# Caring for Older People As a Social Determinant of Health: Findings from a Scoping Review of Observational Studies

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## ABSTRACT

**Background:** Unpaid care is a critical source of support for people with health and social care needs. Unpaid carers are a group facing increasing demands and are at risk of adverse outcomes.

**Objectives:** To assess the breadth of evidence on older carers/carers of older people in UK cohort studies.

**Methods:** Using scoping review methods, we developed a targeted search strategy in three bibliographic databases (Medline, PsycInfo and CINAHL) for studies reporting carer characteristics and outcomes. Data were mapped using Evidence for Policy and Practice Information (EPPI) Reviewer, a web-based programme for managing and analysing data in reviews. The impacts of caring were explored and synthesised.

**Findings:** Eighty-five studies were included. Where studies examined the impact of caring, outcomes were typically health-related; findings were inconsistent. Fewer studies reported the socioeconomic, disability-related, quality of life, or social impacts of caring. Fewer than half of studies reported subgroup analyses or care recipient information, and only five studies stratified carers' outcomes by a measure of socioeconomic status.

**Limitations:** Relying on data from observational studies means that key outcomes or caring pathways may be overlooked due to data collection methods. We therefore cannot infer causation/reverse causation regarding caring and carer outcomes.

**Implications:** Our work highlights specific gaps in evidence regarding the social, economic, health and quality of life outcomes for carers. We also suggest methodological considerations to improve our understanding of care recipients, carers' trajectories, and those at greatest risk of adverse outcomes. This information is vital to the development of research design, policies and interventions to support carers' wellbeing.

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#### **KEYWORDS**:

Cohort studies; caring; caregiving; caregiver burden; carers research; ageing

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## RESEARCH

## BACKGROUND

Unpaid care to family members, neighbours, or friends is a critical source of support for people with health and social care needs (Ophir & Polos, 2022). Caring responsibilities vary but may include helping someone with activities of daily living, accessing medical appointments, managing finances, and providing emotional support (Local Government Association, 2018). The value of care for UK adults was estimated to be worth nearly £60 billion in 2016, equal to a year's worth of full-time work from four million adult social care workers (Storey et al., 2019). Recent evidence suggests that approximately seven percent of the UK population provide unpaid care (Foley et al., 2021).

The demographic characteristics and the demands of caring have led to carers being characterised as a group at risk of adverse outcomes, with unpaid caring being considered as a potential social determinant of health (Spiers et al., 2021). More than half of UK carers identify as women and people aged 55-64 are most likely to provide unpaid care (Foley et al., 2021). However, rates of unpaid caring are growing fastest among both people aged 65 and over (Carers UK, 2019) and in the group caring for more than 50 hours per week (Department of Health and Social Care, 2021). More than half of carers of older people in England are looking after a parent or parent-in-law outside the home (Brimblecombe et al., 2018). Two-thirds of these extra-residential carers are also in paid employment. Considering age, individuals from ethnic minorities are more likely than the white population to care for family members, and this notably includes the likelihood of caring for at least 20 hours per week (56% of ethnic minority populations compared to 47% of the white population) (Carers UK, 2019).

As the demand for care grows with population ageing, the supply of both unpaid and paid-for care is failing to keep pace in many countries (Brimblecombe et al., 2018). Recent projections estimate that the number of people in the UK aged 85 and over in need of unpaid care will more than double between 2015 and 2035 (Brimblecombe et al., 2018, Kingston et al., 2022). However, if the current proportions of unpaid carers remain the same, there will be a shortfall of 2.3 million carers in the UK by 2035 (Brimblecombe et al., 2018). Given the high and growing concentrations of older carers and carers of older people, the importance of understanding the impacts of unpaid care amongst these groups has never been more apparent. This understanding is an essential first step to support carers and address any increased risks for adverse outcomes.

Cohort studies are a major investment of time, resources and energy for researchers and participants. They are also a valuable source of information on unpaid care, with the potential to follow the course of caring and its impact over time. In this study, we 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. Specifically, our goals were to: 1) describe studies of the sociodemographic characteristics, health status and economic activity of carers of older people and older carers; 2) identify evidence of specific subgroups who may be at higher risk of adverse impacts; 3) identify evidence on how consequences of caring vary by socioeconomic status or area-level disadvantage; and 4) 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.

## METHODS

Scoping review methods were adopted for this study as they permit an efficient and transparent mapping of the evidence and identifying gaps for a given topic of research (Arksey & O'Malley, 2005, Peters et al., 2015). Our methods are reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al., 2018).

## SEARCH STRATEGY

Given the volume of nationally representative datasets and cohort studies in the UK (Moore & Hanratty, 2013, UK Research and Innovation, 2022), our search strategy sought to leverage these existing sources in which data on unpaid carers may be routinely collected and analysed. To this end, two published collections were used to generate an initial list of UK cohort studies (Moore & Hanratty, 2013; UK Research and Innovation, 2022). Each cohort study was then assessed to determine whether data about unpaid carers were collected. Websites for eligible cohort studies were searched by two researchers to identify publications containing any of the following keywords: "unpaid" "carer" "caring" "informal" "support" and "assistance". See supplemental materials for a flowchart for assessment of eligible UK cohort studies and a list of those deemed eligible. Eligible publications identified were then used to inform a targeted bibliographic database search with input from an information specialist. We searched three databases, adapting search strings for each as appropriate: 1) 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; 2) APA PsycInfo 1987 to March Week 3 2022; and 3) CINAHL, 30th March 2022. Search strings applied to Medline are available as supplemental material. Results were managed using Endnote 20 (The Endnote Team, 2013).

## **REVIEW CRITERIA**

Table 1 summarises the review criteria. Published works, including grey literature, were eligible for inclusion if published between January 2000 and March 2022 to

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., 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.		

Table 1 Review criteria.

prioritise retrieval of the most contemporary information about carer populations. We included studies of older people and older carers, defined as aged 50 and over. Publications were included if they reported no age but described the study population as older, if the average or majority age of the study population was 50 or older, or if data about older people were reported separately.

#### STUDY SELECTION

Records were managed using Rayyan, an online platform to facilitate screening for systematic reviews (Ouzzani et al., 2016). Titles and abstracts were first screened for relevance; full texts of selected records were subsequently assessed against the review criteria. Both stages of selection were conducted by two researchers independently and conflicts were resolved through discussion with a third researcher.

#### DATA EXTRACTION AND SYNTHESIS

Studies included for analysis were charted using Evidence for Policy and Practice Information (EPPI) Reviewer, a web-based programme for managing and analysing data in reviews (Thomas et al., 2010). Studies were charted by three researchers to identify: 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 subgroup analysis; and any stratification of findings by area deprivation or socioeconomic status. Interactive maps of evidence were then developed using EPPI Mapper (Thomas et al., 2010). Data for studies assessing the association between caring and relevant outcomes were extracted in Microsoft Excel and summarised using a narrative synthesis.

#### QUALITY ASSESSMENT

A quality assessment was not conducted in this study for two reasons. First, as per scoping review methods, our aim was to provide an overview of the existing evidence rather than a critically appraised and synthesised summary (Arksey & O'Malley, 2005, Peters et al., 2015). Second, UK cohort datasets are similar in design and measures, and are typically subject to the same types of limitations. Thus, a quality assessment would have offered little scope to differentiate studies based on sources of methodological bias.

## RESULTS

A total of 85 studies met our review criteria (Figure 1) (Age UK, 2017; Atkinson et al., 2007; Becker & Boreham, 2009; Bell & Rutherford, 2012; Bennett et al., 2020a; Bennett et al., 2020b; Bennett et al., 2020c; Benson et al., 2017; Bom & Stockel, 2021; Burchardt et al., 2021; Buyck et al., 2013; Carr et al., 2018; Carrino et al., 2021; Centre for Ageing Better, 2021; Chan, 2008; Chanfreau & Goisis, 2021; Della Giusta & Jewell, 2014; Di Gessa et al., 2022; Doebler et al., 2017; Evandrou & Glaser, 2002; Evandrou & Glaser, 2003; Evandrou et al., 2002; Evandrou et al., 2015; Evandrou et al., 2016; Gallagher & Wetherell, 2020; Garcia-Castro et al., 2022; Glaser et al., 2006; Glaser et al., 2008; Gomez-Leon et al., 2017; Grande et al., 2018; Gush, 2013; Hanratty et al., 2007; Harris et al., 2020; Henz, 2021; Hirst & Hutton, 2001; Hirst, 2002; Hodiamont et al., 2019; Hutton & Hirst, 2000; Jopling, 2016; Kaschowitz & Brandt, 2017; King & Pickard, 2013; King et al., 2014; Kinnear et al., 2010; Kneale & French, 2018; Lacey et al., 2018a; Lacey et al., 2018b; Lloyd, 2020; Matthews & Nazroo, 2021; Maun et al., 2020; McGarrigle et al., 2018; McMunn et al., 2009; McMunn et al., 2020; Mentzakis et al., 2009; Moriarty et al., 2015; Mortensen et al., 2018a; Mortensen et al., 2018b; Mortensen et al., 2019; MRC Study of Cognitive Function & Ageing, 2000; Netuveli et al., 2006; O'Reilly et al., 2008; Petrie & Kirkup, 2018; Price et al., 2016; Quashie et al., 2022; Rafnsson et al., 2017; Ramsay et al., 2013; Robards et al., 2015; Rutherford & Bowes, 2014; Saadi et al., 2021; Sacco et al., 2021; Shaw et al., 2017; Shiue, 2017; Sin et al., 2021; Smith et al., 2020; Stafford & Kuh, 2018; Stafford et al., 2017; Storey et al., 2019; Storey, 2020; Tseliou et al., 2018; Vlachantoni et al., 2019; Vlachantoni et al., 2020; Vlachantoni, 2010; Wellard & Iparraguirre, 2013; Yeandle & Buckner, 2017; Yuan & Gruhn, 2021; Zaninotto et al., 2021). Almost half (47%) of the studies were published between 2015 and 2020. Data sources for published analyses were typically the British Household Panel Survey/ Understanding Society (Institute for Social and Economic Research, 2022), the English Longitudinal Study of Ageing (ELSA) (Zaninotto & Steptoe, 2019), and UK census data (Office for National Statistics, 2022). Around a quarter of the studies reported only descriptive information on carer populations, and another quarter reported evidence about links to caring (e.g. predictors of providing unpaid



Figure 1 Preferred Reporting Items for Systematic Reviews and Meta- Analyses (PRISMA) flow chart.

care). A majority (n = 48) of studies reported outcomes associated with caring. Links to interactive evidence maps are available in supplemental materials. The sections below present findings in accordance with the four aims that guided this review.

## EVIDENCE ABOUT THE SOCIODEMOGRAPHIC CHARACTERISTICS, HEALTH STATUS AND ECONOMIC ACTIVITY OF CARERS OF OLDER PEOPLE AND OLDER CARERS

Table 2 summarises the data attributes of included studies. Most studies reported evidence about older carers. Studies of older carers did not typically report the care recipient's age, but were usually described as adults when reported. In a minority of studies, older carers were supporting both children and adults, or children alone. All studies reported descriptive, demographic data about carers. Most commonly, demographic information on carers concerned their age, gender, and health status. Roughly half of studies reported information about the carers' employment status or social class and just over half reported other characteristics such as their marital status or parental status.

## EVIDENCE ABOUT SUBGROUPS OF CAREGIVER/ RECIPIENTS WHO MAY BE AT HIGHER RISK OF ADVERSE IMPACTS

Subgroup analyses were reported in fewer than half of the studies (Bom & Stockel, 2021; Burchardt et al., 2021; Buyck et al., 2013; Carr et al., 2018; Chanfreau & Goisis, 2021; Della Giusta & Jewell, 2014; Doebler et al., 2017; Garcia-Castro et al., 2022; Glaser et al., 2006; Gomez-Leon et al., 2017; Grande et al., 2018; Hanratty et al., 2007; Harris et al., 2020; Henz, 2021; Hodiamont et al., 2019; Kaschowitz & Brandt, 2017; King & Pickard, 2013; Lacey et al., 2018a; Lacey et al., 2018b; Lloyd, 2020; Maun et al., 2020; McMunn et al., 2009; Moriarty et al., 2015; Mortensen et al., 2019; O'Reilly et al., 2008; Rafnsson et al., 2017; Ramsay et al., 2013; Saadi et al., 2021; Shaw et al., 2017; Yeandle & Buckner, 2017). Analyses to assess

STUDY CHARACTERISTIC	NUMBER OF STUDIES						
Reports data about:							
Population <sup>1</sup>	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	Age	54					
In relation to carers <sup>1</sup>	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 subgroup analysis	33					
	Stratified by socioeconomic status	5					

Table 2 Summary of included studies.

<sup>1</sup>Not mutually exclusive where studies used multiple populations and outcomes.

the impact of caring in population subgroups included sample stratification, sensitivity analyses, and moderation analyses (interaction terms). The population subgroups explored were mainly based on sex and age, and to a lesser extent, relationship to the care recipient, parent or sibling status, depression, care intensity level (e.g. hours of caring week), and location of the care recipient (coresident, extra-household, or in an institution). The results of these subgroup analyses are further described below.

## EVIDENCE ABOUT HOW THE CONSEQUENCES OF CARING VARY BY SOCIOECONOMIC STATUS OR AREA LEVEL DISADVANTAGE

Five studies reported evidence stratified by area deprivation or socioeconomic status (Hanratty et al., 2007; Henz, 2021; Jopling, 2016; Lacey et al., 2018a; Mortensen et al., 2019). Of these studies, only three reported evidence about the impact of caring. Impacts of caring were health-related, pertaining to overall health stratified

by area deprivation (Hanratty et al., 2007), cortisol levels stratified by employment status (Mortensen et al., 2019), and adiposity markers stratified by employment status (Lacey et al., 2018a). The health-related outcomes reported by these studies are described below.

## EVIDENCE ABOUT ASSOCIATIONS BETWEEN CARING FOR AN OLDER PERSON (OR BEING AN OLDER CARER) AND THE HEALTH, QUALITY OF LIFE, SOCIOECONOMIC AND SOCIAL WELL-BEING OF CARERS

Table 3 summarises studies reporting the impact of caring. For most of these studies, outcomes were health-related. Fewer studies reported evidence about the socioeconomic, disability, quality of life, or social impacts of caring. Though all of the studies were observational in design and just over half included a longitudinal analysis, they have been used to propose a hypothesis about the impact caring.

STUDY AUTHOR	YEAR	POPULATION	MEASURE OF UNPAID CARE <sup>1</sup>	INCLUDES LONGITUDINAL ANALYSIS?	OUTCOMES
Benson	2017	Older carers	Carer status	Yes	Health, disability
Bom	2021	Both	Carer status, caring amount	Yes	Health
Buyck	2013	Older carers	Carer status	Yes	Health
Carr	2018	Both	Carer status, caring amount	Yes	Socioeconomic
Chanfreau	2021	Carers of older people	Carer status	No	Health
Della Giusta	2014	Carers of older people	Carer status, caring amount	Yes	Quality of life
Doebler	2017	Both	Carer status, caring amount	Yes	Health
Evandrou	2003	Older carers	Carer status	No	Socioeconomic
Gallagher	2020	Older carers	Carer status	No	Health, social
Garcia-Castro	2022	Older carers	Carer status	Yes	Health, disability
Glaser	2006	Older carers	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	Carers of older people	Carer status	No	Socioeconomic
Hanratty	2007	Older carers	Carer status, caring amount	No	Health, socioeconomic
Harris	2020	Older carers	Carer status, caring amount	No	Health, socioeconomic
Hirst	2001	Both	Carer status, caring amount	Yes	Socioeconomic
Hodiamont	2019	Older carers	Carer status, caring amount	No	Health
Hutton	2000	Both	Carer status, caring amount	Yes	Socioeconomic
Jopling	2016	Older carers	Carer status, caring amount	No	Socioeconomic
Kaschowitz	2017	Older carers	Carer status	Yes	Health
King	2013	Both	Carer status, caring amount	Yes	Socioeconomic
Kinnear	2010	Older carers	Carer status, caring amount	No	Health
Lacey	2018	Older carers	Carer status, caring amount	Yes	Health
Lacey	2018	Older carers	Carer status, caring amount	Yes	Health
Maun	2018	Older carers	Carer status, caring amount	Yes	Health
McGarrigle	2020	Older carers	Carer status, caring amount	No	Health, quality of life
McMunn	2009	Older carers	Carer status	No	Health, quality of life
Moriarty	2015	Older carers	Carer status, caring amount	Yes	Health
Mortensen	2018	Older carers	Carer status, caring amount	Yes	Health
Mortensen	2018	Older carers	Carer status, caring amount	Yes	Health
Mortensen	2019	Older carers	Carer status, caring amount	No	Health
MRC CFAS Study Group	2000	Carers of older people	Carer status	Yes	Health
Netuvelli	2006	Older carers	Carer status	No	Quality of life
O'Reilly	2008	Older carers	Carer status, caring amount	Yes	Health
Rafnsson	2017	Both	Carer status	Yes	Health, quality of life
Ramsay	2013	Older carers	Carer status, caring amount	Yes	Health
Saadi	2021	Both	Carer status	Yes	Health, social
Shaw	2017	Older carers	Carer status	No	Health
Shiue	2017	Older carers	Carer status	No	Health
Sin	2021	Older carers	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	Older carers	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	Older carers	Carer status	Yes	Health, quality of life

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

<sup>1</sup>Carer status indicates providing/not providing unpaid care; caring amount indicates time spent caring (e.g. hours per week).

### Caring and health outcomes Overall health

Caring status alone was not consistently linked to poorer self-rated health (Harris et al., 2020; Vlachantoni, 2010; Vlachantoni et al., 2020), however poorer self-rated health was associated with greater intensity of caring (Harris et al., 2020; Vlachantoni, 2010). One study found that disadvantaged areas saw higher proportions of carers in poor health and caring at high intensities compared to more affluent areas (Hanratty et al., 2007). Three studies (Benson et al., 2017; O'Reilly et al., 2008; Tseliou et al., 2018) found a lower risk of mortality among carers compared to non-carers. One study (Garcia-Castro et al., 2022) reported an association between caring and lower rates of multiple long-term conditions.

#### Cognitive and mental health

Two studies reported that carers exhibited better memory and verbal fluency compared to non-carers (Garcia-Castro et al., 2022; Yuan & Gruhn 2021). With regards to mental health and loneliness, the impact of caring was inconsistent across studies and varied by carer attributes (Benson et al., 2017; Bom & Stockel, 2021; Chanfreau & Goisis, 2021; Doebler et al., 2017; Gallagher & Wetherell, 2020; Grande et al., 2018; Harris et al., 2020; Hodiamont et al., 2019; Kaschowitz & Brandt, 2017; McGarrigle et al., 2018; McMunn et al., 2009; Moriarty et al., 2015; Rafnsson et al., 2017; Saadi et al., 2021; Shiue, 2017; Sin et al., 2021; Smith et al., 2020; Storey et al., 2019; Vlachantoni et al., 2020). For instance, one study (Mortensen et al., 2019) found that male carers in paid work experienced a more blunted cortisol awakening response than non-carers, an indicator associated with chronic stress; however, female carers in paid work showed a steeper cortisol slope than non-carers, an indicator of healthy cortisol awakening response and thus suggesting a positive effect of caring on stress levels. Another study (Sin et al., 2021) found that mental wellbeing was worse for those caring for a partner compared to caring for a parent, single carers compared to those with a partner, and those caring over 35 hours per week.

### Specific conditions or symptoms

Associations were reported between caring and cardiovascular disease among those already in poor health and those providing high-intensity care (Buyck et al., 2013; Mortensen et al., 2018b); caring and regional pain among women caring for 20 hours or more per week (Harris et al., 2020); caring and chronic obstructive pulmonary disease among men caring for 20 hours or more per week (Harris et al., 2020); caring and chronic obstructive on the per week (Harris et al., 2020); caring and chronic obstructive pulmonary disease among men caring for 20 hours or more per week (Harris et al., 2020); caring and higher cholesterol among men (Lacey et al., 2018b); caring and elevated body mass index among full-time working women over age 65 (Lacey et al., 2018a); and caring and type 2 diabetes among carers with low social support at work (Mortensen et al., 2018a).

#### Disabilities

Few studies reported on disability outcomes, and associations with caring were inconsistent (Benson et al., 2017; Garcia-Castro et al., 2022; Tseliou et al., 2018).

## Caring and quality of life and social wellbeing outcomes

There was an association between caring, particularly at greater intensities, and poor quality of life (Della Giusta & Jewell, 2014; McGarrigle et al., 2018; Netuveli et al., 2006) or declining quality of life over time (Rafnsson et al., 2017; Yuan & Gruhn, 2021). However, this association was moderated by carers' relationship to the care recipient, participation in social activities, and access to formal care services (McGarrigle et al., 2018; McMunn et al., 2009; Vlachantoni et al., 2020). Life satisfaction was lower for female carers but higher for male co-residential carers, compared to non-carers (Della Giusta & Jewell, 2014). Evidence about the association between caring and social participation was inconsistent (Smith et al., 2020).

#### Caring and socioeconomic outcomes

Compared to non-caring populations, caring was consistently associated with leaving paid work, working fewer hours, reduced pension contributions, and smaller private and state pensions (Carr et al., 2018; Evandrou & Glaser, 2003; Gomez-Leon et al., 2017; Gush, 2013; Harris et al., 2020; Hirst & Hutton, 2001; Hutton & Hirst, 2000; Jopling, 2016; King & Pickard, 2013; Vlachantoni, 2010; Vlachantoni et al., 2019). Disproportionate effects on employment were observed among female carers, single carers, carers in poor health, carers experiencing financial difficulties, and carers in lower socioeconomic occupations (Harris et al., 2020; Hutton & Hirst, 2000; Jopling, 2016; Storey et al., 2019; Vlachantoni et al., 2019).

## DISCUSSION

Our review found that much of the existing carer evidence from UK cohort studies focuses on the health outcomes for older carers. Despite information on care recipients being reported less frequently, current and projected rates of care to older spouses suggest that many of these older carers are likely to be providing care for older people (Pickard et al., 2007). A wide range of health outcomes have been reported, often with inconsistent or contrasting conclusions. In particular, outcomes often varied by gender, employment status, or hours caring per week. However, few studies reported on other potentially relevant characteristics such as race/ethnicity, language, and sexual orientation. This reflects the data available in cohort studies, but suggests a future research agenda, to elucidate the interplay of factors impacting on carers' health. Whilst research assessing the finances and employment of older carers was limited, when they were considered, findings were consistent in identifying caring as a risk factor for adverse financial and employment consequences. Only three studies (Hanratty et al., 2007; Lacey et al., 2018a; Mortensen et al., 2019) explored how the impact of caring differed based on a measure of socioeconomic status, and outcomes were health-related in all three. Notably, these three studies leveraged data from different cohort studies and all described limitations in the availability of data points that could have strengthened the evidence presented about the impacts of caring. Future work could improve our understanding of how other consequences of caring differ between the most and least advantaged; methodological considerations are further described below.

Fewer studies reported evidence about the quality of life, disability, and social outcomes of carers. However, when reported, quality of life outcomes for carers did appear to be moderated by carer attributes and other factors. These inconsistent findings suggest that context and time are important in assessing the impact of caring.

Recent reviews assessing the broader caring evidence base have highlighted carers' increased risk for adverse health, emotional, and financial outcomes (Greenwood & Smith, 2016; Larkin et al., 2019; Spiers et al., 2021). These include higher disease prevalence, psychological stress and mental health disorders, social isolation, and reduced ability to remain in paid employment with a subsequent negative impact on pensions. However, these reviews all discussed a fragmented evidence base, conflicting findings, and a need for more robust evidence to more clearly understand the complexity of factors impacting on the outcomes of older carers.

Robust evidence about the trajectories and factors associated with negative outcomes of caring is essential to informing policy and interventions to support older carers' wellbeing. Reviews of interventions to support carers such as respite programmes, mindfulness/stress reduction education, and support groups have determined the evidence base to be weak, highlighting methodological issues and inconsistent findings about their efficacy (Garnett et al., 2022; Larkin et al., 2019; Murfield et al., 2021; Spiers et al., 2021). An enhanced understanding of who is impacted most by caring and associated risk factors will in turn support the development of policies and interventions that are appropriate and tailored to meet carers' needs.

#### STRENGTHS AND LIMITATIONS

This scoping review updates our understanding of the landscape of current evidence about carers from UK cohort studies and specifies areas in need of further research. Our focus on UK cohort studies exploits a wellestablished, robust source of evidence and ensures our conclusions are relevant to national policy, but findings may also be relevant in guiding research elsewhere. Studies published before 2000 were excluded to prioritise the most contemporary evidence about carer populations.

Our scoping review was confined to observational studies and subject to all the limitations of this approach. ELSA and UK census data, for instance, are collected every two or 10 years respectively, meaning that key milestones such as pathways into caring or outcomes of caring might be overlooked by studies using these data. Such observational designs mean that we cannot infer causation, nor can we rule out reverse causation, when considering the relationship between caring and health, social and financial outcomes. Other types of evidence such as service evaluations and qualitative investigations also offer important perspectives on older carers and carers of older people. However, previous work confirms these gaps regarding the outcomes of carers of adults (Larkin et al., 2019).

Few of the studies provided information about the care recipients of older carers, the types of support required, and the conditions in which care is provided. These gaps may be due to the availability of data on carers in cohort studies, but assessing this information and how it changes with time could provide important insights into the varying trajectories of carers. Critically, evidence about caring intensity offered a different picture to evidence about caring status alone, as greater intensity of caring was more consistently linked to poorer health outcomes. Thus, measures of caring intensity, alongside detailed information about care recipients, contexts, and conditions, may improve our understanding about the impact of caring. Whilst this work did not aim to provide a detailed analysis of the design of the cohort studies being leveraged, we recommend that future research explores these methodological issues, including suggested modifications to the data being collected in cohort studies.

Finally, whilst the majority of studies in this review were published in 2016 or later, it must be acknowledged that the COVID-19 pandemic changed the caring landscape dramatically, with approximately one third of UK adults over age 65 acquiring caring roles (Age UK, 2021). Whilst more research is needed to determine the short- and long-term implications of COVID-19 for older carers, early evidence suggests that the pandemic only served to further highlight the importance of unpaid care and to underscore the negative consequences of caring (Bennett et al., 2020a; Bennett et al., 2020b; Bennett et al., 2020c; Foley et al., 2021).

## CONCLUSION

This scoping review furthers our understanding of the evidence about carers of older people and older carers in the UK, highlighting specific conflicts and gaps in evidence regarding the social, economic, health and quality of life outcomes for carers. Future research should aim to clarify the mixed findings about the impacts of caring on health and social well-being as well as address the lack of evidence about other important outcomes such as socioeconomic, disability, and quality of life. Future work should consider the complexity of interplaying factors that may impact outcomes among a heterogeneous group. This information is vital to inform policy and ensure that carers at risk for adverse outcomes are provided adequate support to maintain their wellbeing.

## DATA ACCESSIBILITY STATEMENT

All data analysed in this review are contained in the manuscript and its supporting information.

## ADDITIONAL FILES

The additional files for this article can be found as follows:

- Supplemental File 1. Flowchart for assessment of eligible UK cohort studies. DOI: https://doi. org/10.31389/jltc.207.s1
- **Supplemental File 2.** Eligible cohort studies. DOI: https://doi.org/10.31389/jltc.207.s2
- **Supplemental File 3.** Search applied in MEDLINE. DOI: https://doi.org/10.31389/jltc.207.s3
- Supplemental File 4. Links to EPPI maps. https:// eppi.ioe.ac.uk/cms/Portals/35/Maps/NIHRPRU/2C\_ Studies%20by%20SES\_final.html, https://eppi.ioe. ac.uk/cms/Portals/35/Maps/NIHRPRU/2B\_Studies%20 by%20subgroup%20analysis\_final.html, https:// eppi.ioe.ac.uk/cms/Portals/35/Maps/NIHRPRU/2A\_ Studies%20by%20type%20of%20evidence\_final.html

## DISCLAIMER

The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

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## **COMPETING INTERESTS**

The authors have no competing interests to declare.

## **AUTHOR CONTRIBUTORS**

Melanie Stowell participated in the data extraction, analysis, interpretation of data, and drafting of the manuscript.

Gemma Frances Spiers participated in the study conception and design, data extraction, analysis and interpretation of data, drafting of the manuscript, critical revision of the manuscript and provided administrative, technical support and overall supervision of the study.

Patience Kunonga participated in the data extraction, analysis, interpretation of data, and critical revision of the manuscript.

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Barbara Hanratty participated in the study conception and design, provided critical scientific input, drafting of the manuscript, and critical revision of the manuscript.

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