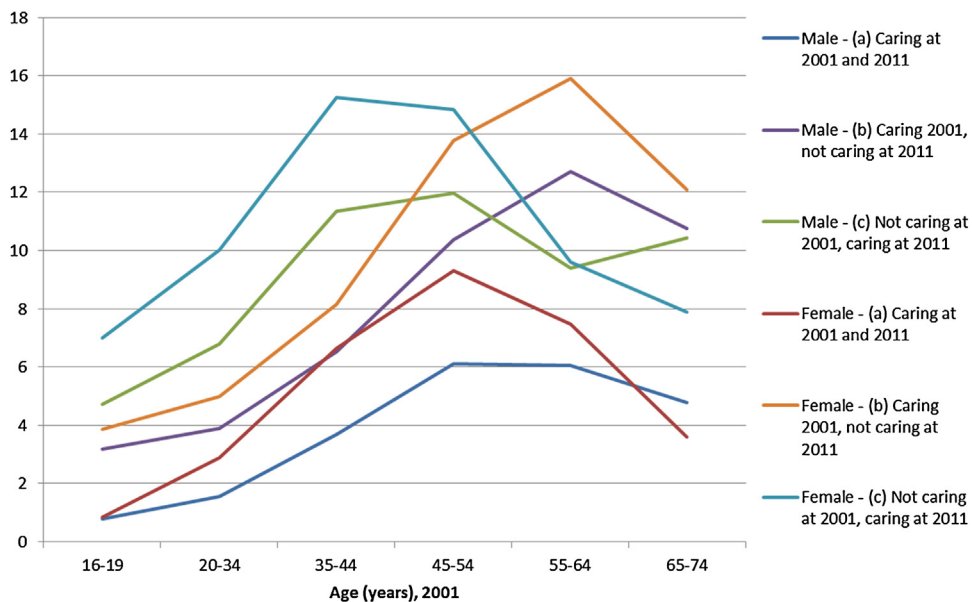


Fig. 1. Prevalence of informal care provision in 2001 and 2011, by age (in 2001) and gender.

Source: Authors' own analysis of ONS LS members aged 16–74 years in 2001.

Table 5
Number and percentage of informal carers in 2001 and 2011, by care intensity.

Description	2001	2011	N	% caring at 2001 and 2011	% of all caring at 2001
<i>(a) Caring at 2001 and 2011</i>					
–	1–19 h/week	1–19 h/week	7011	46.1	16.3
↑	1–19 h/week	20–49 h/week	1208	7.9	2.8
↑	1–19 h/week	50 h+/week	1357	8.9	3.2
↓	20–49 h/week	1–19 h/week	637	4.2	1.5
–	20–49 h/week	20–49 h/week	478	3.1	1.1
↑	20–49 h/week	50 h+/week	690	4.5	1.6
↓	50 h+/week	1–19 h/week	734	4.8	1.7
↓	50 h+/week	20–49 h/week	542	3.6	1.3
–	50 h+/week	50 h+/week	2557	16.8	5.9
	Total – caring at 2001 and 2011		15,214	100	35.3
<i>(b) Caring at 2001, not caring at 2011</i>					
	1–19 h/week	Non-carer	20,819		48.4
	20–49 h/week	Non-carer	2747		6.4
	50 h+/week	Non-carer	4274		9.9
	Total – caring at 2001, not caring at 2011		27,840		64.7
Total			43,054		100

Source: Authors' own analysis of ONS LS members aged 16–74 in 2001.

have a statistically significant difference to those in 'bad' health in terms of their odds of providing informal care again in 2011. However, among those reporting 'good' health in 2001, the odds of caring at 2011 are 9% lower (OR 0.91), although this is only statistically significant at the 5% level. Illustrating further complexity, the model shows that carers reporting a limiting long-term illness were more likely to be caring again in 2011 compared to those without such illness (OR 0.93) (note the statistical significance at the 5% level).

Socio-economic factors also appear to have an effect on a carer's risk of 'repeat' caring 10 years later. The analysis shows that those living in socially-rented housing in 2001 have the highest odds of caring again in 2011 (OR 1.06) compared to those who own outright although this result is not statistically significant ($p=0.097$). The inclusion of education in the model shows that there is a gradient of increasing odds of caring with higher education, as those with the highest educational qualifications have the highest odds of providing care in 2011 while those with no academic/professional qualifications have lower odds of caring in 2011 (OR 0.68). Finally, individuals who were looking after the home (reference category) in 2001 had the highest odds of caring in 2011. Interestingly, among those employed part-time, the odds of caring again in 2011 were lower than for those looking after the home (OR 0.87), while the equivalent odds among those employed full-time or being self-employed were 0.88 and 0.83 respectively. Additional analyses revealed that a large group of ONS LS members transitioned to the retired category between 2001 and 2011 (from all categories), while a similarly large number shifted from looking after the home in 2001 to being in part-time employment in 2011, suggesting that some carers resume employment which is compatible with either continuation of care. The inclusion of occupational social class (NS-SEC) and Government Office Region to further decompose employment types and geographies respectively did not produce statistically significant

findings. Interaction terms for age and education, age and employment, gender and ethnicity, and gender and education were tested but not statistically significant.

In order to illustrate key factors associated with a carer's likelihood of caring again 10 years later, predicted probabilities of caring in 2011 for informal carers in 2001 were calculated for men and women, after controlling for a range of demographic and socioeconomic characteristics in 2001 and one's care intensity in 2001 (as per the final model presented in Table 6). Fig. 2 shows a gradient in the probability of providing care in 2011 with increasing intensity of informal care in 2001. Those who provided care for more than 50 h per week in 2001 were the most likely to be caring in 2011 (for both male and female carers). This result suggests that carers in the 50 h or more per week group may be providing care in a situation where there is a demand for such a high level of care (e.g. co-residential caring) or that once a high level of care has been provided in the past (initiated), the repetition of care of any intensity in the future may be more likely regardless of the characteristics of such caring activity (e.g. care intensity, co-residential or not, relationship to person cared for).

4.4. What are the characteristics associated with providing 'repeat intensive' care?

Given the previous literature on the impact of caring, it is interesting to examine the characteristics of those who were providing care of over 20 h a week at both 2001 and 2011. Table 7 shows sample distribution and the results from the final model of providing 20 h or more informal caring at 2011 among the sample of those aged 16–74 years in 2001 and providing 20 h or more care per week in 2001 ($N=12,621$). The model is in some senses a conditional model (i.e. conditional on providing care 20+ hours in 2001), and answers the question 'what are the characteristics associated with providing repeat intensive care in 2011, given that a person is providing intensive care in 2001?'

Table 6

MODEL 1: Binary logistic regression to predict provision of informal care (of any intensity) at the 2011 Census, amongst those providing informal care at 2001, aged 16–74 years in 2001.

	N	%	Odds ratio	Sig.	95% CI
Sex					
Female (ref.)	25,473	59.4	1		
Male	17,442	40.6	0.86	0.000	0.82–0.09
Age, 2001					
16–19	833	1.9	0.49	0.000	0.40–0.61
20–34	5686	13.2	0.78	0.000	0.72–0.84
35–44 (ref.)	8849	20.6	1		
45–54	12,606	29.4	0.93	0.011	0.87–0.98
55–64	10,135	23.6	0.73	0.000	0.68–0.78
65–74	4806	11.2	0.69	0.000	0.62–0.77
Marital status change, 2001–2011					
Married – Married (ref.)	25,238	58.8	1		
Never married – Married	1581	3.7	0.58	0.000	0.51–0.66
Divorced – Married	666	1.6	0.80	0.006	0.68–0.94
Never married – Never married	5088	11.9	0.64	0.000	0.60–0.69
Married – Separated (still married)	631	1.5	0.55	0.000	0.46–0.66
Married – Divorced	1151	2.7	0.48	0.000	0.42–0.55
Separated (still married) – Divorced	352	0.8	0.76	0.015	0.61–0.95
Divorced – Divorced	2714	6.3	0.62	0.000	0.57–0.68
Married – Widowed	3148	7.3	0.16	0.000	0.14–0.18
Widowed – Widowed	1114	2.6	0.46	0.000	0.40–0.53
Other transition	1232	2.9	0.55	0.000	0.48–0.63
Ethnic group, 2001					
White British (ref.)	38,541	89.8	1		
Irish	452	1.1	1.04	0.711	0.85–1.27
Other white	689	1.6	0.93	0.375	0.79–1.09
Mixed	220	0.5	0.77	0.085	0.57–1.04
Indian	1152	2.7	0.90	0.122	0.79–1.03
Pakistani	695	1.6	0.88	0.145	0.75–1.04
Bangladeshi	285	0.7	0.54	0.000	0.41–0.71
Black	487	1.1	0.93	0.449	0.76–1.13
Chinese and other Asian	297	0.7	0.60	0.000	0.46–0.79
Other ethnic group	97	0.2	0.66	0.073	0.42–1.04
Care intensity, 2001					
1–19 hours per week	30,294	70.6	0.40	0.000	0.37–0.42
20–49 hours per week	4538	10.6	0.63	0.000	0.58–0.68
50+ h per week (ref.)	8083	18.8	1		
Self-reported general health, 2001					
Good	25,071	58.4	0.91	0.032	0.83–0.99
Fair	13,591	31.7	1.04	0.414	0.95–1.13
Bad (ref.)	4253	9.9	1		
Limiting long-term illness, 2001					
Yes, limited a lot/little (ref.)	8998	21.0	1		
No limiting long-term	33,917	79.0	0.93	0.028	0.87–0.99
Housing tenure, 2001					
Owned outright (ref.)	14,782	34.4	1		
Owns with mortgage or loan	19,478	45.4	0.99	0.613	0.94–1.04
Shared ownership	167	0.4	0.91	0.586	0.65–1.27
Socially-rented	6182	14.4	1.06	0.097	0.99–1.14
Privately-rented	1794	4.2	0.95	0.358	0.85–1.06
Lives rent-free	512	1.2	0.93	0.441	0.76–1.13
Highest educational qualification, 2001					
No academic or professional qualification	12,894	30.0	0.68	0.000	0.64–0.73
Level 1 (1–4 GCSEs A–C)	7112	16.6	0.81	0.000	0.76–0.87
Level 2 (5+ GCSEs A–C)	8000	18.6	0.93	0.029	0.87–0.99
Level 3 (2+ A-levels)	2625	6.1	1.03	0.546	0.94–1.13
Level 4 (Degree) or higher (ref.)	8345	19.4	1		
Other qualifications/level unknown	3939	9.2	0.79	0.000	0.73–0.86
Economic activity, 2001					
Looking after home (ref.)	5316	12.4	1		
Employed part-time	6808	15.9	0.87	0.001	0.81–0.95
Employed full-time	14,579	34.0	0.88	0.001	0.82–0.95
Self employed	3757	8.8	0.83	0.000	0.75–0.91
Seeking work and waiting to start job	1099	2.6	0.77	0.000	0.67–0.89
Retired	7233	16.9	0.79	0.000	0.72–0.88
Student	909	2.1	0.80	0.022	0.66–0.97
Sick	2232	5.2	0.81	0.000	0.72–0.91
Other	982	2.3	0.80	0.004	0.69–0.93

Source: Authors' own analysis of ONS LS members aged 16–74 in 2001.

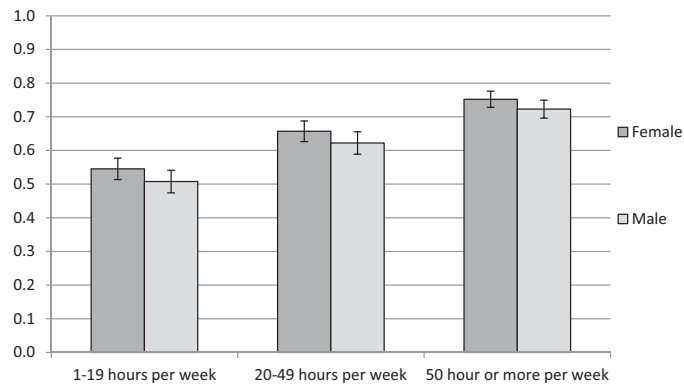


Fig. 2. Predicted probabilities (and 95% confidence intervals) of provision of informal care of any intensity in 2011 for carers aged 16–74 years in 2001 by gender and care intensity in 2001.

Source: Authors' own analysis of ONS LS. Age in 2001 = 35–44 years, marital status change (2001–2011) = married–married, ethnic group in 2001 = White British, care intensity in 2001 = 50 h or more care per week, health in 2001 = bad, Limiting long term illness in 2001 = Yes, limited a lot/a little, Housing tenure in 2001 = owned outright, Highest educational qualification in 2001 = Level 4 or above, Economic activity in 2001 = Looking after the home.

Interestingly, once a person is providing intense care, there is no statistically significant difference between men and women in the odds of providing repeat high intensity caring. In relation to the age profile, we see a very similar pattern to that for caring at any intensity at 2001 and 2011 but with non-statistically different results for those in the 20–34 and 45–54 years age groups. Those married at both 2001 and 2011 show the highest odds of providing intense caring again at 2011 (with reference to the other groups), while those who were married at 2001 but were widowed at 2011 showed far lower odds (OR 0.05), which may signify the end of a higher intensity spousal caring arrangement after 2001 because of a mortality. Indeed, the relative size of this group is more than twice as large in the 20 h or more care per week model compared to the model of any level caring 2001–2011 presented in Table 6 (note the increase from 7.3% in the sample for the first model to 14.5% in the sample for this model). The ethnic group variable shows a greater number of statistically significant categories than in the 'any level care 2001–2011' model. Compared to the White British group (reference category), the Indian and Pakistani groups show lower odds of repeat informal caring at 20 hours or more in 2011 (OR 0.64 and OR 0.62 respectively) but not as low as those in the Bangladeshi and Chinese and other Asian groups (both OR 0.32).

Among the explanatory variables included in the first model presented (any level care 2001–2011), the intensity of informal caring at 2001 was a key predictor, showing an increasing gradient in likelihood of caring at 2011 as intensity at 2001 increased. In model 2 we are only including the high intensity carers at 2001, yet it is evident that those who provided 20–49 h of care in 2001 have half the odds (OR 0.51) of informal caring at 20 hours or more in 2011 compared to the carers providing 50 hours or more care at 2001, again reinforcing the conclusion that high intensity care provision at one point in time is linked to the propensity of repeat/extended caring.

With regard to health status at 2001, those with a fair level of health were more likely to be caring again at 2011

(OR 1.12) but this is only statistically significant at the 10% level. Results for limiting long-term illness are not statistically significant. Results from the housing tenure at 2001 show that social renters have higher odds of providing 20 h or more informal care at 2011 (OR 1.26) compared to those who owned outright (reference category). Interestingly, private renters show similar odds (OR 1.31) but this is only statistically significant at the 5% level. Results by education level in 2001 are not statistically significant. For economic activity in 2001 we see a stronger effect with lower odds for all categories compared to the reference category (looking after the home). As may be anticipated, those employed full-time and self-employed (both OR 0.55) show the lowest odds of caring at 2011. The stronger effects of employment in this model compared with the 2001–2011 any level care model may be anticipated given the commitment 20 h or more of informal caring is alongside other paid employment.

5. Discussion

The aim of this paper was to examine the caring trajectories of individuals observed at two time points which were 10 years apart, using the ONS LS, and to analyse the age/gender profiles of the resulting groups of carers/non-carers as well as the care intensity among those transitioning in/out of a caring role. In addition, the paper has focused on those providing care in 2001 and studied the factors associated with providing care again in 2011 for any duration and also at higher intensities (20 h or more at 2001 and 2011).

Key among the findings was that approximately 4% of the total sample was providing some form of informal care in both 2001 and 2011; moreover among all informal carers in 2001, over one-third were also providing care 10 years later. We found that almost half of those caring in both 2001 and 2011 provided 'modest care' of up to 19 h of care per week (46.1%), however a significant proportion (16.8%) provided very intensive care, i.e. more than 50 h per week, at both points in time. This result adds to our

Table 7

MODEL 2: Binary logistic regression to predict provision of 20 h or more informal caring per week at the 2011 Census for informal carers providing 20 h or more care at 2001 aged 16–74 years, in 2001.

	N	%	Odds ratio	Sig.	95% CI
Sex					
Female (ref.)	8128	64.4	1		
Male	4493	35.6	1.02	0.644	0.93–1.12
Age, 2001					
16–19	142	1.1	0.42	0.003	0.24–0.74
20–34	1638	13.0	0.96	0.617	0.84–1.11
35–44 (ref.)	2659	21.1	1		
45–54	3197	25.3	0.93	0.233	0.83–1.05
55–64	3067	24.3	0.79	0.001	0.69–0.90
65–74	1918	15.2	0.84	0.095	0.68–1.03
Marital status change, 2001–2011					
Married – Married	6824	54.1	1		
Never married – Married (ref.)	321	2.5	0.42	0.000	0.32–0.56
Divorced – Married	151	1.2	0.57	0.002	0.40–0.81
Never married – Never married	1448	11.5	0.35	0.000	0.31–0.41
Married – Separated (still married)	200	1.6	0.28	0.000	0.20–0.40
Married – Divorced	354	2.8	0.27	0.000	0.21–0.35
Separated (still married) – Divorced	96	0.8	0.42	0.000	0.27–0.66
Divorced – Divorced	740	5.9	0.36	0.000	0.30–0.43
Married – Widowed	1833	14.5	0.05	0.000	0.04–0.07
Widowed – Widowed	286	2.3	0.39	0.000	0.30–0.52
Other transition	368	2.9	0.29	0.000	0.23–0.38
Ethnic group, 2001					
White British (ref.)	10,928	86.6	1		
Irish	143	1.1	1.24	0.261	0.85–1.82
Other white	218	1.7	0.77	0.109	0.56–1.06
Mixed	75	0.6	0.48	0.012	0.27–0.85
Indian	428	3.4	0.64	0.000	0.51–0.80
Pakistani	337	2.7	0.62	0.000	0.48–0.79
Bangladeshi	144	1.1	0.32	0.000	0.21–0.48
Black	183	1.4	0.83	0.296	0.59–1.17
Chinese and other Asian	121	1.0	0.32	0.000	0.20–0.53
Other ethnic group	44	0.3	0.66	0.251	0.32–1.34
Care intensity, 2001					
20–49 h per week	4538	36.0	0.51	0.000	0.47–0.56
50+ h per week (ref.)	8083	64.0	1		
Self-reported general health, 2001					
Good	5979	47.4	1.02	0.778	0.88–1.19
Fair	4610	36.5	1.12	0.094	0.98–1.29
Bad (ref.)	2032	16.1	1		
Limiting long-term illness, 2001					
Yes, limited a lot/little (ref.)	3604	28.6	1		
No limiting long-term	9017	71.4	0.96	0.484	0.85–1.08
Housing tenure, 2001					
Owned outright (ref.)	4141	32.8	1		
Owns with mortgage or loan	4422	35.0	1.01	0.805	0.91–1.13
Shared ownership	63	0.5	1.40	0.249	0.79–2.48
Socially-rented	3177	25.2	1.26	0.000	1.11–1.42
Privately-rented	611	4.8	1.31	0.008	1.07–1.60
Lives rent-free	207	1.6	1.03	0.869	0.74–1.42
Highest educational qualification, 2001					
No academic or professional qualification	5754	45.6	0.92	0.210	0.80–1.05
Level 1 (1–4 GCSEs A–C)	1851	14.7	0.94	0.432	0.80–1.10
Level 2 (5+ GCSEs A–C)	1882	14.9	0.98	0.758	0.83–1.14
Level 3 (2+ A-levels)	515	4.1	0.87	0.261	0.69–1.10
Level 4 (Degree) or higher (ref.)	1463	11.6	1		
Other qualifications/level unknown	1156	9.2	0.96	0.657	0.80–1.15
Economic activity, 2001					
Looking after home (ref.)	3088	24.5	1		
Employed part-time	1517	12.0	0.74	0.000	0.65–0.85
Employed full-time	2588	20.5	0.55	0.000	0.48–0.63
Self employed	667	5.3	0.55	0.000	0.45–0.67
Seeking work and waiting to start job	322	2.6	0.87	0.300	0.67–1.13
Retired	2650	21.0	0.75	0.001	0.63–0.88
Student	184	1.5	0.70	0.074	0.47–1.04
Sick	1173	9.3	0.84	0.051	0.71–1.00
Other	432	3.4	0.97	0.811	0.78–1.22

Source: Authors' own analysis of ONS LS members aged 16–74 in 2001.

existing understanding of caring patterns, which showed that cross-sectionally the majority of carers provide care for up to 19 h per week (Doran et al., 2003; ONS, 2013a). The identification of four groups according to their informal care provision status allowed us to disentangle men's and women's caring across different age groups, underscoring significant nuances between the two genders. It was found that the provision of informal care tends to be spread across mid-life (i.e. those aged 35–64 years in 2001) for women, but is concentrated over the age of 55 years for men, which mirrors existing findings of the nature of men's and women's care provision in different age groups (Arber, 2006; Dahlberg et al., 2007; Del Bono et al., 2009). Notwithstanding the caveat of not being able to disentangle whether for 'repeat carers', the care provision was repeated or continuous over the 10-year period, this result is likely to indicate differences between men and women in the relationship with the person cared for, as women have been shown to be more likely to provide care simultaneously to spouses, parents, other relatives and friends, compared to men who tend to provide spousal care into later life (Del Bono et al., 2009). Those caring in 2001 but not in 2011 tended to be older at 'baseline' (2001) among both men and women, reflecting perhaps that cessation of caring may be linked to the mortality of the cared for.

The factors associated with caring again in 2011 among those who provided care in 2001, paint a picture which is harder to locate in existing literature given the novelty of this research. The demographic characteristics of being female as opposed to male, married compared to all other groups and of White British origin compared to Bangladeshi or Chinese/other Asian, were all strongly associated with caring again in 2011, as they have been throughout much of existing research on the correlates of caring from a cross-sectional perspective (Young et al., 2005). Being relatively older (aged 45–54 years) was also strongly associated with the outcome variable, suggesting that this kind of caring pattern or role, whether repeated after 10 years or continued throughout 10 years, is much more likely to occur in mid-life, when individuals are aged between 35 and 54. Providing care for 50 h per week or more in 2001, compared to lower care intensity; looking after the home, compared to all other categories of one's economic activity status; and owning one's home compared to renting privately, were all associated with providing care again in 2011 – and these factors may in turn be related to life course stage. Previous research has also noted the link between informal care provision and owning one's home (McCann, Grundy, & O'Reilly, 2012), although in our analysis, home ownership may facilitate carers to continue or again take up informal care 10 years later, whether caring for the same person or not.

Interestingly, the analysis showed a gradient of increasing likelihood of informal care provision in 2011 by care intensity in 2001, with those in the lowest care intensity category being the least likely to be providing any care again in 2011. This may suggest that the commitment of caring for 50 h or more in 2001 is such that the same caring arrangement may either continue over a number of years, or the carer role was repeated in

2011. It is possible that once a high level of care has been initiated by an individual, then changes to one's economic activity which make such an arrangement sustainable also render the likelihood of the continuation or repetition of a caring role higher in the future. The relatively small difference in odds ratios of caring again in 2011 among individuals employed full- or part-time, contributes to our understanding of the challenge of combining care provision with paid work and has important implications for the support available to carers engaged in the labour market. Longitudinal research on informal caring in the United States identified evidence that families and friends continue to provide care over 'lengthy' time periods (Jette et al., 1992).

The increased likelihood among carers in 2001 to also provide care in 2011 was not clear in relation to health status. Those reporting 'fair' health did not show statistically significant different results to those with 'bad' health. Health status may indicate that an individual has a good enough health status to provide care, but a poor enough health status not to enter the labour market. Previous research has shown that standardising for the intensity of care provided, the health status of the carer, the health status of the person cared for, and the relationship to the person cared for, can produce different results in terms of the relationship between caring at more than one point in time and the carer's health status (Brown & Brown, 2014). It is important to recall that the sample for this analysis is composed of carers from 2001 so it is possible that a poorer health status in 2001 may have contributed to selection into a caring role at that time point.

Among the high intensity carers at 2001 (those individuals providing 20 h or more care) we see a subtly different set of results and stronger effects for some variables included in the regression model predicting 'repeat' high intensity care. One of the key results is the non-statistically significant difference for men compared to women, in contrast to the model for any repeat caring where there are lower odds of caring again at 2011 among men. It appears that once the initial caring intensity in 2001 is controlled for, gender matters less. Results by age are more concentrated around the 35–44 years age group and in a number of cases do not show a statistically significant difference. Of particular note among the higher intensity carers in the second model were the lower odds of caring for those widowed between 2001 and 2011 and the larger relative size of this category – this is likely to relate to spousal caring which is likely to predominate at higher intensities. Also of particular note in the higher intensity repetition model are results by housing tenure, where those who were social renters were much more likely to be caring again at a high intensity than those in the owned outright group. Although social renters had higher odds of repeat caring for all levels of caring, these results are more pronounced for high intensity caring (and not statistically significant for any level of caring). Inclusion of occupational social class (NS-SEC) to further decompose employment types did not produce statistically significant findings; other research in this topic area has shown higher levels of care with decreasing social class (Purdam & Norman, 2013). However, the present research differs by

considering a sample of carers at 2001 and following them up after 10 years and is not just a cross-sectional study of the situation.

The study has a number of limitations which ought to be taken into account when interpreting the findings. Firstly, the dataset is necessarily limited in the scope of information available for analysis: for instance, it is not known whether care was provided continuously between 2001 and 2011, or whether there is a gap between informal caring. Secondly, two important dimensions of the caring activity are also not known: what the relationship is between the carer and the person cared for, and whether the care provision was co-residential. However, this study is important in identifying the characteristics associated with the repetition of informal caring over a 10 year period at a national-level and therefore assists in the estimation of the future supply of informal caring. It is therefore a crucial starting point from which we can elucidate the challenges faced by carers and the ways in which the local and national government can support this important role. Future research may wish to extend findings made in the present study, for example, studying the relationship between the carer and person cared for using survey data.

This study has shed light on a specific group of carers, who either continued to provide care over the space of the 2001–2011 decade, or were observed to provide care at the beginning and end of this period and possibly for some time in between. In addition to key demographic, health and socio-economic characteristics, it is important to note that such a pattern of caring, whether continuous or repeated, was significantly associated with having provided care of 50 h or more per week in 2001. Therefore the findings of this study are in line with previous research on informal caring which have identified that the propensity to care in the past is crucial in predicting the likelihood of caring in the future (Jette et al., 1992). The results highlight that policy makers need to be aware of the heavy burden that carers may face for an extended period and the need for policies to support such as carers, including respite care and assistance with maintaining or re-entering employment where appropriate. Further research on the patterns of informal care from a longitudinal perspective is needed in order to further unravel the characteristics, challenges and resilience of informal carers in England and Wales, and beyond.

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