



REVIEW ARTICLE

The cost of caring: a scoping review of qualitative evidence on the financial wellbeing implications of unpaid care to older adults

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Abstract

Growing numbers of people help and support family members, friends or others due to long-term health problems, disability or older age-related needs. While care-giving can bring fulfilment and meaning to peoples' lives, it can negatively affect individuals' financial wellbeing. Much of the evidence in this area is quantitative, while the subjective, in-depth experience of how unpaid care decisions affect financial wellbeing remains relatively under-explored. This scoping review explores what is known about how unpaid carers experience and understand the financial consequences of providing care. It identified 35 studies containing qualitative evidence and, through thematic analysis, identified four overarching themes: (1) direct and indirect costs of caring; (2) social, cultural and institutional care and work decision-making; (3) the unequal cost of caring; and (4) personal finance and carer wellbeing. Findings indicate that unpaid caring affects financial wellbeing in multiple, overlapping ways. The financial consequences are experienced unequally, with systems, circumstances and contexts serving to exacerbate or reduce these negative effects. Crucially, our analysis reveals the paucity of qualitative research specifically focused on unpaid carers' financial wellbeing. There is a significant gap in the literature regarding whether, and how, individuals understand the future financial implications of unpaid care-giving, or whether longer-term financial consequences are considered when making decisions about care. Future research designed to address this gap, with greater emphasis on the personal, social and structural influences on care-related financial decision-making, could offer important insights for developing policies and practices aimed at improving the financial wellbeing of carers as they age.

Keywords: unpaid care; informal care; financial wellbeing; economic costs; financial security; older adults

Introduction

Unpaid care and financial wellbeing

Unpaid care (sometimes referred to as informal care) is typically defined as providing help and support to a family member, friend, neighbour or others due to long-term

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health problems, disability or needs related to older age (Kelly and Kenny 2018). It has been estimated that there are around 10 million to 12 million unpaid carers in the United Kingdom (Carers Week 2023; Petrillo et al. 2022; Zhang et al. 2019) with the peak age for caring being 55–64 years (ONS 2023; Zhang et al. 2019). The contribution of unpaid carers to our system of care is estimated to be worth £162 billion per year in England and Wales (Petrillo and Bennett 2023) and £5.8 billion per year in Northern Ireland (Zhang et al. 2023), which is more than the value of the National Health Service (NHS). As populations age and fiscal pressures on care systems continue to impact on eligibility levels (Age UK 2019; Baxter et al. 2020; Glasby et al. 2020), the intensity of care is increasing (Office for National Statistics (ONS) 2023; Petrillo and Bennett 2023; Zhang et al. 2023). Moreover, the proportion of the population in the UK who pay for care in later life using their own resources (self-funders) is also increasing; the retrenchment of public provision has knock-on effects for self-funders as well as for those who care for older and disabled people (Bayliss and Gideon 2020; Tanner et al. 2024).

A growing body of quantitative evidence indicates that providing unpaid care is associated with negative employment and income outcomes (Carr et al. 2018; Evandrou and Glaser 2003; Jacobs et al. 2019; Longacre et al. 2017; Petrillo et al. 2022; Yeandle and Buckner 2017) with carers being more likely to suffer from ill health and stress (Magaña et al. 2020; Pinguart and Sörensen, 2003; Stanfors and Jacobs 2023; Vitaliano et al. 2003; Zhang and Bennett 2023; Zhang et al. 2021) and to be forced into early retirement than those who do not provide unpaid care (Petrillo et al. 2022; Szinovacz and Davey 2005). Quantitative evidence also shows that carers are more likely to fall into the ‘underpensioned’ category (Wilkinson et al. 2022), with women more likely to reduce their hours or leave the labour market prematurely (Gomez-Leon et al. 2019; Petrillo et al. 2022). Carers in general are also more likely to be living in poverty (Joseph Rowntree Foundation 2022), especially those with significant caring responsibilities (*e.g.* those providing more than 35 hours of unpaid care per week). Combined, these consequences are likely to have a significant impact on individuals’ financial security in later life.

Although this evidence is helpful in measuring the extent of the problem and identifying what the material consequences are, we know relatively little about the financial lives of unpaid carers from a more subjective, in-depth perspective, and how caring shapes and influences carers’ overall sense of financial wellbeing. Given this gap, we sought to establish the existing international qualitative evidence on the financial wellbeing implications of providing unpaid care. More specifically, we asked:

- What is known from the literature about how unpaid carers experience and understand the financial consequences of providing unpaid care?
- What are the gaps in the existing literature that future research on the financial wellbeing of unpaid carers might address?

While there is still no agreed-upon definition of financial wellbeing, there has been a shift in recent years from assessing it in objective terms (*i.e.* by considering a person’s income, assets, savings and housing wealth) to giving greater attention to the subjective, perceived nature of this concept (Netemeyer et al. 2018; Riitsalu et al. 2023; Riitsalu and

Van Raaij 2022; Warmath 2021). Two of the most commonly used definitions in academic and grey literature encompass this broader conceptualisation, taking account of objective and subjective components, a present and future component, and/or incorporating both financial security and stress or anxiety. For example, Brügger et al. (2017, 229) define financial wellbeing as ‘the perception of being able to sustain current and anticipated desired living standards and financial freedom’, while the Consumer Financial Protection Bureau (CFPB 2015, 5) states that ‘financial well-being is a state of being wherein you have control over day-to-day, month-to-month finances; have the capacity to absorb a financial shock; are on track to meet your financial goals; and have the financial freedom to make the choices that allow you to enjoy life’. The importance of understanding financial wellbeing in the context of unpaid care, and indeed more broadly, is that it is recognised as being important to wellbeing on an individual, societal and global level (Bashir and Qureshi 2023) and might even have a greater influence on a person’s overall wellbeing than factors such as health, relationships and job satisfaction (Netemeyer et al. 2018).

Existing research on the wider wellbeing implications of unpaid care-giving (e.g. Magnaye et al. 2020, 215) suggests that carers’ health and wellbeing would benefit from ‘a shift from understanding the needs of caregivers that focus on their immediate care responsibilities to a more holistic understanding of their goals that span multiple domains of family caregivers’ lives’. Furthermore, Keating et al. (2021) established a wellbeing framework highlighting three components of care-giver wellbeing, arguing that improving the wellbeing of carers is essential to achieving a sustainable care system. They suggest that public policy should support family carers to achieve relational wellbeing (supportive connections needed to ‘be well’), subjective wellbeing (self-evaluation of caring work and personal goals) and material wellbeing (financial consequences of care-giving). Keating et al. (2014) conducted a scoping review to identify the personal financial consequences of providing unpaid care and developed a taxonomy of economic costs with three key domains: out-of-pocket expenses (reducing the ability to meet expenses and to save); care labour (resulting in lost personal benefit from time spent caring); and employment restrictions (meaning reduced income, benefits and pension). This review builds, in the findings it presents, on these three domains of care-related economic costs and takes Keating et al.’s (2014) study as its starting point, reviewing literature post 2014. This date is also significant from the perspective of the Care Act in England and Wales, which drew attention to the wellbeing of carers living in the United Kingdom.

Method

Scoping review framework

We conducted a scoping review to map existing evidence relating to the economic costs and financial wellbeing implications of providing unpaid care to older adults. Specifically, we aimed to identify and synthesise the qualitative, empirical evidence on this topic, as our interest lies in understanding how the subjective experiences and perspectives of unpaid carers are understood.

The review was conducted using the methodological framework outlined by Arksey and O’Malley (2005, 21) which aims to ‘examine the extent, range and nature of

Table 1. Search terms

Carer terms	Cost terms (AND)	Cost terms (OR)	Care recipient terms (AND)
Caregiver	Cost	Savings	Old*[older adults/old age]
Carer	Economic [burden/cost/wellbeing]	Income	Elder*
Unpaid car*	Financ* to capture:	Employment	'Later life'
Informal car*	Financial wellbeing	Expense*	dementia
Working carer*	Financial wellness	Pension	Alzheimer's
Family car*	Financial (in)security	Labour/labor market	NOT child*

*denotes where truncation was used to broaden the search and include variants of words.

research activity' and identify gaps in the existing literature. This approach comprises five stages: (1) identifying the research question, (2) identifying relevant studies, (3) selecting studies, (4) charting the data, (5) collating, summarising and reporting the results.

Our research questions (Stage 1) were developed based on our existing understanding of the limited qualitative evidence on this topic and refined through discussions within the research team. In the context of ageing populations and the subsequent effects on the supply and demand of care (World Health Organization 2015), we focused on the financial wellbeing of those providing unpaid care to older adults rather than those engaged in unpaid childcare. The final search for published research and grey literature was carried out in December 2022 using the following databases: Applied Social Sciences Index & Abstracts (ASSIA); Social Sciences Citation Index; Social Policy & Practice; APA PsycINFO. This search was supplemented with manual reviews of reference lists, searching key journals and identifying publications from relevant organisations. Table 1 shows the search terms used in the search. The final search string used was (caregiver OR carer OR 'unpaid car*' OR 'informal car*' OR 'working car*' OR 'family car*') AND (cost OR economic OR financ*) AND (old* OR 'later life' OR dementia OR Alzheimer's) NOT (child*) OR (savings) OR (income) OR (employment) OR (expense*) OR (pension) OR ('labour market' OR 'labor market'). A Web of Science search alert was also set from January to December 2023, ensuring that we were notified of any new articles meeting the relevant criteria.

Articles were included if they met the criteria similar to those outlined in Keating et al.'s (2014) review: (1) the unit of analysis was informal carers/family members; (2) examined care tasks and services were provided because of the recipient's long-term health condition or disability or needs related to older age; and (3) the study addressed care-giver outcomes with implications for the care-giver's income or expenditures that are directly related to occupying a care-giver role. In order to build on Keating et al.'s (2014) seminal work, the search included manuscripts published after 2014 and our focus was on qualitative evidence. International articles were included in the search as there is an increasing reliance on unpaid care-giving to support long-term care systems globally (Costa-Font and Zigante 2020; Kodate and Timonen 2017; McFarlane and Turvey 2017; Spasova et al. 2018), although the articles included were limited to those published in English.

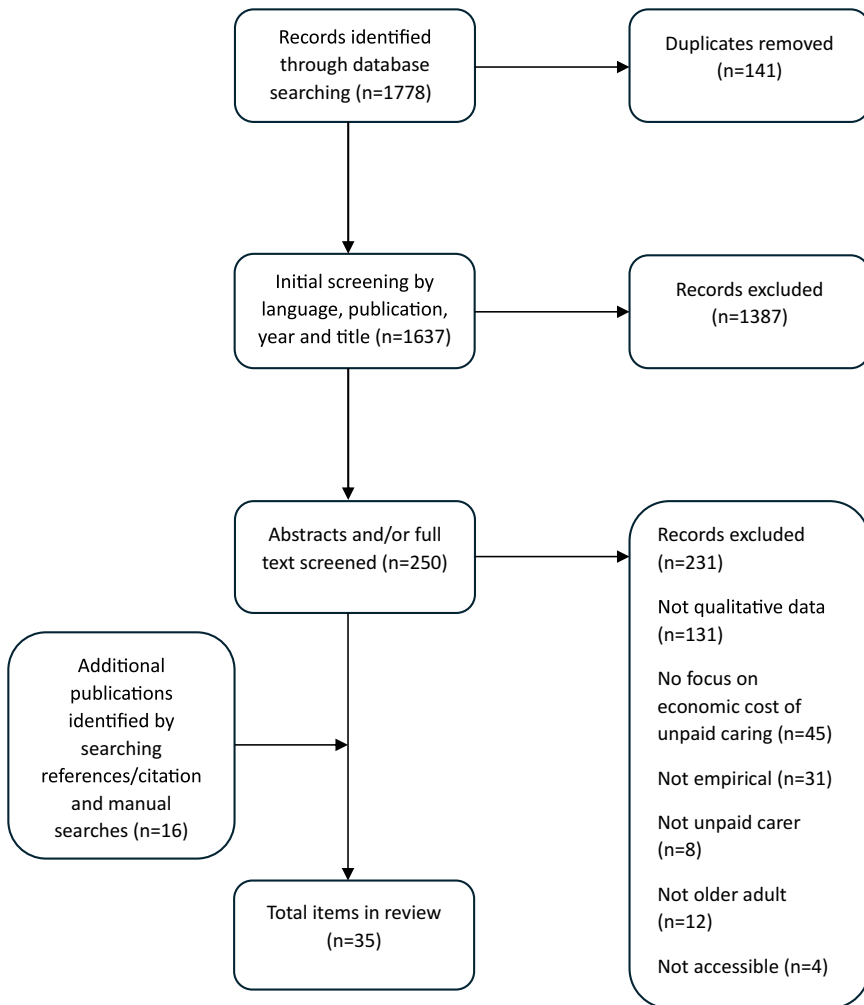


Figure 1. Flow chart showing screening process.

The initial search of the databases produced 1,778 articles. Stage 3 of the scoping review included the screening process outlined in Figure 1. After duplicates were removed, the remaining 1,637 articles were screened by language, year of publication and title. We then carefully checked all citations of the remaining articles and excluded those with irrelevant titles; those published prior to 2014 and those written in a language other than English. This process resulted in the removal of a further 1,387 articles. Abstracts of the remaining 250 articles were reviewed by the authors, and articles with most relevance to the research question were read in full. Exclusions were made according to further criteria outlined in Table 2. Literature reviews were also included if they met the aforementioned inclusion criteria. We subsequently checked the reference lists of the remaining articles and citation searches were carried out. This

Table 2. Inclusion and exclusion criteria

Criteria	Include if...	Exclude if...
Language	English language	In another language
Publication year	2014–present	Pre 2014
Publication type	Peer reviewed research report, PhD thesis, key voluntary organisation research report	Book chapter, book review, magazine article
Article type	Empirical data research findings, review of empirical research	Book review, opinion piece, article with no empirical data
Methods	Includes qualitative research design (e.g. phenomenology, grounded theory, ethnography, narrative inquiry, interviews, observations)	Solely quantitative research design
Population group	Unpaid carers (adults who support a family member, friend or neighbour due to long-term health problems, disability or needs related to old age)	Data relate to care of a child
Subject of evidence	A substantial component of the data relates to the economic cost of unpaid/family care given to older adults; provides synthesized themes or statements with supporting quotes	Economic costs to informal care-givers was not discussed (e.g. articles with a focus only on health or social consequences of care-giving) or the focus is about pragmatic challenges of combining work and care, rather than the cost of reduced labour participation
Accessibility	Full text is accessible	Full text is not accessible

process produced a total of 35 articles to be included in this review. Study designs included qualitative approaches ($n = 31$), mixed methods ($n = 2$) and qualitative literature reviews ($n = 2$).

We charted the final studies (Stage 4) by providing an overview of each study on an Excel spreadsheet. [Table 3](#) provides a summary of the key characteristics and research aims of the studies included in the current scoping review. The final stage of the scoping review (Stage 5) involved bringing the final studies together and reporting the findings. We used NVivo qualitative analysis software to support a thematic analysis (Braun and Clarke 2006) of the literature and to answer our research questions in a robust and systematic way. Data contained in the studies were examined in depth and codes were then generated and refined by the authors through reviewing, note-taking and subsequent discussions. This approach enabled us to consider the existing literature in relation to subjective notions of financial wellbeing (Brüggen et al. 2017; Riitsalu et al. 2023) as well as the material costs associated with care-giving.

Findings

The results of this review are reported according to four overarching themes. First, we outline the direct and indirect costs of providing unpaid care. Second, we explore the

Table 3. Simplified table of results

Publication	Location	Aim	Data collection and analysis method	Sample	Findings relating to financial wellbeing
1 Aimamani et al. (2020)	Uganda	To explore the burden of care and the experiences of formal and informal carers of people living with Alzheimer's and other related diseases	Interviews with informal care-givers in local language until thematic saturation achieved and translated to English; thematic analysis	10 informal care-givers, 5 formal care-givers	Out-of-pocket expenses, labour withdrawal
2 Alzheimer's Research UK (2015)	United Kingdom	To understand both the experience of providing full-time care for a loved one with dementia and the relationship between a person with dementia and their carer	Researcher spent a day with each family observing them as they cared for loved ones; carers also completed a care diary for one week; thematic analysis	Family carers for people with dementia	Direct costs, missed work opportunities, financial strain
3 Balfe et al. (2016)	Republic of Ireland	To explore the overall financial impact of head and neck cancer on care-givers (average age of care recipient: early to mid-60s)	Telephone interviews (semi-structured); thematic analysis	31 care-givers – 28 were spouse/partner, 3 were other relationships	Indirect costs, influences on labour market participation, inequalities in economic costs, carer wellbeing
4 Bijnsdorp et al. (2021)	Netherlands	To provide insight into experiences of combining paid work and family care for patients at the end of life	Semi-structured interviews (first round of interviews); thematic analysis	18 family care-givers	Supportive workplace, attitudes to paying for care
5 Bower et al. (2020)	United States	To understand the challenges low-income women face and the resiliencies they form to cope with the demands of care-giving	Semi-structured interviews; thematic analysis	10 low-income African American women (mothers and adult daughters)	Labour withdrawal, workplace environment, gendered expectations, current finances, financial strain

6	Brémault-Phillips et al. (2016)	Canada – Edmonton	To hear the voices of family care-givers of older adults	Three 2-hour focus groups; thematic analysis	23 family care-givers of persons with complex needs attended the focus groups, each of which was composed of 7–8 care-givers	Labour with/drawal, risk factors/financial strain
7	Carden (2020)	United States	To understand and describe the lived experience of women in a dementia care-giving role in relation to financial stress, coping and decision-making	Semi-structured interviews; grounded theory – constant comparison of data	Primary care-givers (women, spousal) who provide assistance with financial management and decision-making	Direct costs, cultural expectations, stress, carer wellbeing, support needs
8	Carers Trust (2016)	England	To increase knowledge of older carers' needs and consider what actions might help them and other potential carers to plan in the future	Six focus groups; analysis methods not stated	92 carers in total participated, aged between 60 and 88, with diverse backgrounds including Black, Asian and minority ethnic groups	Direct costs
9	Carers UK (2022)	United Kingdom	To provide a snapshot of carers' experiences, exploring the impact that caring has on carers' lives	Online survey – including the opportunity to write freely in response to open questions; thematic analysis	13,415 carers and former carers responded from diverse populations across the UK	Direct costs, loss of income, care recipient preferences, supportive workplace, work skills, access to care, isolation, stress, needing financial support
10	Corvin et al. (2017)	United States – Tampa Bay	To explore the influence of care-giving on those who provide support to partners, family members and/or friends coping with co-morbid chronic illness related to old age and depression	4 focus groups; analysis methods not stated	17 individuals who self-identify as Latino who assisted with care	Lost income, multiple caring responsibilities, accessing appropriate care

11	Gibson et al. (2019)	United States – Midwest	To understand caregivers' perceptions of knowledge, access and internet-related caregiving services for rural dementia care-givers	Semi-structured interviews; thematic analysis	11 participants from Ohio and Kentucky	Worries about finances
12	Cohen et al. (2019)	Mexico	To explore the experiences of informal care-givers regarding the dynamics of care for dependent older adults	Semi-structured interviews; thematic analysis	48 participants who were care-givers of older adults (aged 60+)	Labour market withdrawal, no social life
13	Gott et al. (2015)	New Zealand	To explore the nature and range of financial costs incurred by whānau (family) care-givers within a palliative care context	Semi-structured interviews; narrative analysis	30 participants (non-Maori and Maori)	Direct and indirect costs, care recipient preferences, gendered and cultural expectations about caring, multiple care-giving, current finances
14	Griffiths and Bunrayong (2016)	Thailand	To investigate the problems and needs of care-givers who help older people with dementia	Individual interviews; inductive analysis	30 participants – care-givers of older people living with dementia	Direct costs, government allowances, needing financial help
15	Han et al. (2019)	Singapore	Explores the perspectives on decision-making among older Singapore end-stage renal disease (ESRD) patients and their care-givers	Semi-structured interviews; thematic analysis	23 participants, of which 7 were care-givers (5 female, 2 male)	Duty to care, gendered expectations, access to care services
16	Herat-Gunaratne et al. (2020)	United Kingdom	To explore the experiences of South Asian family carers for people with dementia in the UK	Semi-structured interviews; inductive thematic analysis	Family care-givers; South Asian ethnicity included those who identified as Indian, Pakistani or Bangladeshi	Employment, care recipient preferences, duty to care, expectations, risk factors

17	Iwuagwu et al. (2022)	Nigeria	To explore the challenges faced by female rural older adults caring for their very old parents in Nigeria	Semi-structured interviews; content analysis	14 older adults with experience caring for an older parent aged 80+	Gendered expectations, low income
18	Jolanki (2015)	Finland	To understand how working women argue for and against their decision of working and caring for an older person	Interviews; discourse analysis	48 Finnish women	Employment income, justifying decisions around employment, sense of duty
19	Kyei-Arthur and Codjoe (2021)	Ghana	To describe care-givers' challenges and coping strategies in an urban poor context	Interviews; phenomenological analysis	31 care-givers (15 primary, 16 secondary)	Expenses, employment, gendered expectations, care-giver attitudes about cost of care
20	Lafferty et al. (2022)	Ireland	To explore family carers' experiences of altering work arrangements to accommodate care-giving responsibilities	Semi-structured interviews (face-to-face); thematic analysis	10 participants (7 women, 3 men) aged 38–65	Leaving employment, feelings of burnout, justifying care/employment decisions
21	Lee et al. (2022)	United States	To examine the relationships between economic hardship and care-giver burden	In-depth interviews; thematic analysis	33 participants completed in-depth interviews – Korean Americans	Early retirement, supportive manager, severe hardship risks
22	Lindeza et al. (2020)	International	To understand the holistic experience of caring for a person with dementia	Qualitative systematic review	81 studies in the final synthesis	Cost of formal care services, concerns about the future
23	Mahomed& Pretorius (2022)	South Africa	To explore the contextual factors that might impact the dementia family care-giving experience	In person interviews; reflexive thematic analysis	30 care-givers of a family member who has a diagnosis of dementia	Direct and indirect expenses, access to care services
24	Maynard et al. (2019).	Canada	To understand the specific challenges that male working carers experience regarding social life and paid work	Each participant took part in two interviews; thematic analysis	8 men combining paid work and care	Missed promotions at work, flexible working

25	Mehta and Leng (2017).	Singapore	To understand the caregiving journey on the lives of family care-givers to older persons and foreign domestic workers (FDWs)	Interviews; thematic analysis	45 participants (30 adult children, 15 FDWs)	Lost income, sense of duty
26	Nguyen et al. (2021)	Vietnam	To understand the day-to-day lived experience of family care-giving	Interviews; thematic analysis	24 participants (12 family care-givers, 12 non-family informants/professionals)	Loss of income, sense of duty, gendered expectations
27	Oliveira et al. (2020)	United Kingdom	To understand what older carers' priorities are in terms of life quality	Qualitative single open-ended question within a paper questionnaire; thematic analysis	150 carers of people with dementia	Flexible working, considering own care needs in the future, needing financial support to access formal care
28	Palacios et al. (2021)	Chile	To identify the reasons adult children caring for their parents or parents-in-law give for exiting or remaining in the workforce	Interviews; inductive thematic analysis	30 primary family carers	Supportive workplace, self-perception as lacking skills, sense of duty, gendered expectations about work and care, support from government
29	Roberts and Struckmeyer (2019).	United States	To examine how two care-givers in late-life marriages navigate the challenges of caring for a spouse with dementia	Semi-structured interviews; thematic analysis	2 female spousal care-givers	Direct and indirect costs, later-life marriage as risk, thoughts about future finances, stresses and concerns
30	Santini et al. (2016)	Sweden, the Netherlands, the Slovak Republic and Italy	To assess the impact of incontinence management on informal care-givers of older persons	Semi-structured interviews, face to face; grounded theory analysis	50 participants (male and female)	Direct and indirect costs

31	Stamatopoulos (2018).	Canada	To explore the lived realities of young people providing unpaid familial care-giving	2 focus groups and 1 in-depth interview; thematic analysis	Young carers aged 15–19, providing a minimum of 5 hours' care per week	Indirect costs – employment and education related, missed opportunities, young carers as vulnerable to future financial insecurity
32	Talley et al. (2021)	International	To critically appraise and synthesize qualitative literature on the experience of informal care-givers who are managing incontinence	Meta-aggregation of literature	7 studies included in the final review	Direct and indirect costs
33	Tawodzera (2021)	United Kingdom and Zimbabwe	Explores how Zimbabwean migrant care workers and their 'left behind' family members negotiate aged care arrangements	In-depth interviews; thematic analysis	Zimbabwean migrant care workers	Direct costs – sending remittances to family
34	Vlachantoni et al. (2021)	Great Britain	To understand what factors affect the economic activity of working, mid-life carers in Great Britain	In-depth, semi-structured interviews at age 50; thematic analysis	122 informal carers	Reasons for reducing paid employment hours
35	Zhong et al. (2022)	China – Shanghai	To explore the experiences of Chinese people caring for a person with Parkinson's disease	Participant observation and semi-structured interviews; thematic analysis	15 family care-givers	Direct costs, cultural expectations, structural stressors

Table 4. Themes and sub-themes with reference publications

Themes	Sub-themes	Reference publication
The direct and indirect costs of caring	Out-of-pocket expenses	1, 2, 7, 8, 9, 13, 14, 19, 23, 29, 30, 32, 33, 35
	Labour market participation and loss of income	1, 3, 5, 6, 9, 10, 12, 13, 16, 18, 19, 20, 21, 23, 25, 26, 29, 30, 32, 34
	Missed work opportunities	2, 9, 24, 26, 31
The social, cultural and institutional context of care and work decision-making	Sense of duty or obligation felt by family members	5, 7, 9, 13, 15, 16, 17, 19, 24, 25, 26, 28, 33
	Critical moments in carers' lives	20
	Enabling or constraining nature of workplace policies and environments	3, 4, 5, 9, 20, 21, 24, 27, 28
The unequal cost of caring	Vulnerable groups	6, 13, 16, 19, 21, 24, 26, 28, 29, 30, 31, 35
	Multiple caring responsibilities	10, 13
	Current financial situation and resources	3, 5, 6, 9, 13, 17, 23, 35
	Welfare state systems and public support	9, 14, 17, 28, 35
Personal finance and carer wellbeing	Long-term planning and financial wellbeing	5, 21, 22, 25, 27, 29
	Losing social connections	5, 6, 9, 12, 17, 19, 26, 30, 31
	Stress and mental health	3, 7, 9, 11, 12, 25, 29
	Needing financial support (social and structural)	9, 14, 22, 27, 28

social, cultural and institutional context of care and work decision-making. Third, we recognise the unequal cost of caring, with some people being more vulnerable to financial strain and insecurity than others. Finally, we focus on the associations between personal finance and carer wellbeing. These overarching themes, and corresponding subthemes, are presented in [Table 4](#).

Before discussing these themes in detail, it is important to note that of the 35 studies included in this review, just six contained a primary focus on the costs of providing unpaid care to an older adult, four of which explored the costs relating to a specific illness or stage of illness such as cancer, incontinence or dementia. The financial implications of combining paid work and unpaid care were the focus of five studies, while the majority (24 studies) centred on the overall experience of unpaid care-giving, such as the social, emotional, relational and financial aspects.

The direct and indirect costs of caring

We first identified a common theme relating to the kinds of cost associated with looking after an older adult with care needs. These are categorised as direct costs, which were outlined in 14 of the articles, such as the extra money spent on food, heating, electricity, transport and medical devices, as well as more formal care costs and charges for community services (e.g. Ainamani et al. 2020; Griffiths and Bunrayong 2016; Mahomed and Pretorius 2022; Zhong et al. 2022). In the context of transnational care (the focus of one of the studies in this review), we also identified remittances as a particular feature of these direct costs (Tawodzera 2021). Participants in this study explained how sending money home to help with care for ageing parents was an obligation felt by those who had migrated to the UK; for those on insufficient salaries, these remittances had been funded by pay day loans, which had negatively impacted their credit score.

While direct costs, sometimes referred to as out-of-pocket expenses (see e.g. Keating et al. 2014; Shoostari et al. 2017), have previously been identified as a key element of the financial implications of unpaid care, our analysis suggests that the nature and the extent of these costs, as well as the strategies deployed for meeting them, vary according to the needs of the care recipient (e.g. the nature and or progression of the illness or disability they have), as well as the existing financial circumstances of carers. In some cases, carers resorted to using money from their savings, including pension savings, or accruing debt to cover these costs (Carers UK 2022; Carers Trust 2016; Roberts and Struckmeyer 2019; Talley et al. 2021): *'It [caring for husband] is a financial cost. To be honest, I had to borrow the money to do it, too. I couldn't get it out of my pension. The beds are costing me over a thousand dollars. Just for two. But I've still got to get all the coverings for them'* (female carer, Australia, Talley et al. 2021).

The literature also makes clear that one of the most significant 'indirect' costs associated with unpaid caring responsibilities is the knock-on effect of changes in labour market participation and the subsequent loss of income. This takes many forms, including deciding to leave employment (Ainamani et al. 2020; Balfe et al. 2016; Brémault-Phillips et al. 2016; Gott et al. 2015; Herat-Gunaratne et al. 2020; Mehta and Leng 2017); being 'let go' by the employer (Bower et al. 2020; Corvin et al. 2017); taking unplanned early retirement (Lafferty et al. 2022; Lee et al. 2022; Roberts and Struckmeyer 2019); or reducing paid working hours (Carers UK 2022; Giraldo-Rodríguez et al. 2019; Jolanki 2015; Kyei-Arthur and Codjoe 2021; Nguyen et al. 2021; Santini et al. 2016; Vlachantoni et al. 2021). The inability to take on additional (higher-paying) roles and responsibilities through promotion or training was also experienced by some, as illustrated in the report by Alzheimer's Research UK (2015): *'They asked me to be a team leader at work. As soon as they asked me, I was like, "Well, my mum." I could have gone for it but, because of Mum, pretty much didn't'* (male unpaid carer, United Kingdom).

Again, employment restrictions are a well-documented phenomenon in research on unpaid care (see e.g. Carr et al. 2018; Keating et al. 2014; Longacre et al. 2017; Yeandle and Buckner 2017), but our analysis for this review points to a number of sub-themes related to the broader, contextual factors shaping care and work decision-making. These are discussed in more detail in the next section.

The social, cultural and institutional context of care and work decision-making

In seeking to understand how and why unpaid care influences people's decisions about work and associated financial wellbeing, we identified several factors that, taken together, can be categorised as the social, cultural and institutional contexts of care and work decision-making. These include the sense of duty or obligation felt by family members to provide care, critical moments in carers lives, and the enabling or constraining nature of workplace policies and environments. Before detailing these findings, it is important to emphasise that care-giving can be unexpectedly imposed on individuals, with bounded choices (Bryant and Garnham 2017) and little opportunity for (optimal) decision-making. For example, Baxter et al. (2020) argue that care provision (either formal or informal/unpaid) is often organised following a critical event, such as discharge from hospital, when there are considerable time pressures, restricted availability of formal support services and an absence of alternative options. This means that other choices may not be available and so the notion of care and work 'decision making' should be viewed in the context of these barriers and constraints.

Turning to the literature identified for this review, we found that feelings of obligation, duty and responsibility to care seemed to stem from situational factors such as the nature and degree of help required or the (non-)existence of other potential carers and the interaction with societal and cultural norms and expectations. For instance, care recipients' desire to receive end-of-life care at home (Gott et al. 2015) or their reluctance to accept formal care services (Carers UK 2022; Herat-Gunaratne et al. 2020) meant that family members often felt obligated to provide their care. But carers also reported feeling a sense of duty to provide care for ageing parents (Carden 2020; Maynard et al. 2019; Mehta and Leng 2017; Nguyen et al. 2021; Palacios et al. 2021) or to pay for additional care services (Han et al. 2019; Tawodzera 2021) due to deeply ingrained beliefs about family relationships, reciprocity or 'intergenerational solidarity' (Bengtson and Schrader 1982; Roberts et al. 1991).

I'm just doing my duty as her child. She took care of us till we are all grown up, isn't it? But she can't take care of us forever. So now it's our turn to take care of her. We have the capabilities to do so or whatever you call it. We can take care of her till her demise. She took care of us in the past so now we must take care of her. This is my duty as a son. (male unpaid carer, Singapore, Mehta and Leng 2017)

It is my duty to take care of my parents because they brought me to this world and looked after me and made me who I am today; for that alone, I am very grateful. In our culture, it is our duty to look after our parents, anyway who would do it if we do not? (male carer, Tawodzera 2021)

Money never came into the equation ... It was a lot of hard work but when I look at it, I'm glad I was there and not strangers. (family carer, New Zealand, Gott et al. 2015)

The qualitative literature also revealed a gendered dimension to decisions about caring (Bower et al. 2020; Han et al. 2019; Iwuagwu et al. 2022; Kyei-Arthur and Codjoe 2021), in line with much quantitative evidence on this topic (see e.g. Gomez-Leon et al. 2019;

Petrillo et al. 2022), with women's obligations to kin being, or being perceived as being, stronger than men's and an assumption that it is more 'natural' for them to provide hands-on care (Maynard et al. 2019). These beliefs often served to reinforce gender stereotypes about care-giving:

Often the parents live with the eldest son while the eldest daughter-in-law will do the caregiving. If other children live nearby, they can lend a hand here and there, adding a little bit of help. It is like that everywhere, not just here. But those caring tasks like feeding, bathing, washing laundry are women's jobs. (female carer, Nguyen et al. 2021)

These findings suggest that motivations to care are often prioritised over considerations about any personal financial consequences of providing care. While there is some recognition of the financial implications of reduced income in the short term, unpaid carers who feel they have a responsibility to care for family members could be compromising their own financial wellbeing in the longer term.

Critical moments in carers' lives also played a part in their employment decisions. For example, the well-documented emotional strain of some caring situations (Magaña et al. 2020; Stanfors and Jacobs 2023) was also uncovered in the literature for this review, but in a way that emphasised its role in triggering key work–life decisions, partly for the purpose of care-giver self-preservation, where formal care and support services were absent, but also for the purpose of enabling carers to continue providing help and support to their care recipients:

I really was losing my mind – do you know what I mean? I was really stressed ... I felt like I was going to end up ... in a psychiatric hospital ... so way back then the stress was there for a long time you know, the feeling of 'this is too much, I never get a break' ... that made me decide to give up [work]. (female unpaid carer, Ireland, Lafferty et al. 2022)

Workplace policies and environments also influenced carers abilities to combine work and care. Where carers did continue in employment, the need to work flexibly, in a way that enabled care responsibilities to take priority, was reported as being central to a sustainable work–life balance (Balfe et al. 2016; Bijnsdorp et al. 2021; Carers UK 2022; Lee et al. 2022). Yet many also felt that existing measures were insufficient and did not go far enough in facilitating the reconciliation of work and caring roles: *'I have four care leave days a year and that's just not enough. I think that should definitely be increased a bit; it costs me a lot of money too. I work in the care sector, but my feeling is that they don't care that much for the staff'* (male unpaid carer, Netherlands, Bijnsdorp et al. 2021)

Participants' experiences suggested that while sympathetic work colleagues and line managers could support both subjective and financial wellbeing, more formalised and supportive employment policies and practices, such as a right to request part-time or flexible working arrangements or carers' leave (Bijnsdorp et al. 2021; Lafferty et al. 2022; Oliveira et al. 2020; Palacios et al. 2021), would help to mitigate the financial strain for all those with caring responsibilities.

The unequal cost of caring

There was also a clear pattern of inequality associated with the financial costs of caring, with some groups being more vulnerable to financial strain and insecurity than others. Stamatopoulos's (2018) study reported on the financial challenges faced by younger adult care-givers, finding that work and education opportunities can be compromised by caring responsibilities, while Brémault-Phillips et al. (2016) note that young adult carers are often ineligible for financial assistance.

As financial security in later life is highly dependent on long-term, uninterrupted employment and savings histories (Ekerdt and Adamson 2024; Grenier et al. 2017; Hardy 2009; Polivka 2020; Price and Livsey 2013), these delayed or compromised earnings opportunities are likely to disproportionately affect later-life financial wellbeing for those with caring responsibilities in young adulthood. The experiences of one of the participants in Stamatopoulos's (2018) study highlight this risk, and give a sense of the weight of responsibility felt by those trying to manage competing priorities and needs: *'I doubt I can leave them, and I don't want anything bad to happen to them so I am thinking about holding back on college and university until they are better ... even if I have to wait until I'm 40 I will ... but I won't go until they are better'* (female unpaid carer, Canada)

Another group of carers identified as being particularly susceptible to financial strain was those with high-intensity caring roles. Several of the studies recognised that spousal carers (Lee et al. 2022; Maynard et al. 2019; Roberts and Struckmeyer 2019), primary carers (Kyei-Arthur and Codjoe 2021; Maynard et al. 2019; Palacios et al. 2021; Santini et al. 2016) and those caring for people in later stages of illness (Gott et al. 2015; Herat-Gunaratne et al. 2020; Nguyen et al. 2021) often spend more time caring, and subsequently experience greater difficulty balancing paid work with caring. Moreover, those with multiple caring responsibilities (Brémault-Phillips et al. 2016; Corvin et al. 2017; Gott et al. 2015) involving more than one older adult or dividing time between caring for an ageing parent and a young family, known as 'sandwich' or 'pivot' generation carers (Burke 2017; Pierret 2006; Železná 2018), talked about the stress of supporting an older relative alongside other financial responsibilities and the impact on their own financial security: *'I mean I was supporting 8 years you know on my income; it was very difficult. Still had a mortgage, still had 3 children living at home, so there wasn't anything there for me'* (carer, Canada, Brémault-Phillips et al. 2016).

Furthermore, carers' existing financial circumstances and resources also play an important role in shaping how the financial implications of care are experienced. Those with relatively low levels of existing debt, low outgoings or a buffer of wider financial resources to draw on were more protected from the added financial strain. In two of the studies in this review (Balfe et al. 2016; Gott et al. 2015), participants discussed the importance of owning their house outright and feeling fortunate that they did not have to manage mortgage costs as well as additional care costs. They appeared more financially resilient in the face of these expenses having accumulated some (housing) wealth by the time they were faced with the costs of caring: *'I owned my house, we've no mortgage. We've been lucky'* (unpaid carer, Republic of Ireland, Balfe et al. 2016).

These experiences underscore the significance of personal asset-holding in a system where care costs, and the associated risks, are highly individualised rather than

pooled (Bayliss and Gideon 2020; Tanner et al. 2024). And while retrenchment of public provision is increasingly shaping the care landscape in the UK, in less advanced economies, including in parts of Africa and Asia, the long-standing inadequacy of social welfare packages and retirement security significantly increases the financial burden for unpaid carers (Griffiths and Bunrayong 2016; Iwuagwu et al. 2022). Griffiths and Bunrayong (2016) explored the experience of care-givers looking after a relative with dementia in Thailand, and note that accessing adult day-care services adds an additional financial strain: *'I am tired. I have to care for him and also, I have to pay extra for a care-giver, the government allowance for older people is just 500 baht a month [~10 GBP], it is not enough'* (unpaid carer, Thailand).

The consequences of such inadequate protection for these financial wellbeing risks go beyond individual financial security to encompass significant broader societal and economic effects. In this sense, the concept of social risk, or indeed new social risk (Bonoli 2007; Taylor-Gooby 2004), is applicable to the contingencies facing carers. Yet, as Morgan (2018) makes clear, while states, including the UK, have implemented care policies to address some of these risks, inadequate and inconsistent protection means that the primary poverty and welfare risks associated with unpaid care remain privatised to a greater or lesser extent. Furthermore, the inequalities in care policy design and implementation create secondary risks, in part by increasingly forcing individuals to rely on market or family-based solutions to manage their social risks, but also by 'inter-relational risk-shifting ... where policy mechanisms socialise the care-related risks of one risk-bearer whilst simultaneously generating or maintaining financial or welfare risks for the other' (Morgan 2018, 191). In England, one of the clearest examples of this is in the rules governing Carer's Allowance and care recipients' means-tested benefits such as Severe Disability Premium (SDP). Here, the system is designed to support care recipients' costs providing unpaid carers do not receive Carer's Allowance for looking after them. This leaves carers and care recipients having to 'decide' which of them will forgo financial support, not only affecting their immediate and future financial security (since Carer's Allowance provides carers with National Insurance Contributions towards full state pension entitlement, for example) but also creating potential dilemmas and conflicts for care relationships (Morgan 2018, 2019).

A better understanding of the nature and extent of these primary and secondary risks for unpaid carers could support the case for more effective policies which provide them (and their vital work) with adequate time, money and support. This is something we return to when we consider directions for future research in the final section of this article.

Personal finance and carer wellbeing

Considering the three components of Keating et al.'s (2021) care-giver wellbeing framework (subjective, relational and material), a number of studies in our review suggest that the direct and indirect costs of providing care could have a negative influence on carers' wider sense of wellbeing, impacting longer-term planning and future goals (Bower et al. 2020; Lee et al. 2022; Mehta and Len 2017; Oliveira et al. 2020; Roberts and Struckmeyer 2019). A small number of carers quoted in the literature had thought about getting older, and considered how care costs could impact their future financial

wellbeing: *'My main worry is the financial part, the drain on my retirement funds'* (female unpaid carer, Singapore, Mehta and Leng 2017); *'I pay for all my spouses' care, which will impact on my own future'* (unpaid carer, United Kingdom, Oliveira et al. 2020).

Lindeza et al. (2020) also note that carers of people with dementia are often anxious about the uncertainty of how long the disease will last, as a longer duration may lead to increased financial burden: *'I knew we had money if mom lived for one to two years, but if she lived for 20 ... it was a big worry and a burden. I don't have an unlimited amount of money for my mom'* (unpaid carer, USA).

While several studies highlighted the social isolation experienced by care-givers due to constraints on their free time (Bower et al. 2020; Carers UK 2022; Giraldo-Rodríguez et al. 2019; Iwuagwu et al. 2022; Jolanki 2015; Nguyen et al. 2021; Santini et al. 2016; Stamatopoulos 2018), Brémault-Phillips et al. (2016) argued that some carers simply did not have the money to engage in social activities: *'I'm on social assistance, I have no budget whatsoever to do anything sociable'* (unpaid carer, Canada).

Gibson et al. (2019) found that social lives could also be disrupted for those who had left their employment due to caring responsibilities, with some participants reporting a sense of isolation from their friends, community and wider networks: *'I really liked going to work and now that is cut short ... I had a very active social life and now that's gone, and it weighs on me'* (female unpaid carer, Mexico).

As unpaid carers age, these limited opportunities for establishing and maintaining social connections could leave them particularly vulnerable to loneliness and isolation, and to the negative health and wellbeing outcomes now widely associated with this (Glass et al. 2006; Hodgson et al. 2020; Shankar et al. 2015).

Some of the studies also presented data where carers talked about feelings of financial strain influencing their general sense of wellbeing, expressing their concerns about navigating personal finances (Balfe et al. 2016; Carden 2020; Carers UK 2022; Gibson et al. 2019; Giraldo-Rodríguez et al. 2019; Mehta and Leng 2017; Roberts and Struckmeyer 2019). While these studies reported that the financial impact of caring can be significant and concerning, Balfe et al. (2016) note that care-givers often withhold financial information from the person they care for in order to protect them: *'We needed money, it was tough, trying to keep everything in control. I didn't want him to worry'* (female unpaid carer, Republic of Ireland).

Our analysis therefore suggests that while carers often prioritize the wellbeing of care recipients, regardless of the direct and indirect costs of providing care, shouldering the financial strain of care-giving can add an additional burden and negatively influence carers' subjective, relational and material sense of wellbeing (Keating et al. 2021).

Discussion

We identified and reviewed 35 studies that included qualitative evidence associated with the costs of care-giving. With our emphasis on qualitative literature and the lived experience of providing unpaid care, the analysis advances our understanding beyond an identification of what the key costs and financial consequences are, to reveal the role of individual, contextual and structural circumstances in shaping how these costs

are experienced and how decisions are made. The key themes suggest that there are experiences and challenges that unpaid carers face which are common across countries despite cultural, socio-economic and structural differences. However, the review also highlights inequalities in the subjective experience of care-giving in terms of economic costs and resources, family and societal expectations, and social protection systems.

In addition to the *direct and indirect costs of caring*, as similarly outlined in Keating et al.'s (2014) taxonomy of economic costs, we developed a further three themes on *the social, cultural, and institutional context of care and work decision-making*, *the unequal cost of caring* and *personal finance and carer wellbeing*. The synthesis and presentation of these themes extends the previous literature on the economic costs of unpaid caring by foregrounding carers' subjective experience and underscoring associations with their sense of financial wellbeing. The themes also support the notion of multiple components of financial wellbeing as outlined by Riitsalu et al. (2023) (*i.e.* subjective and objective; financial security and stress or anxiety; present and future).

Furthermore, our findings emphasise the temporal nature of unpaid carers' financial wellbeing. For example, younger people who miss out on employment and educational opportunities due to care-giving responsibilities could be vulnerable to financial insecurity in later life (D'Amen et al. 2021). While it has been reported that carers in midlife (aged 50–64) are at risk of leaving employment prematurely, particularly if they are female (Gomez-Leon et al. 2019; Petrillo et al. 2022; Schofield et al. 2019), this review also suggests that younger adult carers are less likely than their counterparts with no such caring commitments to continue with higher education, which could potentially lead to lower earnings and a cumulative negative impact on future financial wellbeing. Some of the literature also reports on the effect of care-giving on labour market participation over time, suggesting further cumulative costs, particularly for those with multiple caring responsibilities.

While the working women in Jolanki's (2015) study cite previous caring responsibilities as justification for staying in paid employment, recent quantitative literature has recognised those who provide care for different people at different life stages (Palmer 2022; Zhang and Bennett 2023) and the 'cycles of care' across a lifecourse (Petrillo et al. 2022). Taking a qualitative approach, Rodrigues et al. (2022) drew on lifecourse concepts to explore pathways into care-giving and argue that care-giving decisions can be understood as processes that are associated not only with family dynamics and relationships but with other influences, such as attachment to the labour market, work trajectories of carers and those of their siblings. While it has been recognised that the influences of care and care-giving are cumulative across the lifecourse (Keating et al. 2019), the qualitative studies in this review tended to provide a snapshot of carers' lives and finances, rather than an understanding of the impact on carers' sense of financial wellbeing over time.

Our analysis has also emphasised the cultural and social influences on care and work decisions and circumstances where adult children felt a desire and/or obligation to provide care for parents and older relatives. Some of these experiences presented in this review support Glauber's (2016) suggestion that gender norms are internalised, meaning that caring is often viewed as women's work. Swinkels et al. (2019) suggest that care-giving in older age is likely to be an extension of previous caring roles

for women, implying that unpaid caring could have a greater cumulative impact on financial wellbeing for women over time.

The findings of this review also suggest that the financial impact of caring can be mitigated, to some extent, by having savings, assets and a degree of financial security prior to being faced with caring and its associated costs. Meanwhile, the cost of caring has a more detrimental impact for those without this buffer, and for individuals in already financially vulnerable circumstances. This is concerning as the most recent Census for England and Wales found that a higher percentage of people who provide unpaid care are living in the most deprived areas (ONS 2023). Our analysis also underscored the connection between financial strain and carers' subjective sense of wellbeing, with knock-on effects for participation in social activities and potentially, therefore, reduced support when it is needed most. Quantitative evidence supports these findings, suggesting that care-givers who experience financial difficulty are more likely to have depressive symptoms (Nam 2016) and that care-givers' perceptions of financial strain add to the long-term stress of the care-giving role (Liu et al. 2019). Our findings also align with a study by Steptoe et al. (2020) who found associations between financial strain and emotional wellbeing, which suggests that the financial wellbeing of unpaid carers should be considered within the broader relational and subjective wellbeing framework proposed by Keating et al. (2021). However, where Keating and colleagues use individual income as a measure of material wellbeing (Keating 2023), our findings suggest that a broader concept of financial wellbeing, one that includes savings, assets and housing wealth, would better represent the complexity of carers' finances across the lifecourse and at different life stages.

Limitations

As with all scoping reviews, the formulation of research questions, selection of search terms and sources and the inclusion/exclusion criteria employed can all be considered limitations to the study. Furthermore, while the systematic procedures outlined here were followed to identify appropriate literature, we acknowledge that some relevant articles may not have been included. We also cannot make any claims about the quality of evidence included in this review, since the aim of a scoping review is to map the available evidence on a topic, without following a process for quality assessment.

Nevertheless, we would suggest that this scoping review has highlighted the paucity of qualitative research with a specific focus on the financial wellbeing implications of unpaid (or informal) care-giving. Although some previous quantitative studies have recognised carer characteristics that might exacerbate the impact of financial stressors, for example ethnicity, care-giving intensity (Cohen et al. 2019) and gender (Ferrant et al. 2014), there is very little focus on how the influence of diversity and inequality (e.g. ethnicity, gender, socio-economic status, education level, age and family composition) might shape the economic impact of unpaid care within the qualitative literature. Moreover, while there is a recognition of longer-term financial consequences of leaving paid employment to care, such as reduced pension income and savings (Duncan et al. 2020), as well as challenges when re-entering the workforce (Palmer 2022), we found

no studies that explored how care-givers themselves understand these future economic consequences and whether they considered them when making decisions about labour market participation in relation to unpaid care.

Recommendations for future research

The gaps identified in this scoping review suggest an obvious opportunity for more in-depth research on carers' financial wellbeing to advance our understanding of the nature of this key social policy issue. Qualitative longitudinal research, in particular, would be advantageous for capturing the temporality of this phenomenon, and the ways in which unpaid caring experiences and financial wellbeing outcomes change over time. Relatedly, studies adopting a sociological lifecourse approach could provide valuable insights into the structural drivers of care risk inequalities within and across generations, as well as the role of cumulative (dis)advantage in shaping later-life financial wellbeing outcomes (Kendig and Nazroo 2016).

The potential to understand the extent of these issues, and the combination of factors linked to financial vulnerability among unpaid carers at different life stages and in different circumstances, might also be usefully supported by the maturation of large-scale panel household studies such as Understanding Society – the UK Household Longitudinal Study. A more holistic, mixed methods approach to understanding carers' financial lives could inform the development of much-needed policies aimed at acknowledging and protecting carers' long-term financial wellbeing. Indeed, the implications of inadequate protection are significant not only for individual financial security but also for wider social and economic inequalities. If the growing numbers of people with caring responsibilities do not get the right support now, there will be millions more relying on state support in the future given their diminished opportunity to earn adequate income and make sufficient savings to meet their own income and care needs in later life.

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Ethical standards. As this paper is a review of existing literature ethical approval was not required.

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