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## Article

## Trajectories of informal care and health

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## ABSTRACT

The evidence of the impact of informal care provision on the health of carers presents a complex and contested picture, depending on the characteristics of the care studied, including its duration, which has been relatively short in previous research (up to 4 years). Drawing on data from the Office for National Statistics Longitudinal Study, a 1% sample of linked Census records for respondents in England and Wales ( $N=270,054$ ), this paper contributes original insights on the impact of care provision on the carer's health ten years later. The paper explores differentials in self-reported health in 2011 between individuals according to their caring status at 2001 and 2011, and controlling for a range of demographic and socio-economic characteristics. The results show that individuals providing informal care in 2011 (regardless of carer status in 2001) exhibit lower odds of poor health in 2011 than those who did not provide care in both 2001 and 2011. Taking the intensity of care into account, 'heavy' carers in 2001 (i.e. caring for more than 20 h per week) who were not caring in 2011 show a higher likelihood of reporting poor health than non-carers, while those who were 'heavy' carers in both 2001 and 2011 are around one-third less likely to report poor health at 2011 compared to non-carers (2001 and 2011). These findings provide new insights in relation to repeat caring and its association with the carer's health status, further contributing to our understanding of the complex relationship between informal care provision and the carer's health.

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## 1. Introduction

The provision of unpaid or informal care is an increasingly common experience, particularly at older ages, and an important component of social care in England and Wales (Doran, Drever, Whitehead, & Duncan, 2003; Hirst, 2002; Pickard, Wittenberg, Comas-Herrera, Bleddyn, & Darton, 2000; Pickard, 2015; Vlachantoni, 2010). Driven by increasing longevity and changes in living arrangements (Robards, Evandrou, Falkingham & Vlachantoni, 2012; Grundy & Tomassini, 2010; Norman & Purdam, 2013), informal caring in England and Wales increased at a faster pace than population growth between 2001 and 2011; the largest growth was among those providing 50 h or more care per week (Office for National Statistics, 2013a). From a social policy perspective, understanding health patterns among the carers' population is important as carers' health status is crucial both in relation to their ability to provide support and in terms of their own care need. Existing empirical evidence regarding the relationship

between informal caring and health outcomes is mixed, depending on a range of factors such as the study type (cross-sectional vs. longitudinal) (Vlachantoni, Evandrou, Falkingham & Robards, 2013), the specific health outcome measured (Brown & Brown, 2014; Jones & Peters, 1992) and health characteristics of the person cared for (Capistrant, Moon, Berkman, & Glymour, 2012). Much of the research investigating care trajectories and their impact on the carer's physical or mental health has focused on relatively short time periods (see for example Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003); less is known about the impact of caring for individuals at more than one time point in the life course, and where the time points are one decade apart. This study contributes to that part of the literature which aims to understand health outcomes among informal carers across different time points and compared to individuals who have not provided any informal care. Using the Office for National Statistics (ONS) Longitudinal Study (LS), a nationally representative 1% sample of linked Census data for England and Wales, this paper follows informal carers between 2001 and 2011 in order to explore their health status in 2011. By studying this relationship across 10 years, the paper contributes original insights into our understanding of the impact of different care trajectories on the health of the carer.

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## 2. Previous research on informal care provision and health

Previous studies exploring the link between provision of informal care and health reflect the complexity of researching this topic area. Cross-sectional analyses may be limited in examining the factors preceding or following an individual's provision of informal care provision; however they can highlight the importance of distinguishing between particular types of care, or the importance of exploring the intensity of care provision (Evandrou, 1996). For example, analysis of 2001 UK Census data showed that non-carers were slightly more likely than carers to report good health (Doran et al., 2003). However, O'Reilly, Connolly, Rosato, and Patterson (2008), using data from the 2001 Northern Ireland Census, found that although carers were less likely than non-carers to report a limiting long-term illness (LLTI), health outcomes were worse among men providing 50 h of care per week or more. Similarly, Young, Grundy, and Kalogirou (2005), using 2001 census data for England & Wales and focussing on couples aged 65 and over in 2001 where at least one of the two spouses reported a LLTI, found that those who provided 20 h of care per week or more reported poorer health than those who provided fewer hours of care per week. More recent results analysing data from the 2011 UK Census indicate that informal carers are generally more likely to report 'not good' general health but that such likelihood increases in line with the hours of unpaid care provision, although this work does not control for the demographic characteristics of carers (Office for National Statistics, 2013a, 2013b).

Longitudinal analyses can identify the effect of informal care provision on the carer's health, as well as their mortality risk (Vlachantoni, Evandrou, Falkingham & Robards, 2013). Studying informal carers at more than one point in time, identifying 'care trajectories', and their impact on individuals' wellbeing is increasingly important in the context of both population ageing and increasing diversity in household structures (Robards, Evandrou, Falkingham and Vlachantoni, 2012), the combination of which can require individuals to manage or combine multiple economic and caring roles (Evandrou & Glaser, 2004). For instance, Rahrig Jenkins, Kabeto, and Langa (2009) explored the impact of informal care provision by spouses in 2000 on the carers' health status two years later, and did not find a negative effect. In contrast, Lawton et al. (2000) studied over 600 women aged 65 and over for 4 years, and found that women who had cared for at least 12 months were more likely to report poor physical and mental health compared to those who had not provided any care or care of a shorter duration during that time. In relation to the health and mortality of carers, O'Reilly et al. (2008) used data from the 2001 Northern Ireland Census on the health status of informal carers in order to explore their mortality risk 4 years later, and found that, controlling for a range of demographic and socio-economic characteristics, caregivers had a lower risk than non-caregivers, however such risk increased among caregivers as the number of hours of care provided increased. A similar study for England and Wales, using a comparable dataset, found that carers were more likely to report poorer health at baseline, yet survival analyses showed that they were at a significantly lower risk of dying (Ramsay, Grundy, & O'Reilly, 2013). Indeed, similar research in the US found lower mortality among caregivers leading to the suggestion that it may be premature to conclude that health risks for caregivers are due to providing active help (Brown et al., 2009) and caregivers may benefit from providing care. Indeed some empirical work has drawn attention to the potential health benefits arising from informal carer roles, which may include improved self-worth, 'proximity' to a spouse and health benefits from 'helping behaviour' (Poulin, Brown, Dillard, & Smith, 2013; Kramer, 1997).

Longitudinal analyses have also stressed the importance of taking into account the specific characteristics of the caring

activity, for example the type of care provided (e.g. personal and/or instrumental) and the health characteristics of the person being cared for. Research on the provision of informal care in England and Wales between 2001 and 2011 found that over one-third of carers in 2001 were also providing care after 10 years (Robards, Vlachantoni, Evandrou, and Falkingham, 2015), suggesting a high propensity to continue to provide care once such a role has been initiated. Research from the United States using the US Changing Lives of Older Couples survey has highlighted the importance of the duration of spousal care provision on the carer's psychological wellbeing following widowhood and found that care provision of a longer duration appears to have a more positive effect than shorter care provision (Keene & Prokos, 2008). Other research using the same dataset found that individuals who had provided instrumental support to friends, relatives and neighbours were 50% less likely to die in the following five years than those who had not provided any support (Brown, Nesse, Vinokur, & Smith, 2003). Interestingly, however, although much of the research highlights positive physical health outcomes, worse mental health outcomes have been noted as a result of caregiving responsibilities for heavy informal carers (providing 20 h or more of care per week) (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011). Simon, Kumar, and Kendrick (2009) in a cohort study of 105 informal live-in carers of new stroke patients, found that informal carers were 2.5 times more likely to experience psychological distress than non-carers.

Taylor, Ford, and Dunbar (1995) critically evaluated a range of studies examining effects of caring on health and argued that selection into caring roles is an important consideration. An alternative, albeit smaller, body of research has therefore focused on the opposite direction of the relationship between care provision and health, exploring the effect of one's health status on their caring activity at a later point. For example, Young and Grundy (2008) analysed data from two Census points and found that individuals reporting a LLTI in 1991 and/or in 2001 were more likely to be providing informal care in 2001 than those not reporting a LLTI (Young & Grundy, 2008). Relating to these findings are those of Burton et al. (2003), who showed that, among 428 individuals studied at baseline and five years later, those with higher levels of health-risk behaviour were more likely to take up caring roles than those who did not report any such behaviour. By contrast, McCann, Grundy, and O'Reilly (2012) followed individuals for three years; respondents with good physical health were more likely to become caregivers and to continue caring, although such continuation of the caring role was also associated with declining mental health.

In summary, varying results on the relationship between caring and poor health have been identified from study to study leading to an ongoing debate on the relationship and the relative weight of 'selection' of individuals with worse health into the caring role because their worse health status makes them available to provide care to others (Brown & Brown, 2014). Against this background, the present paper aims to improve our understanding of the relationship between care trajectories and the carer's health, when such care is provided at more than one time points, and over the space of one decade. It investigates the association between past caring (2001) and present caring (2011), with poor health at 2011, after controlling for baseline health at 2001 and a range of demographic, socio-economic and area-based variables known to be associated with health. The key research question addressed in this paper is 'how does the provision of informal care in 2001 and 2011, and the intensity of such care provision, affect the carer's report of poor health in 2011?'

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