

Demographic profile of end of life family caregivers in the UK: an observational study.

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Background: Unpaid carers play a vital role in supporting people towards the end of life. However, there are no population level estimates of the number of unpaid end of life (EOL) carers in the UK and little is known about the demographic profile of this group, including their financial situation.

The aim of this study was to estimate the number of unpaid EOL carers in the UK and describe demographic characteristics of this group.

Design: Secondary analysis of observational data from the UK Household Longitudinal Survey (UKHLS).

Methods: UKHLS collects annual data from around 40,000 households in the UK. We used data from 2009 - 2020 (inclusive). Unpaid EOL carers were defined as participants aged ≥ 18 years, who self-identified as a carer for someone in their household, where the care dependent died before the household's next annual interview. We estimated the proportion of people in UKHLS who are EOL carers each year, then combined this with Office for National Statistics data on population size to estimate how many people provide EOL care annually.

Results: The number of EOL household carers in the UK varied between approximately 135,000 and 180,000 per year (fig.1). We did not find major differences between the distribution of EOL carers and the general population regarding country of residency (England, Scotland, Wales, Northern Ireland) or ethnicity.

EOL carers were older (60% aged between 50 to 79 years compared with 42% in the general population) and more likely to be female (57% vs 52% in the general population) and with lower education levels (44% had left school at the minimum age vs 26% in the general population).

Using two measures of poverty, we found a considerable proportion of EOL carers (between 10-15%) are living in poverty. The proportion of EOL carers living below the poverty line increased dramatically (up to 20-25%) in the year after they are bereaved (figs 2&3).



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Figure 1: Number of EOL carers over time in the UK

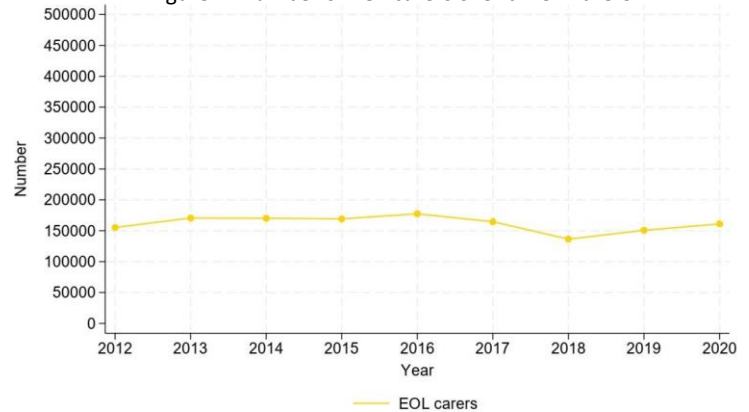


Figure 2: Percentage of EOL carers below 60% of median income (where care dependent dies between year 0 and year 1)

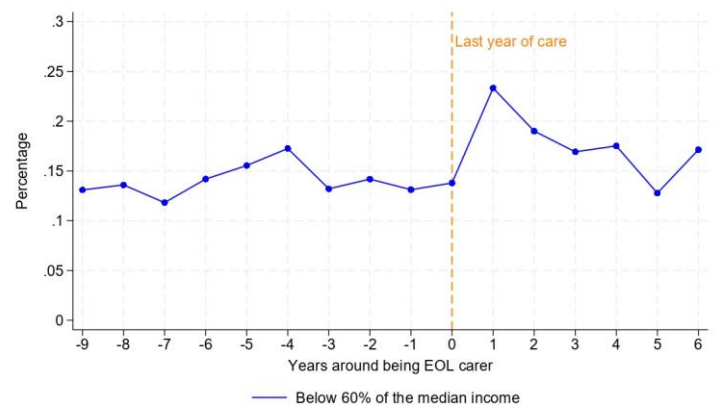
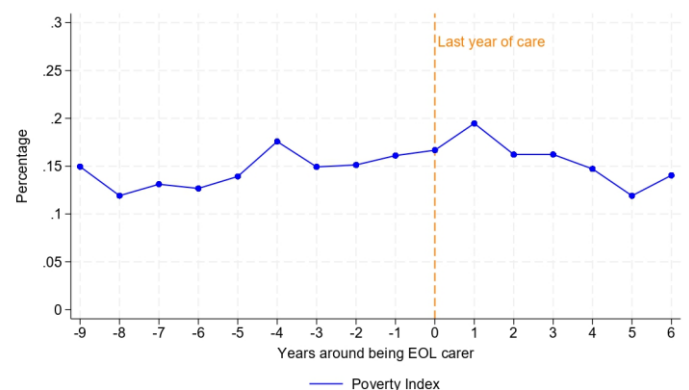


Figure 3: Percentage of EOL carers below the Social Metrics Commission poverty threshold (where care dependent dies between year 0 and year 1)



Conclusion: This is the first study to use representative population data to establish the number of unpaid EOL household carers in the UK. EOL carers are more likely to be older, female and have lower educational levels. Many EOL unpaid carers are living in poverty, and this is exacerbated in bereavement, showing a need for policy initiatives to support them.