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Caring for older people as a social determinant of health

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Executive Summary

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Key messages

- Policy and public health efforts to support unpaid carers must be underpinned by evidence.
- A scoping review was undertaken to summarise current evidence from UK cohort studies about carers and identify key gaps to shape future research.
- The current scope of evidence indicates that whilst there is evidence about carers of older people and older carers, we know very little about **who** older carers are supporting.
- Evidence largely focussed on **health** outcomes; there was less evidence about the link between caring and **quality of life, and social and financial wellbeing**.
- The link between caring and health was complex; findings varied across different measures, and some evidence may reflect reverse causation (i.e. that people in better health are more able to accommodate caring responsibilities).
- There was some evidence that linked caring to lower quality of life.
- Few studies reported social outcomes; there was evidence to link caring to loneliness, but the link with social participation was unclear.
- A small but consistent evidence based linked caring to adverse consequences for carers' employment and finances.
- Some evidence indicated that the consequences of caring differed depending on factors such as **gender, loneliness, participation in activities, as well as the quality of the carer-recipient relationship**.
- Consideration of how the outcomes of caring for older people or being an older carer differ for the richest and poorest populations is largely missing from the evidence.
- Important methodological considerations for future analyses include the measure of caring, important covariates, and detail on who older carers are supporting.
- All studies were observational; we therefore cannot rule out reverse causation.

Executive summary

Background

Research about and for carers is essential to inform policy and public health efforts to support this population. Critically, more evidence is needed about who is providing unpaid care to older people, the consequences for carers, and which groups of carers are most vulnerable to these adverse outcomes. In the first part of our work about unpaid caring for older people and older carers, we undertook a scoping review to assess the landscape of current UK evidence and identify key gaps to target our subsequent analyses.

Review aim and objectives

This review aimed to map research evidence from relevant UK cohort studies, on the health, wellbeing, social and economic status of carers of older people, and older carers.

The review objectives were to use evidence from UK cohort studies to:

- Describe studies of the sociodemographic characteristics, health status and economic activity of carers of older people and older carers.
- Identify evidence about associations between caring for an older person (or being an older carer) and the health, quality of life, work and finances of carers
- Identify evidence about how consequences of caring for an older person (or being an older carer) vary by socioeconomic status or area level disadvantage
- Identify evidence on specific subgroups of caregiver/recipients who may be at higher risk of adverse impacts, including co-resident/extra-resident carers, high-intensity carers, carers of people with specific long-term conditions, people living in socioeconomic disadvantage

Methods

Scoping review methods were used.

Search strategy

To identify evidence from UK cohort studies, we searched two data sources: websites of UK cohort studies and three bibliographic databases. Searches were limited to publications dated from 2000.

Review criteria

We included publications from UK cohort studies, published between 2000-2022, that reported evidence about carers of older people or older carers. We defined ‘older’ as populations aged 50 and over. Publications were also included if they reported no age but described study populations as older.

Study selection

Records were screened in Rayyan, an online platform to facilitate study selection for reviews.[1] Titles and abstracts were screened for relevance. The full texts of selected records were then assessed against the review criteria. Both stages of screening were undertaken by two researchers independently, and disagreements resolved through consensus with a third.

Data extraction and synthesis

Studies were coded in EPPI to identify key study characteristics. For studies that examined the association between caring and relevant outcomes, we extracted summary data about findings using an Excel template. Study data were visualised using EPPI mapper software[2] to summarise the coverage of evidence and key gaps. A narrative synthesis summarised findings about the impact of caring.

Findings

We identified 85 studies that reported evidence about carers of older people or older carers.

Most studies reported evidence about older populations who were carers, compared to any aged populations caring for older people. Studies of older carers did not typically report the age of the care recipient. This may be due to an inability to identify whether care recipients were older people exclusively, or older people as well as disabled adults and/or children, in some datasets. Where the care recipients' age was reported in publications, older carers were typically supporting adults. In a minority of studies, older carers were supporting both children and adults, or children alone.

A majority (n=48) of studies reported analyses of the impact of caring. Around a quarter of studies reported data that only described carer populations, and another quarter reported evidence about links to caring (e.g. predictors of unpaid care). Almost half (47%) of studies were published between 2015-2020. Data sources for published analyses were typically the British Household Panel Survey/Understanding Society, the English Longitudinal Study of Ageing, and ONS and census data.

The largest concentration of evidence was for health outcomes for carers of older people and older carers where the recipient's age was unknown. Fewer studies reported evidence about socioeconomic, disability, quality of life, and social wellbeing outcomes across all study populations.

Five studies reported evidence stratified by area deprivation or socioeconomic status. Of these, just three reported evidence about the impact of caring. Stratification was by work status and area deprivation.

Sub-group analyses were reported in less than half of the identified studies. Population sub-groups explored were mainly sex and age, and to a lesser extent, employment status, relationship to care recipient, mothers/fathers, with and without depression symptoms, care intensity, area deprivation, and care recipient at home or an institution.

Evidence about the impact of caring indicated there was mixed evidence for health outcomes, depending on the measure of health. Quality of life was also lower for carers compared to non-carers, and declined over time. A small but consistent evidence based linked caring to adverse outcomes for carers' finances and employment. In the few studies that reported social outcomes, there was some evidence linking caring to loneliness, but inconsistent evidence about the impact of caring on social participation.

Some studies indicated that the association between caring and health, quality of life, social and financial outcomes was attenuated by factors including gender, area deprivation, loneliness, participation in activities, as well as the quality of the carer-recipient relationship.

Discussion

Key evidence gaps revealed in this study mean that we know very little about carers' health over long time periods, and the impact of caring on social outcomes, such as loneliness and social participation. We also know very little about how the impact of caring on all outcomes differs for the rich and poor. A greater focus on these areas would enhance our understanding of the consequences of caring.

All studies were observational. This means that we cannot infer causation, and nor can we rule out reverse causation. For example, some evidence pointed to better health outcomes for carers than non-carers. This may reflect that carers in better health may be more able to accommodate care responsibilities than those in poor health. Future work could clarify the impact of caring on health by exploring carers' health trajectories over time.

Our review also indicates a number of methodological considerations that are important for future analyses. These include the measure of caring, key covariates, and detail on who older carers are supporting.

Implications for policy

Supporting unpaid carers is a key policy and public health concern. Approaches to supporting carers must be evidence informed. Our work considers the landscape of UK evidence and points to key gaps in our current understanding. These knowledge redundancies will be used to target our subsequent analysis for this programme of work, thus maximising the utility of evidence to inform policy.

Conclusion

This scoping review of UK cohort studies has summarised evidence about carers of older people and older carers. A greater focus on carers' health trajectories and social outcomes would enhance our understanding of the consequences of caring. Consideration of how the outcomes of caring differ for the richest and poorest populations is also critical.

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