



Exploring the financial and employment impacts of end of life unpaid caregiving in the UK: Executive Summary

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Introduction

Family members, friends and neighbours, who we refer to as ‘unpaid carers’, play a vital role in supporting people towards the end of life. Internationally, research has confirmed that end of life (EOL) unpaid carers need more support and information, and calls have been made for enhanced welfare, improved employment legislation and targeted interventions to improve the support offered to unpaid carers^{1,2}. A prerequisite for developing effective interventions and support for EOL carers is information about their specific needs and characteristics. However, the UK lacks reliable population level estimates of the numbers of EOL unpaid carers and little is known about the demographic characteristics of this group. In addition, whilst evidence suggests that unpaid caring can influence peoples’ financial situation and employment,^{3,4,5} little is known about the causal impact of providing unpaid EOL care on financial and employment outcomes.

The aim of this study was firstly to establish a population level estimate of the number of EOL unpaid carers across the UK, and to describe key demographic characteristics of this group. Secondly the study aimed to explore the causal impact of EOL caring on various financial and employment outcomes.

Methods

Data were analysed from the UK Household Longitudinal Survey (UKHLS), which has collected detailed information on social, economic, and behavioural factors from the same households annually since 2009. Respondents who provided end of life care to someone within their household (termed EOL household carers) were identified from UKHLS, and a population estimate of EOL household carers was extrapolated using census data from the Office for National Statistics. Demographic characteristics of EOL household carers were explored, and EOL carers were compared with other household carers and the general population, on a range of financial and employment variables. While the analysis of UKHLS data provided a robust estimate of the minimum number of EOL carers, it systematically excluded some carers, such as people who care for someone in another household. As a comparison, estimates of the number of EOL carers in the UK were also calculated based on the 2013 and 2017 editions of the Health Survey for England (HSE), which is an annual repeated cross-sectional survey of a representative sample of around 8,000 people from across England.

Key findings

- This study provides the first UK population level estimates of the number of EOL carers annually. Using data from UKHLS it is estimated there are between 150,000-180,000 household EOL carers in the UK annually, using data from HSE this estimate rises to between 686,000-762,000 EOL carers in the UK annually. The higher estimate equates to just over 1% of the UK population.
- The data from UKHLS suggest that the number of EOL household carers represents approximately 4% of all household carers in a given year, the data also suggest that 16% of household carers will become EOL household carers at some point.
- No major differences were found between EOL household carers and others (non EOL carers and general population) regarding country of residency (England, Scotland, Wales, Northern Ireland), ethnicity or rural vs urban living.

- EOL household carers were significantly older when compared to household carers and the general population. EOL household carers were more likely to be female, and more likely to have lower education levels, in comparison to the two other groups.
- Using two measures of poverty, a considerable proportion of EOL household carers (between 10-15%) were found to be living in poverty.
- The proportion of EOL household carers living below the poverty line increased dramatically (between 7 and 19 percentage points depending on the measure) in the year after they were bereaved.
- After they had been bereaved, EOL household carers were more likely to retire before reaching the pension age, suggesting EOL carers are more likely to exit the labour market early.

Conclusions and Recommendations

This study has provided the first estimate of the number of EOL carers in the UK, with at least 150,000-180,000 people, and potentially up to 762,000 people providing care to someone at the end of life each year. The difference between these two estimates is likely due to a number of reasons, including differences in the way data were collected between the two datasets, and the difficulties inherent in identifying unpaid end of life carers (many carers do not self-identify as such).⁶ The higher of our estimates equates to just over 1% of the UK population. This highlights both the size of the population and the need for support, in addition to a need for further research with prospective data collection to better understand the size of the EOL carer population in the UK.

EOL household carers are older, more likely to be female, and more likely to have left school at the minimum age than carers in general and the UK population. These findings support previous research which has indicated that EOL carers internationally are more likely to be older and female.^{7,8} Many carers were of working age and therefore potentially needing to balance the demands of employment and caring. Changing policies in care provision and policies aimed at prolonging participation in the labour market mean that more people will have to combine paid work and unpaid care over coming years, with significant implications for workplaces and the wider economy.

A large number of EOL household carers (between 10-15%) were found to be living in poverty, a finding which was robust to the measure of poverty being used. There was a notable rise in poverty in the first year of bereavement, and EOL household carers were more likely to take early retirement after they had been bereaved. Previous evidence suggests that caring for someone at the end of life creates a financial burden for households,^{2,9,10} however our findings extend these insights by showing that the financial situation continues to deteriorate after the death of the person being cared for, with a noticeable drop in income and an increased likelihood of early exit from the job market. The findings show a need for initiatives which provide better support for EOL carers, including addressing inadequacies in current policy and benefits, and identifying innovative solutions which span the workplace, the care environment and clinical practice. Box 1 outlines the recommendations from the study.

Recommendations for policymakers:

- Undertake a review of Carers Allowance to consider the feasibility of providing financial support into bereavement (up to six months) and simplify application processes.
- Consider new legislation that builds on the Carer's Leave Act 2023 and ensures all employees who have unpaid caring responsibilities are entitled to paid Carer's Leave.
- Raise awareness and improve communication about Bereavement Support Payment, for those under state pension age.
- Address housing insecurity for those providing EOL care, including into bereavement. Consider a six month grace period for bereaved co-habitants after the original tenant dies, and support to find alternative tenancies.
- Consider ways to tackle funeral poverty including addressing societal expectations of funerals, expanding funeral pre-planning and greater awareness of Funeral Expenses Payment.
- Reform adult social care so that older person households, including carers, feel supported with all aspects of ageing.
- Expand provision of free or low cost financial advice and planning (currently prohibitively expensive for many).

Recommendations for practice:

- Consider routine Carers Needs Assessment for EOL carers to help better identify the needs of EOL carers, and provide appropriate support.
- Ensure EOL carers are linked into local carer services and can benefit from local voluntary, community embedded initiatives.
- Provide EOL carers with information on sources of financial support and advice, as a routine part of clinical or social care practice.

Recommendations for employers:

- Employment policy should consider age equality policies to enable older carers to remain in work and avoid taking early retirement unnecessarily.
- All employers should have a policy on care leave and compassionate leave, so carers feel supported in the workplace.
- Tackle sexism and ageism in employment to avoid further discrimination against those groups over-represented among end-of life carers (older people and women).

Recommendations for research:

- Further research exploring how the financial and employment impacts of EOL caring persist into bereavement.
- Further research to better understand the size and characteristics of the EOL carer population in the UK, for example by collecting data prospectively

Box 1: Recommendations for policy, clinical practice, employers and research

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