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Caring for older people as a social determinant of health

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Final Report

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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.

Full report

Background

Unpaid (or informal) care to family members, relatives, or friends is a critical source of support for people with health and social care needs. The value of care for UK adults was estimated to be worth nearly £60 billion in 2016, the equivalent of a year's worth of full-time work from four million adult social care workers.[3] Whilst estimates vary, recent evidence suggests that approximately seven percent of the UK population provide unpaid care.[4]

More than half of UK carers are women and those aged 55-64 are most likely to provide unpaid care.[4] However, rates of unpaid caring are growing fastest among those aged 65 and over.[5] Among carers of older people in England, more than half are supporting a parent or parent-in-law outside the home.[6] Two-thirds of these extra-residential carers are simultaneously in paid employment, of which 11% provide 20 or more hours of care per week. Black, Asian and Minority Ethnic (BAME) individuals are also more likely than those of White backgrounds to provide at least 20 or more hours of care per week for family members.[7]

Given these demographic characteristics and the demands of caring itself, carers have been characterised as a group at high risk of adverse outcomes. Recent work commissioned by Public Health England asserts that unpaid care should be considered a social determinant of health.[8,9] This is particularly important to consider in light of the £6.1 billion gap in adult social care funding observed over the past ten years.[10] Furthermore, the UK's ageing population means that need for care is fast outpacing the growth in supply.[6] Recent projections suggest that the number of people aged 85 and over in need of unpaid care will more than double between 2015 and 2035.[6] However, if the current proportions of unpaid carers remain the same, there will be a shortfall of 2.3 million carers by 2035.[6] The need for unpaid carer has never been more critical.

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 and older carers, 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. The purpose of this work was to identify key gaps to inform the development of further work in this area.

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 and are described below in accordance with the PRISMA-ScR checklist.[11]

Search strategy

To identify evidence from UK cohort studies, we searched two data sources: websites of UK cohort studies and bibliographic databases.

A list of UK cohort studies was generated from two published compilations.[12,13] Each cohort study was assessed to determine whether the study contained data about unpaid carers (**Box 1**). A list of eligible cohort studies is provided in Appendix A. The websites of eligible cohort studies were then searched using the keywords: "unpaid" "carer" "caring" "informal" "support" and "assistance". Studies identified using this approach were then used to develop a targeted search strategy for the bibliographic databases.

Using this search strategy, we searched three databases:

- OVID MEDLINE (R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions 1946 to March 29, 2022
- APA PsycInfo 1987 to March Week 3 2022
- CINAHL, 30th March 2022

Searches were limited to publications dated from 2000. The search strategy applied to MEDLINE is in Appendix B.

Box 1. Assessing the eligibility of UK cohort datasets for searching

Is information available about all data collected in the cohort study (e.g. a data dictionary)?

a. Yes → does information confirm that data are available about unpaid carers and caring?
   i. Yes: **Select for website searching**
   ii. No: Not eligible.
b. No → Contact data guardian to query if cohort study collects data about unpaid carers and caring
   i. Response confirms yes: **Select for website searching**
   ii. Response confirms no: Not eligible
   iii. No response → Ask experts in the field if they are aware that this dataset collects data about unpaid carer and caring
      1. Response confirms yes or maybe: **Select for website searching**
      2. Response confirms no: Not eligible

Review criteria

The review criteria are summarised in table 1. We defined older people and older carers as populations aged 50 and over. Publications were also included if they reported no age but described study populations as older. To maximise the scope of identified evidence, we included studies of mixed age populations if: the average age, or the majority of the sample was, 50+ years; or data were reported separately for the older study participants.

Table 1. Review criteria

Population	Carers of older people (50+ years). Older carers (50+ years) of any aged recipient, including children.
Exposure	Unpaid caring, including stratification by a measure of socioeconomic status or area deprivation.
Comparator	No comparison (i.e. if a descriptive analyses of carer populations), non-carers, carers of populations other than older adults.
Outcome	Any measure of health, quality of life, economic activity (including employment and volunteering), financial circumstances.
Study design	UK observational studies published 2000-2022.

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: the type of carer population, outcomes or descriptive variables used, whether studies reported the impact of caring, factors linked to caring, or described carer populations, the use of a sub-group analysis to identify populations likely to experience adverse outcomes, and any stratification of findings by area deprivation or socioeconomic status. 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 (figure 1). [3,14-97]

Figure 1. PRISMA Flowchart

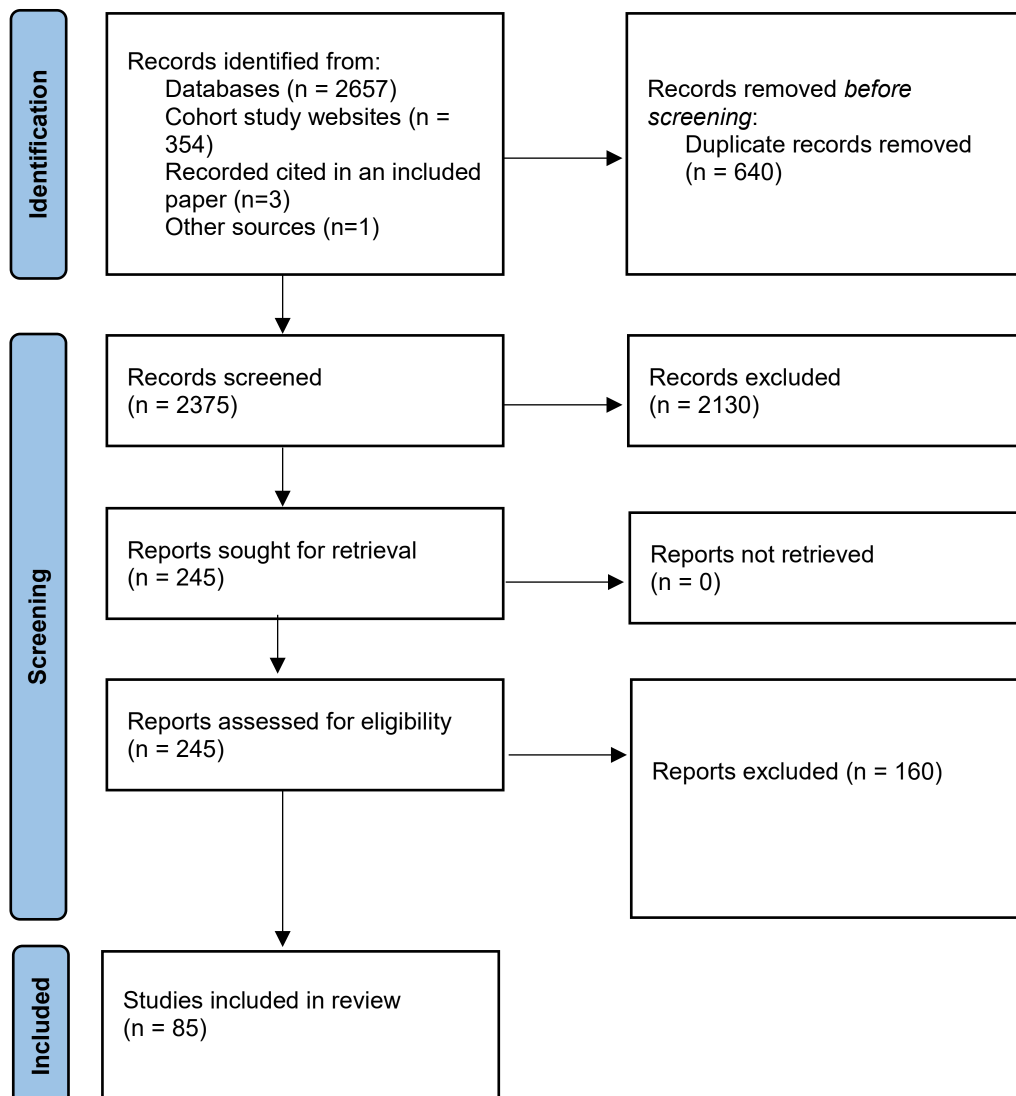


Table 2 summarises the characteristics of the populations, focus and analyses of included studies.

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.[1] 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.

All studies reported descriptive, demographic data about carers. Where studies examined the impact of caring, outcomes were typically health-related. Fewer studies reported evidence about the socioeconomic, disability-related, quality of life, or social impact of caring.

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 (figure 2). 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 (figure 3).

[1] Questions used to identify carers often asked if the participant was providing help to older adults or disabled relatives, without differentiation of the two populations.

Table 2. Summary of included studies

Study characteristic		Number of studies
Reports data about:		
Population*	Carers of older populations	33
	Older carers of children	2
	Older carers of adults	20
	Older carers of children and adults	7
	Older carers (recipient unknown)	52
Outcomes and descriptive data reported in relation to carers*	Age	54
	Gender	54
	Ethnicity	16
	Education	24
	Other demographic	46
	Work/employment/social class	42
	Finances	20
	Other socioeconomic	15
	Health	53
	Disability	8
	Quality of life	8
	Social wellbeing/contacts/relationships	13
Type of data	Impact of caring	41
	Links with caring	15
	Impact of caring and links with caring	7
	Describes carer populations only	21
Analyses	With a sub-group analysis	33
	Stratified by SES/socioeconomic status	5

*Not mutually exclusive where studies used multiple populations and outcomes.

Figure 2 Percentage of studies identified by publication year

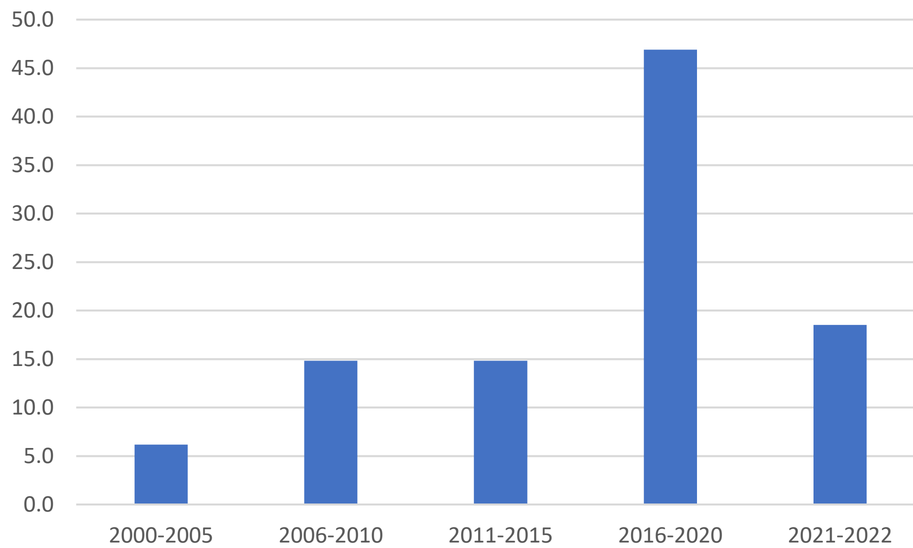
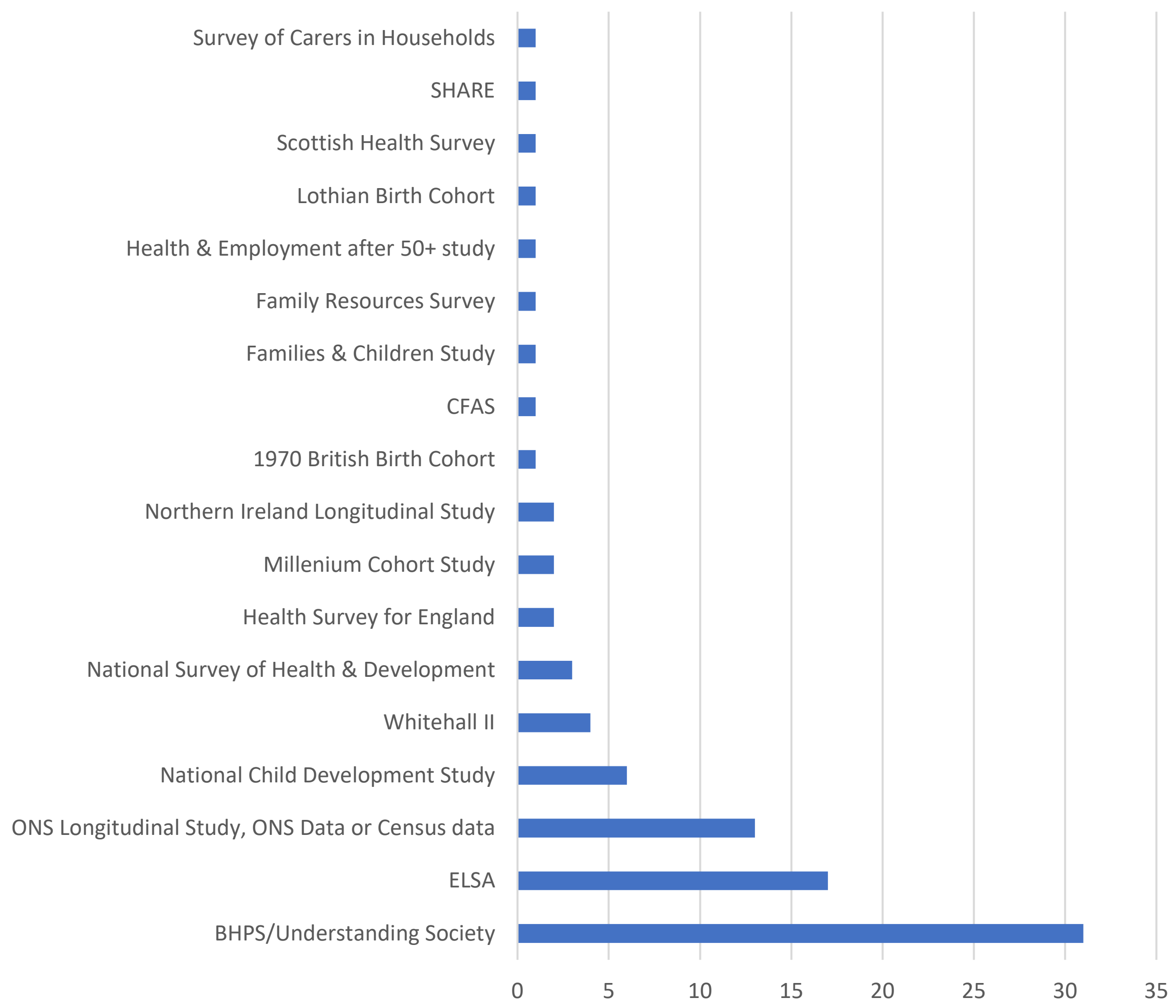


Figure 3 Data sources for included studies



Evidence coverage and gaps

Interactive maps A, B and C show the concentration of evidence by study population and outcomes, filtered by the type of evidence (**map A**), availability of a sub-group analysis (**map B**), and whether studies stratified by area deprivation of socioeconomic status (**map C**).

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.

Evidence about how consequences of caring for an older person (or being an older carer) vary by socioeconomic status or area level disadvantage

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

Evidence about specific subgroups of caregiver/recipients who may be at higher risk of adverse impacts

Sub-group analyses were reported in less than half of the identified studies. Analyses to assess the impact of caring in population sub-groups included sample stratification, sensitivity analyses, and moderation analyses (interaction terms). Population sub-groups explored were mainly sex and age, and to a lesser extent, employment status, area deprivation, relationship to care recipient, mothers/fathers, with and without depression symptoms, care intensity, and care recipient at home or an institution.

Evidence about the impact of caring

Forty-eight studies reported evidence about the association between caring and health, socioeconomic or social outcomes (table 3).[3,21,22,24,25,29,30,32,36,38-41,43-46,49-54,56,58,59,62,63,65,67-72,76,77,80,82-85,89-92,95,97] We have used these studies to make an inference about the impact of caring, although all were observational in design. We provide a brief summary of this evidence below.

Mental health

The association between caring and mental wellbeing and depression was inconsistent across studies.[21,22,29,32,39,44,46,50,53,63,65,67,76,80,83,84,91] There was some evidence that mental health outcomes were worse for carers who experienced loneliness, low levels of social participation and felt underappreciated by the care recipient.

Self-rated health

Caring status alone was not consistently linked to poorer self-rated health.[46,90,91] However, poorer self-rated health was linked to greater intensity of caring.[46,90] In one study, carers in poor health were more likely to be living in the most deprived areas.[97]

Mortality

Mortality risk was lower in carers than non-carers in three studies.[21,72,89]

Cognition

Evidence suggested that memory and verbal fluency were better for carers compared to non-carers.[40,95]

Health conditions

There was some evidence linking caring to: cardiovascular disease for carers in poor health and carers providing more hours of care/week;[24,70] regional pain for women caring 20+ hrs/week;[46] COPD for men caring 20+ hrs/week;[46] higher cholesterol for men;[59] and, larger waist circumference and higher BMI for women aged 65+ combining caring with full time work.[58] A biomarker of stress (cortisol awakening response) was worse for male carers.[69] Caring status alone was not linked to type 2 diabetes, but carers with low social support at work were more likely to have diabetes.[68] Caring was linked to lower multimorbidity in one study.[40]

Disability

Few studies considered disability outcomes (e.g. ADLS, mobility). There was little consistent evidence linking caring to disability.[21,40,89]

Quality of life

There is some evidence that caring, and greater intensity of caring (hours/week) is linked to poor quality of life.[30,63,71] A decline in quality of life over time was also observed for carers in two studies.[76,95] However, there was also evidence that this relationship was moderated by carers' participation in social activities, the quality and type (e.g. spouse, child) of their relationship with the care recipient, and access to formal care services.[63,65,91] Life satisfaction was lower for female carers, but higher for male carers who lived with the care recipient, compared to non-carers.[30]

Employment and finances

Caring was linked to exit from employment, working fewer hours, fewer pension contributions and lower private and state pensions compared to populations who did not provide unpaid care.[25,36,43,45,46,49,51,52,54,90,92] The link between caring and employment is not homogenous across all carers. Female carers, single carers, carers in poor health, carers experiencing difficult financial situations, and carers in low socioeconomic occupations are more likely to see their employment affected.[3,46,51,52,92]

There was also evidence in one study that as caring intensity (hours/week) increased, the proportion of carers employed decreased.[90] Beyond this, however, there was little clear evidence about the link between caring intensity and impact on employment and finances.

Social outcomes

There was evidence of higher rates of loneliness among carers, but this varied by carer attributes.[3,85] Two studies also found that loneliness moderated carers' risk of depression but one only found this to be true for carers of partners with dementia.[39,80] Evidence about the association between caring and social participation was inconsistent.[41,85] However one study found that social participation moderated the relationship between caring and quality of life.[91]

Summary

The evidence gaps revealed in this study mean that we know very little from UK cohort studies about who older carers are supporting, and what the consequences are for carers' social wellbeing. We also know very little about how the impact of caring on all outcomes differs by area deprivation or socioeconomic status. Evidence about health offered a contrasting picture; it is not clear to what extent reverse causation accounts for this picture. For example, evidence of better health outcomes for carers than non-carers may reflect that

people in good health are more able to accommodate caring responsibilities when they arise than those in poor health. Analysis that explores carers' health trajectories over multiple time points may clarify the impact of caring on health.

Table 3. Summary of studies reporting evidence about the impact of caring

Study author	Date	Population *Older carers (OC); Carers of Older People (COP); Both*	Measure of unpaid care *Carer status (carer/not a carer), amount of care (e.g. hours)*	Includes longitudinal analysis?	Outcomes *Health, disability, quality of life, socioeconomic, social*
Benson	2017	OC	Carer status	Yes	Health, disability
Bom	2021	Both	Carer status, caring amount	Yes	Health
Buyck	2013	OC	Carer status	Yes	Health
Carr	2018	Both	Carer status, caring amount	Yes	Socioeconomic
Chanfreau	2021	COP	Carer status	No	Health
Della Giusta	2014	COP	Carer status, caring amount	Yes	Quality of life
Doebler	2017	Both	Carer status, caring amount	Yes	Health
Evandrou	2003	OC	Carer status	No	Socioeconomic
Gallagher	2020	OC	Carer status	No	Health, social
Garcia-Castro	2022	OC	Carer status	Yes	Health, disability
Glaser	2006	OC	Carer status, caring amount	No	Social
Gomez-Leon	2017	Both	Carer status, caring amount	Yes	Socioeconomic
Grande	2018	Both	Carer status	No	Health
Gush	2013	COP	Carer status	No	Socioeconomic
Hanratty	2007	OC	Carer status, caring amount	No	Health, socioeconomic
Harris	2020	OC	Carer status, caring amount	No	Health, socioeconomic
Hirst	2001	Both	Carer status, caring amount	Yes	Socioeconomic
Hodiamont	2019	OC	Carer status, caring amount	No	Health
Hutton	2000	Both	Carer status, caring amount	Yes	Socioeconomic
Jopling	2016	OC	Carer status, caring amount	No	Socioeconomic
Kaschowitz	2017	OC	Carer status	Yes	Health
King	2013	Both	Carer status, caring amount	Yes	Socioeconomic

Kinnear	2010	OC	Carer status, caring amount	No	Health
Lacey	2018	OC	Carer status, caring amount	Yes	Health
Lacey	2018	OC	Carer status, caring amount	Yes	Health
Maun	2018	OC	Carer status, caring amount	Yes	Health
McGarrigle	2020	OC	Carer status, caring amount	No	Health, quality of life
McMunn	2009	OC	Carer status	No	Health, quality of life
Moriarty	2015	OC	Carer status, caring amount	Yes	Health
Mortensen	2018	OC	Carer status, caring amount	Yes	Health
Mortensen	2018	OC	Carer status, caring amount	Yes	Health
Mortensen	2019	OC	Carer status, caring amount	No	Health
MRC CFAS Study Group	2000	COP	Carer status	Yes	Health
Netuvelli	2006	OC	Carer status	No	Quality of life
O'Reilly	2008	OC	Carer status, caring amount	Yes	Health
Rafnsson	2017	Both	Carer status	Yes	Health, quality of life
Ramsay	2013	OC	Carer status, caring amount	Yes	Health
Saadi	2021	Both	Carer status	Yes	Health, social
Shaw	2017	OC	Carer status	No	Health
Shiue	2017	OC	Carer status	No	Health
Sin	2021	OC	Carer status, caring amount	No	Health
Smith	2020	Both	Carer status	Yes	Quality of life, social
Storey	2019	Both	Carer status, caring amount	No	Socioeconomic, social
Tseliou	2018	OC	Carer status, caring amount	Yes	Health, disability
Vlachantoni	2010	Both	Carer status, caring amount	No	Health, socioeconomic
Vlachantoni	2019	Both	Carer status, caring amount	Yes	Socioeconomic
Vlachantoni	2020	Both	Carer status, caring amount	No	Health, quality of life, social
Yuan	2021	OC	Carer status	Yes	Health, quality of life

Discussion

This scoping review has summarised evidence about caring for older people and older carers from UK cohort studies. Our work identifies critical gaps in our understanding of the consequences of unpaid caring. Table 4 outlines these gaps and summarises suggested avenues of future research.

Table 4. Evidence gaps and suggested avenues for future research

Evidence gap	Suggested research	Policy relevance
Impact of caring on health *over time*	Explore carers' health trajectories, including how these are attenuated by socioeconomic factors.	May aid identification of critical time points for delivering support to carers.
Clarify impact of caring on social outcomes	Explore impact of caring on social outcomes, such as social participation, loneliness, and social relationships.	Social wellbeing is important for health and may offer a useful approach to support the health of carers.
How outcomes of caring differ for the rich and poor	Future research should consider the role of carers' socioeconomic status and how this attenuates the impact of caring.	A critical angle to support mitigation of health inequalities and understanding potential implications of the differential impact of caring.

The impact of caring on health over time: although health outcomes occupy a large space in current evidence, the inconsistent findings point to a need for clarification. Understanding carers' health trajectories over time may be particularly important for ruling out issues relating to reverse causation.

The impact of caring on social outcomes: few studies were identified that reported social outcomes, such as loneliness, social participation and relationships. Those that did offered a mixed picture, indicating the need for greater clarification.

How the outcomes of caring differ for the rich and poor: few studies explored how the impact of caring - on any outcomes – differed by a measure of socioeconomic status. This is a critical omission and should be given greater attention in future research.

Other potential avenues of research

The review identified a small but consistent evidence base about the adverse impact of caring on employment and finances – particularly for women, single people, people in poor health and people in low socioeconomic occupations. Further research could expand this evidence by exploring ways to mitigate the impact of caring on employment and support the financial wellbeing of people providing unpaid care.

Our review also demonstrated that we know little about *who* older carers are supporting. This may be due to the data available within cohort studies. Our understanding of older carers could be enhanced if future data collection included questions about care recipients.

Methodological consideration for future analyses

Based on the work of this review, we suggest a number of methodological considerations for future analyses about the consequences of caring for older people, or being an older carer.

- Measures of caring in the identified studies included both carer status (compared to non-carers) and caring intensity, often measured as hours per week. This distinction may be important; some evidence indicated that the amount of care given was more important than caring status alone when considering outcomes.
- Where possible, some detail of who older carers are supporting would enhance our understanding of evidence for this population.
- Some evidence hinted that associations between caring and health were attenuated by social factors, such as loneliness, participation in activities, as well as the quality of the carer-recipient relationship. Similarly, patterns of evidence sometimes differed for men and women. These may be important covariates to consider in future analyses.
- Some studies used multiple datasets, confirming the possibility of data linkage to enhance the size of the study sample.

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.

Strengths and limitations

Our focus on UK cohort studies exploits a valuable source of evidence and ensures our conclusions are relevant to UK policy. Studies published before 2000 were excluded to prioritise the most contemporary evidence about carer populations.

A subset of studies reported evidence about the association between caring and a health, socioeconomic or social outcome. We have used these studies to make an inference about the 'impact' of caring. However, all studies were observational. This means that we cannot infer causation, and nor can we rule out reverse causation. This is particularly important when interpreting evidence about carers' health.

The intention of this scoping review was to provide a summary of the UK evidence landscape. We did not therefore use a quality assessment to differentiate low and high quality studies. However, many of these studies are similar in design and measures; a quality assessment may have offered little scope to differentiate studies based on methodological limitations. A critical consideration for these observational studies is whether analyses made use of longitudinal or cross sectional data. Longitudinal analyses allow us to draw an inference about changes in outcomes over time for carers, whereas cross sectional analyses do not. We have therefore supplied this information for the reader's reference (table 3).

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 over time, and their social wellbeing 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. Methodological considerations for future analyses include the measure of caring, important covariates, and detail on who older carers are supporting.

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Appendix A: Eligible cohort studies

Data Set/Cohort Name
1970 British Cohort Study
Avon Longitudinal Study of Parents and Children
British Household Panel Survey
British Regional Heart Study
British Women's Heart and Health Study
Caerphilly Health and Social Needs Electronic Cohort Study
Caerphilly Prospective Study
Cambridge City over-75s cohort
Census for England and Wales/ONS Longitudinal Study (ONS LS)
Cognitive Function and Ageing Study I & II
Determinants of Adolescent Social Wellbeing and Health (DASH)
English Longitudinal Study of Ageing (ELSA)
European Prospective Investigation of Cancer, Norfolk (EPIC-Norfolk)
Generation Scotland: Scottish Family Health Study
Health and Employment After 50 Study (HEAF)
Health and Lifestyle Survey
Health Survey for England
Healthwise Wales
Hertfordshire Cohort Study
Life Opportunities Survey
Lothian Birth Cohorts of 1921 and 1936
Millenium Cohort Study
Million Women Study
Melton Mowbray Cohort (1980–88)
National Child Development Study (NCDS)
National Survey of Health and Development (NSHD)
Newcastle 85+ Study
Next Steps
Northern Ireland Census
Northern Ireland Longitudinal Study
Scottish Health Surveys Cohort
Scotland's Census
Scottish Longitudinal Study (SLS)
Southall and Brent Revisited (SABRE)
Southampton Ageing Project (1977–02)
UK Biobank
Understanding Society
West of Scotland 11-16 and 16+ Study
West of Scotland Twenty-07 Study
Whitehall II study

Appendix B: Strategy applied in MEDLINE

#	Searches	Results
1	"1970 British cohort*".ti,ab,kw.	124
2	"Avon Longitudinal Study of Parents and Children*".ti,ab,kw.	1573
3	"British Household Panel*".ti,ab,kw.	252
4	"British Regional Heart*".ti,ab,kw.	157
5	"British Women's Heart and Health*".ti,ab,kw.	102
6	"Caerphilly Health and Social Needs*".ti,ab,kw.	15
7	(Caerphilly adj3 (cohort or study or prospective)).ti,ab,kw.	165
8	(cambridge city adj3 (cohort or study or prospective)).ti,ab,kw.	35
9	(census adj3 (england or wales or "northern ireland" or scotland)).ti,ab,kw.	139
10	"ons longitudinal study*".ti,ab,kw.	45
11	"office for national statistics longitudinal study*".ti,ab,kw.	46
12	"Cognitive Function and Ag?ing*".ti,ab,kw.	385
13	"Determinants of Adolescent Social Well being and Health*".ti,ab,kw.	6
14	"English Longitudinal Study of Ag?ing*".ti,ab,kw.	804
15	("European Prospective Investigation of Cancer*" adj3 (norfolk or oxford)).ti,ab,kw.	295
16	"generation Scotland*".ti,ab,kw.	119
17	"Scottish Family Health*".ti,ab,kw.	69
18	"Health and Employment After fifty*".ti,ab,kw.	12
19	"Health and Lifestyle Survey*".ti,ab,kw.	186
20	"Health Survey for England*".ti,ab,kw.	547
21	"Healthwise Wales*".ti,ab,kw.	10
22	"Hertfordshire Cohort*".ti,ab,kw.	129
23	"Life Opportunities Survey*".ti,ab,kw.	7
24	"Lothian Birth Cohort*".ti,ab,kw.	237
25	"Millenium Cohort*".ti,ab,kw.	2

26	"million women study*".ti,ab,kw.	184
27	"Melton Mowbray Cohort*".ti,ab,kw.	0
28	"National Child Development Study*".ti,ab,kw.	313
29	"National Survey of Health and Development*".ti,ab,kw.	286
30	"Newcastle 85*".ti,ab,kw.	83
31	(next steps adj3 (cohort or study)).ti,ab,kw.	50
32	"Longitudinal Study of Young People in England*".ti,ab,kw.	25
33	"Northern Ireland Longitudinal*".ti,ab,kw.	24
34	"Scottish Health Survey*".ti,ab,kw.	176
35	"Scottish Longitudinal*".ti,ab,kw.	25
36	"Southall and Brent Revisited*".ti,ab,kw.	28
37	"Southampton Ag?ing*".ti,ab,kw.	0
38	"UK Biobank*".ti,ab,kw.	3582
39	"Understanding Society*".ti,ab,kw.	166
40	"UK Household Longitudinal Study*".ti,ab,kw.	122
41	("west of scotland" adj3 (study or cohort)).ti,ab,kw.	244
42	"Whitehall II study*".ti,ab,kw.	433
43	or/1-42	10796
44	Caregivers/ or Caregiver Burden/	44888
45	exp Child Care/	21111
46	(care* or caring or childcare or unpaid or informal).ti,ab,kw.	1919954
47	44 or 45 or 46	1934828
48	43 and 47	818

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