Characteristics of and living arrangements amongst informal carers in England and Wales at the 2011 and 2001 Censuses: stability, change and transition

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Note: The results presented are based on a test version of the LS database incorporating 2011 Census data. Figures may be subject to change when the final version of this database is released in November 2013.

Results presented at EPC 2014 will be based on the final version of the dataset due for release at the end of November 2013. As experienced LS users we were invited to test a preliminary version of the dataset for any errors or inconsistencies – for more information please see https://www.ucl.ac.uk/celsius/beta-testing-of-the-2011-census-ls-data-linkage.

Abstract

In the context of population ageing and expenditure cuts in local services of adult social care, informal care provision is a critical policy issue. Evidence from the British context shows that more people are likely to become informal carers at some point in their lives (ONS, 2013a) and informal caring of 20 hours or more per week has increased. This paper uses data from the 2001 and 2011 England and Wales Censuses in order to investigate the characteristics of informal carers at the two time points, as well as patterns of stability and change in the carers' population over this period. Results from the analysis of the 2011 Census suggest that provision of informal care has increased since 2001. The Office for National Statistics (ONS) Longitudinal Study (LS), which is a 1% sample of linked census data, allows us to follow-up informal carers from the 2001 Census in order to examine their caring activity ten years later. Using the ONS LS, this analysis classifies the range of possible groups of carers and non-carers between 2001 and 2011, as well as changes in the number of hours of care provided. The results suggest a greater number of people may have started caring between 2001 and 2011 than stopped caring. A third of those caring at the 2001 Census were also caring ten years later. Multivariate analyses suggest that those who were providing the highest intensity of care at 2001 were most likely to also be providing care at 2011 with an ascending likelihood for the medium and low intensity groups.

1. Introduction and background

The provision and receipt of informal care in the UK have become key social policy issues and increased in prominence in the policy debate on the provision and funding of adult social care (Commission on Funding of Care and Support, 2011; Department of Health White Paper, 2012). Understanding the

characteristics of informal carers is critical, as they continue to contribute to the supply of social care, and changes in the size and composition of the carers' population will have a direct impact on the future design of social care and the distribution of its financial cost. In addition, current demographic changes may affect both the supply of and demand for social care, for example improving life expectancy for men at older ages may increase the amount of spousal care provided by men, while population ageing is projected to place greater pressure on local governments to provide social care for older people. For the recipient of informal care, such receipt can have health benefits, may delay their movement into formal care settings and contribute to their motivation to stay at home for as long as possible (McCann et al., 2012; Ramsay et al., 2013).

Analysis of 2001 Census data identified the prevalence of informal caring nationally for the first time with over a million people aged 65 years and over providing informal care at the 2001 Census (Doran et al., 2003). Dahlberg et al. (2007) showed that while informal caregiving was most common among those in their mid-life, elderly people spent a greater amount of time caregiving than younger people, pointing to elderly people who may be frail and often are in a spousal relationship with the care-recipient, and middle-aged women with multiple roles, as two groups who are likely to be adversely affected by informal caring. More than a third were caring for at least 50 hours per week and more than a quarter with a heavy burden of care rated their health as 'not good'. Half of those aged 85 years and over and providing care did so for 50 hours or more per week (Evandrou, 2005). Analyses of the 2001 Census data also identified an adverse effect of informal caring on the self-reported health and economic activity of informal carers (Young et al., 2005; Dini, 2010), while analysis of the English Longitudinal Study of Ageing has found that the prevalence of economic activity decreased as the intensity or number of hours of care provision rose (Vlachantoni, 2010). Research examining associations between employment history, marital status and unpaid care provision has stressed a gender dimension in care provision interacting with marital status and employment (Young and Grundy, 2008).

Recent analysis of the 2011 Census shows that in England and Wales, the percentage of individuals providing informal care has increased from 2001, especially among those providing between 20-49 hours, and 50 hours or more, of care per week (ONS, 2013a). In addition, local authorities with a higher percentage of their population reporting 'a lot of limitation' in their daily activities showed a higher percentage of informal carers. Gender differences permeate such findings, with 58% of informal cares being female and 42% male (ONS, 2013b), although such differences narrow in older age groups, where male informal care towards spouses becomes more prevalent (ONS, 2013c). Such analysis has also reported ethnic differences in informal care provision, with the White ethnic group being more likely than other groups to provide informal care (ONS, 2013d). Among the economically active population, part-time workers were more likely than full-time workers to provided informal care (ONS, 2013b), while, overall, non-carers were more likely to report good general health than carers. Although such analysis can improve our understanding of the demographic and health characteristics of informal carers, nevertheless

a more detailed analysis of changes in the overall patterns of informal caring and the number of hours of care provided between 2001 and 2011, is lacking.

Against this background, this paper aims to unravel the changes in the characteristics of informal carers between 2001 and 2011, focusing on the number of hours of care provided. The use of longitudinal data has the potential to answer research questions around changes in an individual's economic and health status before/ after their take-up of informal caring responsibilities. The repetition of the same questions on informal caring and health status at the 2001 and 2011 Censuses provide new opportunities to follow-up on those providing informal care at 2001 and ask 'what became of the carers in 2001'? The paper uses a longitudinal extract of census records, the Office for National Statistics (ONS) Longitudinal Study (LS), which is an approximate 1% sample of England and Wales individual 2011 Census records linked to earlier census responses (1971, 1981, 1991 and 2001). This provides information on the life course and transitions in the life course among study members (Blackwell et al., 2003). The linkage of the 2001 and 2011 Censuses data allows the identification of outcomes for carers from 2001 ten years later. Earlier work as part of this project has validated the number and percentage of informal carers at 2001 and 2011 against the aggregate census results and identified characteristics of informal carers at 2001 and 2011 using bivariate and multivariate analyses (Evandrou et al., 2013). This provides information on the key predictors of informal caring at 2001 and at 2011.

2. Research questions

i. Between the 2001 and 2011 Census points, what proportion of individuals were:
   a) carers at both 2001 and 2011 Census points.
   b) non-carers at both 2001 and 2011 Census points.
   c) non-carers at the 2001 Census and carers at 2011 Census.
   d) carers at 2001 Census and non-carers at 2011 Census.

ii. What are the demographic and socio-economic characteristics of each of these four groups of individuals?

iii. Among carers at 2001 what are the main predictors of caring at the 2011 Census?

iv. Among carers at 2001 what are the main predictors of providing low, medium and high intensity care at the 2011 Census?

3. Method

In answering research question one on the number of ONS LS members at each census we use a sample of ONS LS members at both 2001 and 2011 to identify how many were caring at each census. Table 1 highlights the caring types considered. By using 2011 data, it is possible to identify the number of carers (and non-carers) which fall into each transition type and identify the proportion of carers from 2001 also caring in 2011 and the proportion of people who were not caring in 2001 who were caring at 2011. The analysis is also disaggregated by the number of hours caring per week at each census. It is not possible to

know for carers at 2001 and 2011 if there was continuous provision of informal care, at all or at the same level, throughout the 2001-2011 time period, or who the care was provided towards, or whether the care was provided towards someone in the same household.

In order to answer the second research question, cross tabulations for each of the groups are completed using key socio-demographic characteristics, including age, sex, health status, living arrangements, marital status, employment status and ethnicity.

Table 1: Groups of carers/ non-carers in 2001 and 2011

<table>
<tr><th colspan="2"></th><th colspan="2">2011</th></tr>
<tr><th colspan="2"></th><th>Carer</th><th>Non-carer</th></tr>
<tr><th rowspan="2">2001</th><th>Carer</th><td>Caring at 2001 and 2011 (a)</td><td>Caring at 2001, not caring at 2011 (d)</td></tr>
<tr><th>Non-carer</th><td>Not caring at 2001, caring at 2011 (c)</td><td>Not caring at 2001 and at 2011 (b)</td></tr>
</table>

In order to answer the third research question, a sample of only those ONS LS members caring at 2001 is used and a binary logistic regression model of any level of caring at 2011 is specified. The sample is therefore conditional on being a carer at the 2001 Census and recorded in the ONS LS at the 2001 and 2011 Censuses. Using predictors from the 2001 Census we therefore identify ONS LS member characteristics from 2001 associated with informal caring at the 2011 Census.

In order to answer the fourth research question, a multinomial logistic regression model is specified to predict the caring intensity at 2011 for informal carers from the 2001 Census.

4. Selected initial results

4.1 Transitions between caring roles 2001-2011: *A third of informal carers at 2001 were also caring 10 years later*

Table 2 shows the overall number and percentages of ONS LS members in each of the caring groups for all ONS LS members at both the 2001 and 2011 Censuses. Of the total sample (419,530), 80.2% (336,348) were not caring at either census, which would be anticipated given the sample considers ONS LS members of all ages. A total of 3.7% (15,696) were caring at both the 2001 and 2011 censuses. ONS LS members who were not caring at 2001, but were caring at 2011 composed 9% (37,837) of the sample. Slightly fewer LS members, 7.1% (29,649), were caring at 2001 and not at 2011. The results suggest that there is a relatively small group of informal carers who provided care at both 2001 and 2011 while there were more people who may have initiated caring between the two Census time points.

Table 2: Number and percentage of ONS LS members by informal caring status at 2001 and 2011

		2011	
		Carer	**Non-carer**
2001	**Carer**	3.7% N=15,696	7.1% N=29,649
	Non-carer	9.0% N=37,837	80.2% N=336,348

Source: ONS LS

Table 3 provides more detail on these results by focusing on those providing 50 hours or more of care per week at 2001 (the highest intensity of care). Of those who were caring for 50 hours or more per week in 2001 (8,739) 54.8% were not caring in 2011 (4,791). Therefore, the results show a high proportion of individuals who provided care for 50 hours or more per week at one of the two time points, but not at both time points. Other results show that of all those caring at 2001 and 2011 (15,696), 16.8% (2,636) were providing 50 hours or more care at both 2001 and 2011. Among those who were providing 50 hours or more care per week in 2011 (12,657), 62.2% were not providing any care in 2001 (7,870). Such dramatic changes in individuals' circumstances, particularly for those who were not providing any care in 2001 but were providing 50 hours or more of care in 2011, have important policy implications which relate to support provided by social services and the government. Almost a third (30.2%) of those providing the highest intensity of care at 2001 (2,636) were also providing the same high intensity of care at 2011.

Table 3: Number and percentage of informal carers providing 50hrs or more care per week at 2001 and care provision at 2011

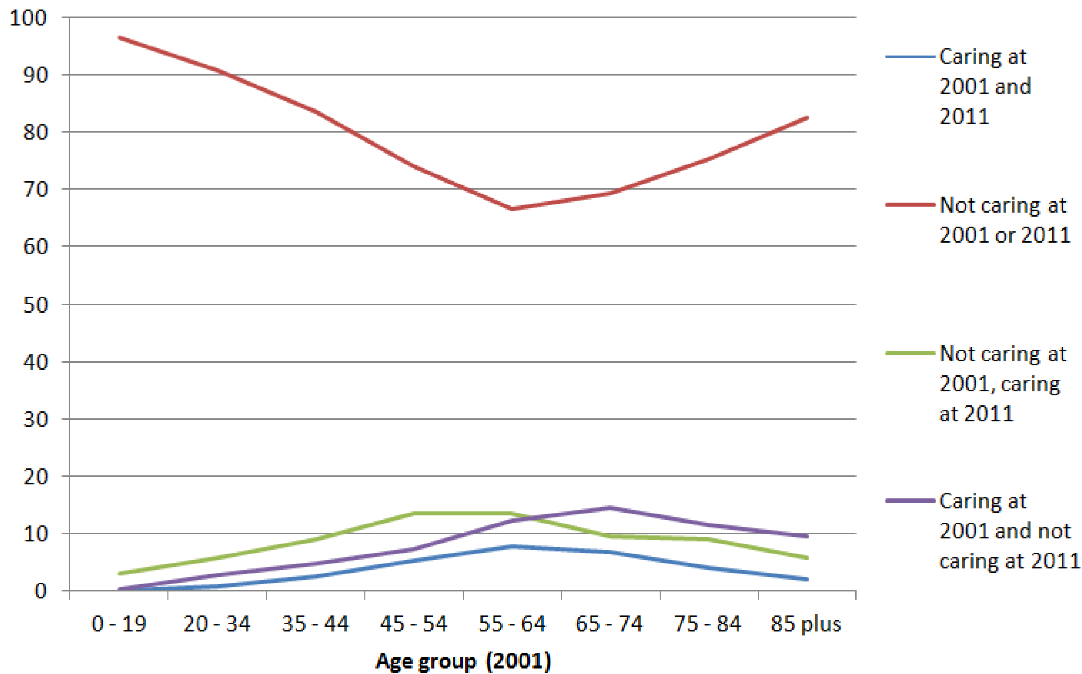
Description	2001	2011	N caring 50hrs+ at 2001	% caring 50hrs+ at 2001
Caring at 2001 and 2011 (a)	Carer	Carer		
decrease in caring	50 hours+ / week	1-19 hours / week	759	8.7
decrease in caring	50 hours+ / week	20-49 hours / week	553	6.3
same caring level	50 hours+ / week	50 hours+ / week	2,636	30.2
Caring at 2001, not caring at 2011 (d)	50 hours+ / week	Non-carer	4,791	54.8
Total			**8,739**	**100**

Source: ONS LS

4.2 Characteristics of informal carers at 2001 and at 2011: *Informal carers at both 2001 and 2011 were mainly aged 75-84 years at 2011*

Figure 1 shows the age profiles for the four groups of carers/ non-carers. It is clear that there is a gradual decline in the percentage who were not providing care at either Census towards the mid-life years (45-54 years) and then an increase again at older ages, where the receipt of informal care becomes more likely. Carers at 2001 and 2011 were mainly concentrated in the 55-64 and 65-74 years age groups (at 2001). For those who were providing care in 2001 but not in 2011, the highest percentage was in the 65-74 years age group (at 2001). Conversely, individuals who were not providing care in 2001 but were providing care in 2011 show the highest percentages in the mid-life years (45-54 and 55-64 years) with declines thereafter.

Figure 1: Percentage of ONS LS members by informal caring status at 2001 and 2011 by age at 2001



Source: ONS LS

4.3 Among informal carers at 2001, what are the main predictors of providing care ten years later? *Informal carers from 2001 who were looking after the home and providing high intensity care at 2001 are more likely to provide care at 2011*

Among the group of informal carers at the 2001 census (45,345), characteristics associated with caring ten years later can be identified. Table 4 presents a binary logistic regression model estimating the odds among those providing care in 2001, of providing care in 2011. The results show that across the range of ages, when a range of factors are controlled for, those most likely to be providing care at 2011 are in the 35-44 years age group (at 2001) compared to all other ages. The 45-54 years age group also show high odds of caring at 2011. The results in relation to marital status are consistent with past findings with those married having higher odds of caring at 2011 compared to all other groups. Among informal carers at 2001, those in not good health show the highest odds of caring in 2011, which may be related to being out of the labour market because of ill-health at 2001. Finally, those who were providing the highest intensity of care at 2001 were most likely to also be providing care at 2011 with an ascending likelihood for the medium and low intensity groups.

Table 4: Among informal carers in 2001, odds ratios of providing informal care in 2011

	Odds ratio	Sig.
Sex		
Female (reference)	1	
Male	0.96	ns
Age (2001)		
35-44 (reference)	1	
0-19	0.67	***
20-34	0.78	***
45-54	0.92	***
55-64	0.67	***
65-79	0.48	***
80 plus	0.26	***
Tenure (2001)		
Social rented (reference)	1	
Owned outright	1.00	ns
Owns with mortgage or loan	0.99	ns
Shared ownership	0.84	ns
Private rented	0.92	ns
Lives rent free	0.88	ns
Ethnic group (2001)		
white british (reference)	1	
irish	1.03	ns
other white	0.93	ns
mixed	0.90	ns
indian	0.92	ns
pakistani	0.92	ns
bangladeshi	0.56	***
black	0.94	ns
chinese and other asian	0.63	***
other ethnic group	0.65	ns
Marital status (2001)		
married (reference)	1	
never married	0.73	***
separated (still married)	0.85	*
divorced	0.78	***
widowed	0.62	***
Employment category (2001)		
looking after home	1	
employed PT	0.86	***
employed FT	0.82	***
self employed	0.79	***
seeking work and waiting to start job	0.72	***
retired	0.78	***
student	0.64	***
sick	0.83	***
other	0.77	***
not applicable - economically inactive	0.53	***
Health (2001)		
not good (reference)	1	
good	0.90	**
fair	1.01	ns
Caring level (2001)		
50+ hours (reference)	1	
1-19 hours	0.50	***
20-49 hours	0.73	***
High qualification (2001)		
Level 3: 2+ A levels, 4+ AS levels, Hig (reference)	1	
No academic or professional qualificati	0.7	***
Level 1: 1+O levels/CSE/GCSE (any grade	0.8	***
Level 2: 5+O levels, 5+CSEs (grade1), 5	0.9	*
Level 4/5: First degree, Higher degree	1.0	ns
Other qualifications/ level unknown: Ot	0.8	***

*Source: ONS LS (sig. ns = not significant, * = 0.05, ** = 0.01, *** = 0.001)*

5. Conclusions and next steps

This is the first analysis to present results for informal carers at 2001 and identify whether they were caring ten years later. Such analysis is permitted by the high quality longitudinal Census data available for England and Wales and the questions at 2001 and 2011 on informal caring provision. The 2011 Census question on informal caring highlights both the importance of following up on questions first asked at 2001 and the need for continuity between questions asked in the census. It also reflects the value of asking questions with high public policy relevance.

Informal carers who were providing care at 2001 and 2011 were mainly aged between 55-85 years in 2011. Our results suggest a greater number of people may have started caring between 2001 and 2011 than stopped caring. This is in keeping with the aggregate census results which show a slight increase in the percentage of the population providing informal care in 2011. A third of those caring at the 2001 Census were also caring ten years later. Among all informal carers at both 2001 and 2011, a total of 16.8% were providing 50 hours or more care per week at both dates. High percentages (54.8%) of those providing 50 hours or more care per week in 2001 did not provide care at 2011. In subsequent analyses we will seek to identify the reasons for these transitions, in particular the degree to which they are related to the cessation of spousal caring arrangements or because of changes in health status of the informal carer.

Multivariate analyses presented also suggested that those who were providing the highest intensity of care at 2001 were most likely to also be providing care at 2011 with an ascending likelihood for the medium and low intensity groups. Subsequent work will contribute to on-going debates on the health status and compatibility of caring roles with employment and consider employment-related transitions.

Acknowledgements and contributors

This research has been completed in collaboration with Julie Jefferies and Angele Storey of the Office for National Statistics Population Statistics Division.

We are grateful for the on-going help and assistance of the ONS LS Development Team, James Warren, Shayla Leib and Kevin Lynch.

The authors wish to acknowledge the support of colleagues in the Engineering and Physical Sciences Research Council (EPSRC) Care Life Cycle (CLC) project (grant number EP/H021698/1) and the Economic and Social Research Council (ESRC) Centre for Population Change (CPC) (grant number RES-625-28-0001) at the University of Southampton.

The permission of the Office for National Statistics to use the Longitudinal Study is gratefully acknowledged, as is the help provided by staff of the Centre for Longitudinal Study Information & User Support (CeLSIUS). CeLSIUS is supported by the ESRC Census of Population Programme under project ES/K000365/1. The authors alone are responsible for the interpretation of the data.

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