NIHR Policy Research Unit Older People and Frailty



Caring for older people as a social determinant of health

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June 2023

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Integrated Summary

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This report presents independent research funded by the National Institute for Health and Care Research (NIHR) Policy Research Unit in Older People and Frailty. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Policy Research Unit Programme Reference Number PR-PRU-1217-21502

Background and approach

Unpaid carers are a critical resource in the UK care landscape. Amid a struggling care sector and increasing need for support by ageing populations, carers are likely to absorb the consequences of this care deficit. Evidence to improve the lives of carers will therefore feature strongly in the health and social care policy agenda.

Over the past two decades, research about carers has grown substantially. Going forward, it is essential to ensure that further research can usefully add to what we already know by prioritising under-researched questions and topics. This requires an understanding of key gaps in evidence.

To support this, we:

- a. Reviewed and mapped evidence from UK cohort studies about who carers are and the impact of caring on health, quality of life, and social and financial wellbeing;
- b. Reviewed and mapped international evidence about interventions to support carers and the outcomes evaluated;
- c. Analysed data from the English Longitudinal Study of Ageing to understand how characteristics of and outcomes for carers differ between the rich and poor;
- d. Held a workshop with stakeholders to discuss our findings and identify topics and questions that should be addressed in future research to support carers.

The findings of each component are detailed in their own reports, with supplementary evidence gap maps (projects *a* and *b*).¹ In this document, we summarise the key findings across each of these projects and highlight the implications for policy and research.

Evidence about unpaid carers: coverage and gaps

Although evidence about unpaid carers is vast in quantity, our reviews and stakeholder workshop highlight several important gaps. These gaps relate to: (i) the impact of caring on carers; (ii) what works best to support carers, and; (iii) impact of societal and population factors on carers (figure 1).

The impact of unpaid caring on carers

- Evidence about the impact of unpaid caring has largely focused on carers' physical health outcomes.
- Far fewer studies have explored the impact of unpaid caring on carers' financial and social wellbeing, and their quality of life.

¹ Our work was inclusive of both carers of older people, and older carers of any aged care recipient.

- 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 differ for the richest and poorest populations is largely missing from the evidence.
- Evidence is needed about 'hidden' groups of carers, including carers of people with substance misuse, mental ill health, and people on the autistic spectrum.
- Consideration of the long-term outcomes for carers is important, including impact on outcomes for those no longer providing care.

What works best to support carers?

- Research about what works to support carers has typically evaluated the impact of therapeutic and educational interventions on carer burden and carers' mental health.
- Evidence is needed about interventions addressing other aspects of carers' lives, such as their physical health, quality of life and their social and financial wellbeing
- Research could appraise the effectiveness of retirement communities on carers, interventions to support carers' digital inclusion and networking, and interventions for carers of people with young onset dementia.
- Many carers face barriers to engaging with interventions; evidence about how these barriers can be removed or overcome would be beneficial.
- There is little evidence about whether interventions produce equitable outcomes across diverse populations of carers.

The impact of societal and population factors on carers

- Evidence is needed about the impact of policies, care provision and systems on carers. This includes evidence about:
 - \circ the consequences of the reduced uptake of care homes on carers;
 - \circ $\,$ the uptake and outcomes of carers assessments;
 - \circ $\,$ the nature, variation and impact of health trusts' carers policies;
 - the impact of policy investment in young people with disabilities on older carers.

- Our understanding of the impact of unpaid caring should also consider the role and consequences of the pandemic on carers.
- Current evidence about carers would benefit from greater understanding about the transition from carer to care recipient, including how to anticipate when carers will acquire their own care needs, and carers' experiences of this.

Characteristics and outcomes for carers: differences between the rich and poor

Our work identified a dearth of evidence about how the outcomes of caring differed between the rich and poor. An exploratory analysis of data from the English Longitudinal Study of Ageing indicates that a number of health outcomes are socioeconomically patterned. Carers in the poorest wealth quintile had poorer health compared to carers in the middle wealth quintile. By contrast, carers in the richest wealth quintile had better health.

Implications for policy and research

Policy efforts to support carers must be underpinned by evidence. Our work points to a number of areas that could be targeted by future research. Gaps and questions have been identified relating to the impact of unpaid caring on carers, the impact of societal and population factors on carers, and what works to support carers. All are important and will enhance current evidence.

Our work also identified three methodological considerations for future research about carers. First, appraisals of impact should consider using a measuring caring intensity instead of caring status alone; evidence suggests that the former offers a more granular picture of the consequences of caring. Second, data about older carers contain limited information about care recipients. This is important to understand the nature of the care provided. Third, carers are not homogenous populations. Research about impact should consider how consequences vary between groups, whilst evaluations should consider the equity of interventions. Figure 1. Evidence gaps and topics to inform future research for unpaid carers

Impact of unpaid caring

Impact of caring of quality of life, social and financial wellbeing, long-term outcomes for carers; socioeconomic patterns of the impact of unpaid caring; experiences of hidden groups of carers.

What works to support carers?

Effectiveness of: interventions to support carers' social and financial wellbeing, physical health and quality of life; retirement communities, interventions to promote digital inclusion and networking; support for carers of people with young onset dementia; barriers to engaging with support. Impact of societal and population factors on carers

Impact of policies, provision, and systems on carers; uptake and outcomes of carers' assessments; anticipating when carers' become care recipients; long-term impact of pandemic on carers.

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