






Challenges of combining work and unpaid care, and solutions: A scoping review

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Abstract

The number of people who combine work and unpaid care is increasing rapidly as more people need care, public and private care systems are progressively under pressure and more people are required to work for longer. Without adequate support, these working carers may experience detrimental effects on their well-being. To adequately support working carers, it is important to first understand the challenges they face. A scoping review was carried out, using Arksey and O'Malley's framework, to map the challenges of combining work and care and solutions described in the literature to address these challenges. The search included academic and grey literature between 2008 and 2018 and was conducted in April 2018, using electronic academic databases and reference list checks. Ninety-two publications were mapped, and the content analysed thematically. A conceptual framework was derived from the analysis which identified primary challenges (C1), directly resulting from combining work and care, primary solutions (S1) aiming to address these, secondary challenges (C2) resulting from solutions and secondary solutions (S2) aiming to address secondary challenges. Primary challenges were: (a) high and/or competing demands; (b) psychosocial/-emotional stressors; (c) distance; (d) carer's health; (e) returning to work; and (f) financial pressure. This framework serves to help those aiming to support working carers to better understand the challenges they face and those developing solutions for the challenges of combining work and care to consider potential consequences or barriers. Gaps in the literature have been identified and discussed.

KEYWORDS

challenges; support and solutions, conceptual framework, scoping review; international, unpaid care, working carers

1 | BACKGROUND

Global population ageing and medical progress see more people, of all ages, living with increasingly complex care and support

Abbreviations: HCP, healthcare professional; PRC, person receiving care; UK, United Kingdom.

needs (Cohen et al., 2011; Foresight, 2016; WHO, World Health Organisation 2015). Caring situations are usually very diverse and dynamic. Care needs can fluctuate and include everything from assistance with activities of daily living (ADLs; i.e. personal hygiene, toileting, moving around, subsistence), complex instrumental activities of daily living required for an independent life (IADLs; e.g.

medication management, shopping, preparing meals), social or emotional support, or monitoring health and safety in the home (Mlinac & Feng, 2016; NHS, 2010).

The 2008 financial crisis led to extensive austerity measures in the UK which affected the provision of home care and community-based services and access to publicly funded care (Deusdad, Pace, & Anttonen, 2016; Humphries, Thorlby, Holder, Hall, & Charles, 2016). As fewer people receive publicly funded care, families are increasingly under pressure to bridge this gap in service provision. 6.5 million people, roughly 10% of the general population, currently provide unpaid care to an ill, frail or disabled family member, friend or neighbour in the UK (Carers UK, 2015; Kelly & Kenny, 2018). (In this article, the term 'carer' refers to family members, friends or neighbours providing care unpaid. The terms 'formal care' or 'care worker' will be used explicitly to describe care provided by a person who is paid and formally employed.) This saves the economy £132bn per year which is near the total public spending on the National Health Service (Buckner & Yeandle, 2015). Most carers are of working age (NHS, 2010; ONS, Office for National Statistics 2011). According to the 2011 census, around 3 million people, about half the carer population, were combining caring for a loved-one with paid work (Carers UK, 2015). This number is expected to increase in the coming years as more people require care, less formal services are available or affordable to address their needs due to austerity, and more people are needed in the job market for longer to support an ageing society—especially women who provide care more often (Broese van Groenou & De Boer, 2016; Buckner & Yeandle, 2015; Round, 2017; Yeandle & Buckner, 2007).

Combining work and care is a very complex issue and can have massive impacts, both negative and positive, on carers' mental and physical health, their relationships and their employment (Carers UK & Age UK, 2016; Yeandle & Buckner, 2007). King and Pickard (2013) found that providing care for 10 hours a week or more significantly impacted the likeliness of the carer to leave work. Carers UK (2019) have calculated that 600 carers on average left work to care every day over the past 2 years and total numbers of carers leaving employment have increased from 2.3 to 2.6 million since 2013. Giving up work not only affects the long-term financial situation of carers; it also negatively impacts the economy and the public purse. Lost tax revenue and increased spending on benefits to support unemployed carers cost the UK economy £1.7bn a year (Pickard, King, Brimblecombe, & Knapp, 2018). Additionally, there are costs to employers in terms of loss of skilled labour, recruitment and training expenses (Carers UK, 2013). Combining work and care should not be problematised in general as many carers want to do both. Caring can give them a sense of purpose, an opportunity to reciprocate and to support their loved-one in their hour of need (Bourke, Pajo, & Lewis, 2010; Eldh & Carlsson, 2011; Hamblin & Hoff, 2012). Work, on the other hand, is not merely a source of income but offers them respite from caring, social support and an opportunity for fulfilment outside of caring (Bourke-Taylor, Howie, & Law, 2011; Bruns & Schrey, 2012; Calvano, 2013). However, as both care and work can create

What is known about this topic?

- There are currently about three million working carers in the UK, and the number is increasing.
- Combining work and care is a very complex, dynamic and diverse commitment.
- If not properly supported, it can put carers' employment, relationships and well-being at risk

What this paper adds?

- This paper is the first to comprehensively map the international literature on working carers' challenges and solutions.
- It introduces a conceptual framework which helps to better understand their challenges and how solutions can create additional challenges.
- Several areas have been identified where more research is required.

significant demands on carers, it is essential that they receive the support they need to be able to fulfil both their roles without risking their own well-being.

Adequately supporting working carers requires a comprehensive understanding of the challenges they face, and which solutions can address them. This review thus aims to find out what is already known about the challenges of combining work and care and support or solutions which address these in the international literature and to identify any gaps. Although the knowledge base on working carers is steadily growing, there has been, to date, no comprehensive review to that end. Previous reviews have addressed specific solutions, namely workplace-based support and technology, or looked at the challenges of combining work and caring for an older person (Andersson, Erlingsson, Magnusson, & Hanson, 2017b; Calvano, 2013; Ireson, Sethi, & Williams, 2018). This review takes a more inclusive approach, not limiting itself to any specific solutions or age of people needing care. Furthermore, it includes both academic and grey literature, as some solutions might only have been reported on by non-peer-reviewed sources. This article does not discuss the role legislation and public policy could play in supporting working carers; this is discussed elsewhere, for example, in Bouget, Spasova, and Vanhercke (2016), Jungblut (2015), Kröger and Yeandle (2013), Yeandle (2017) and Yeandle and Buckner (2017).

2 | METHODOLOGY

The scoping review, first described by Arksey and O'Malley (2005), is a method for evidence synthesis of heterogeneous source materials.

This method can be used to summarise and characterise an emerging or established field of research and is particularly useful as it allows synthesising both academic and grey literature (Colquhoun et al., 2014). It typically starts out with a broad research question and

is characterised by an iterative yet systematic approach to reviewing the literature (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Daudt, van Mossel, & Scott, 2013). The main steps are displayed in Table 1.

TABLE 1 Summary of the scoping review framework (adapted from Davis et al., 2009)

Stage 1	Identify the initial research questions, determine which aspects of the question are particularly important to facilitate the most appropriate search
Stage 2	Identify the relevant studies, comprehensively answer the central research question(s) including any time, date, budget constraints and range of sources
Stage 3	Study selection, similar to systematic review but from the outset adopts greater flexibility with eligibility criteria, as familiarity with data progresses search terms may be redefined (iterative process)
Stage 4	'Charting' the data, takes a broader approach than data extraction in a systematic review. Uses a narrative descriptive-analytical framework method but does not attempt to 'weigh' the methodological quality of evidence
Stage 5	Collate, summarise and report the results using a framework approach
Stage 6	Optional consultation with key stakeholders has the potential to add value, additional references and valuable insights

TABLE 2 Operationalised concepts and corresponding inclusion & exclusion criteria

Concept	Explanation
Working carer	A person in paid work who provides unpaid care ^a for a relative, friend or neighbour; care is understood as providing assistance with ADLs (activities of daily living) and IADLs (instrumental activities of daily living) as well as social or emotional support and monitoring the health and safety of the cared for person; no restriction in terms of condition of the person receiving care (e.g. carers of stroke survivors)
Included	Unpaid or 'informal' carers: no formal training; no monetary reimbursement ^a ; carer is not employed with a care provider or hired by the care recipient or their relatives Carer is in paid employment or self-employed or had to give up work to care; no restrictions in terms of work hours or workplace Publication is focused on the challenges of combining work and care
Excluded	'Normal' childcare (bringing up a healthy child); short-term care (acute illness or accident); voluntary work; domestic work Publication does not focus on reconciling work and care
Needs	What do working carers struggle with; how do they experience their dual responsibility; Holistic view: physical, emotional, social, financial (safety), esteem, self-actualisation needs
Solutions	Interventions/ solutions/ strategies which have been identified to address their needs
Included	Support carers currently receive or want (e.g. workplace interventions, technology, community initiatives, public or private care services, etc.)
Excluded	Publications which only focused on government legislation or policy (e.g. carer leave schemes) ^b
Also excluded	Non-English publications; incomplete references; film or book reviews; protocols

^aIn some countries, carers may receive carers allowance or people receiving care may support them financially. These carers are still considered 'unpaid' as they are not in official employment of a care provider or the person they care for.

^bDue to the temporal and spatial context-specificity of government policies and legislation relevant for working carers (e.g. regulation of flexible work and care leave) it was decided that they fall outside the scope of interest.

2.1 | Constructing and running the search (stages 1–3)

A review protocol described the search strategy and operationalised the major concepts. Table 2 presents the operationalised concepts which were used to create the search terms, as well as the corresponding inclusion and exclusion criteria. A pilot search revealed that the search terms used to capture the 'working carers' concept, consisting of terms used for 'work' and 'carer', were, by necessity, so broad and unspecific, that a large number of articles were picked up which used these terms in irrelevant contexts. Hence, to increase the precision and relevance of the search, the 'needs' and 'solutions' concepts were incorporated and combined with Boolean operators. The search construct is displayed in Figure 1.

The search was conducted between 2008, the start of the financial crisis which contributed to austerity in the UK and increased the pressure on families to provide care in the community, and the day of the search, the 25th of April 2018 in the MEDLINE, CINAHL, PsycINFO, ASSIA, Social Care Online and Google Scholar databases. It was limited to literature published in English and, where possible, restricted to papers with an available abstract. This search identified a total of 6,738 publications (The term 'publications' is used hereafter to refer to both peer-reviewed articles published in academic journals and grey literature, that is, non-peer-reviewed research reports, book chapters, theses, pamphlets). After removal of duplicates, the references were imported into MS Excel for the screening of titles and abstracts. The titles were screened to eliminate publications which did not focus on working carers and to formulate the eligibility criteria (see table 2 and decision tree in Appendix S1A). A second reviewer screened the titles independently to validate the developed eligibility criteria and to ensure that they were employed consistently. The weighted Cohen's Kappa was 0.62, indicating substantial inter-rater agreement (Landis & Koch, 1977). This process reduced the eligible publications to 1,163, which either addressed combining care and work explicitly or where this could not be ascertained from just the title. The abstracts of these 1,163 publications were again screened by both reviewers (Kappa = 0.65) which developed the eligibility criteria further. A third reviewer resolved any disagreements. The 114 publications remaining after this stage of the screening process were

read in full by the first reviewer, which excluded 47 publications. Screening the reference lists of the remaining 67 identified 25 publications which were added to the final selection. Figure 2 depicts the search process.

2.2 | Data analysis/synthesis (stages 4&5)

The selected publications were charted to capture their key aspects. Information charted includes authors, date of publication, study location, study design and discipline as well as more specific information including research aims, carers and people receiving care (see Appendix S1B). NVivo Pro 11 software was used for thematic analysis of the included publications. Relevant content, namely any information relating to challenges of combining work and care and solutions and support, was analysed inductively. The result was a framework which is illustrated in Figure 3.

2.3 | Stakeholder consultations (stage 6)

As per Davis, Drey, and Gould's (2009) suggestions, stakeholder consultations have been held to get feedback on the findings of the review. Discussions have been held with members of carer support organisations and academics specialised on carers in the Netherlands and the UK between October and December 2018. Ethical approval and consent from stakeholders were not required as they were approached solely to validate the findings of the review and provide feedback on the structure, design, usability and ease of use of the developed framework.

3 | RESULTS

3.1 | Description of the included publications

Of the included publications, 68 were journal articles: 29 quantitative, 16 qualitative, 10 mixed-methods studies, five reviews, four commentaries, four case studies. Of the 15 reports, six were case studies, four each were qualitative and quantitative and one was mixed-methods. Five book chapters were included: two reviews, two mixed-methods and one qualitative study. Additionally, three pamphlets and one quantitative PhD thesis were included in the analysis. Studies had been conducted in a variety of disciplines, including health sciences, social sciences, psychology, business studies and economics. The majority originated from North America ($n = 46$), followed by Europe ($n = 31$), Australasia ($n = 6$) and Asia ($n = 5$), as well as four multinational studies. Regarding the cared-for person, 39 publications focused on older people, 10 on adults, 12 on children with special needs, eight on a combination thereof, and 23 did not specify this. It should, however, be noted that authors used different age-limits to define these groups. The complete data chart is presented in Appendix S1B.

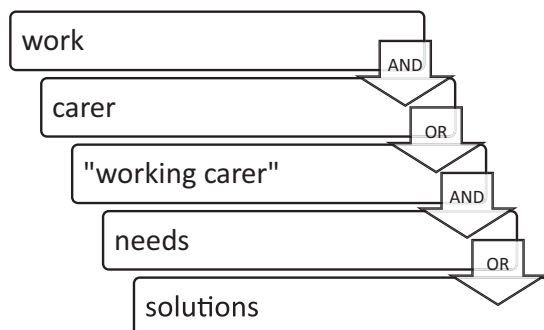
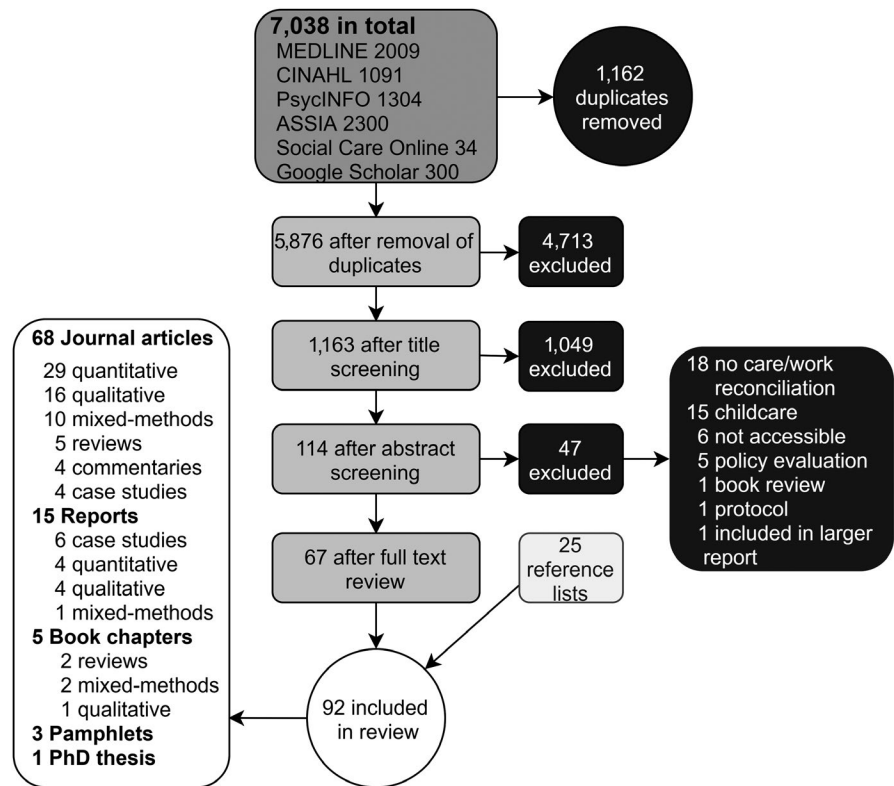
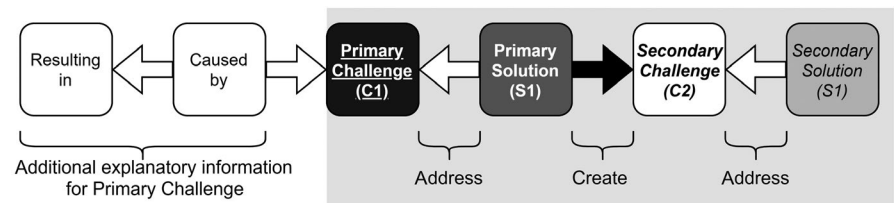


FIGURE 1 Search construct

FIGURE 2 Flowchart of the search process**FIGURE 3** Illustration of the conceptual framework of primary and secondary challenges and corresponding solutions/support

3.2 | Conceptual framework of challenges and solutions

During analysis, it became clear that the relationship between the identified challenges and solutions was not straightforward. The conceptual framework illustrated in Figure 3 resulted from this observation. **Primary Challenges (C1)** incorporate challenges which originate directly from combining work and care. These are (a) high and/or competing demands; (b) psychosocial/-emotional stressors; (c) distance; (d) carer's health; (e) returning to work; and (f) financial pressure. Additional explanatory information for Primary Challenges include causes and consequences and are presented on the left side of the diagram. **Primary Solutions (S1)** describe solutions or support which aim to address Primary Challenges. Some of these can create additional challenges for carers (**Secondary Challenges, C2**), mostly resulting from accessibility issues. In a few cases, **Secondary Solutions (S2)** are described which aim to address Secondary Challenges.

The order in which Primary Challenges are now presented, together with a diagram, does not represent prioritisation and it should be noted that combining work and care is a dynamic effort. Consequently, carers might experience different, and indeed multiple,

challenges from one day to the next and their priorities for solutions may change accordingly. The framework will not be representative of every working carer's individual experience but rather represents an abstract generalisation onto which challenges individual carers face and solutions which aim to address these can be mapped.

4 | THEMATIC FINDINGS

4.1 | C1A) High and/or competing demands (Figure 4)

Caring created particularly **high demands** if the cared-for person required time-intensive care, especially at night, had to be monitored constantly to ensure their safety and survival, was severely limited in their mobility or exhibited demanding behaviour. Cohabitation often increased the pressure on carers' time, making them feel that they were never 'off-duty'. Paid work too created high demands, especially if it required long work hours. Added up, these demands left little time to take care of personal needs including health [see C1D] and spending time with friends and family, leading to a decline in the quality of relationships and isolation [see C1B]. **Competing**

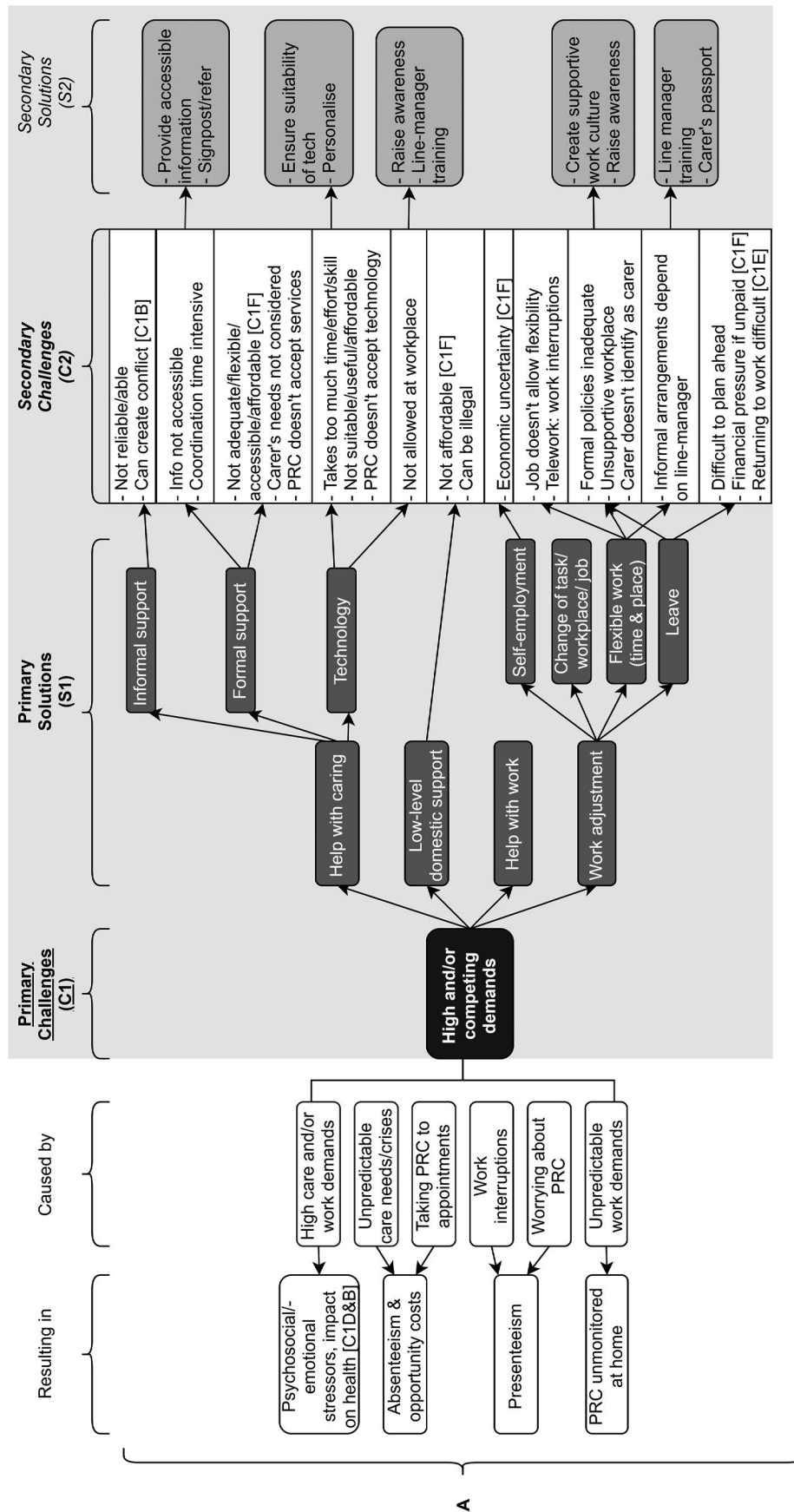


FIGURE 4 Application of the framework for Primary Challenge C1A 'High and/or competing demands' (PRC, person receiving care)

demands arose when the work interfered with caring and vice versa. Unpredictable, fluctuating care needs, and emergencies were one significant source of these demands leading to absenteeism as the carer unexpectedly had to stay home or leave work to attend to the cared-for person. Caring could also compete with work if the carer had to take the cared-for person to medical or similar appointments. Although these could be scheduled in advance, carers still had to take time off as consultations often coincided with their work time. The resulting absenteeism could have a detrimental impact on carers' career prospects or ability to remain in work. Constantly worrying about the safety and well-being of the person they cared for and exhaustion could lead to presenteeism, meaning that carers were not able to concentrate and work productively. Care-related presenteeism also occurred when carers were continuously interrupted at work by calls of the cared-for person or members of their care network, or when they had to coordinate appointments or services with restricted business hours. Carers often incurred opportunity costs. For example, they were unable to participate in job training, networking opportunities or company events relevant for their career progression were unavailable for overtime or business trips or felt unable to accept promotions because they feared that they would not be able to cope with the additional demands and responsibilities. Work could also create unpredictable demands such as unplanned extra-shifts or overtime. This could lead to difficulties with the care arrangement and could result in the cared-for person being unmonitored or unsupported at home.

Help with caring, either providing 'hands-on-care' (assisting with ADLs and IADLs), monitoring the cared-for person's well-being or taking them to appointments, was identified as a very valuable solution for carers, enabling them to concentrate on work. **Informal** help was provided by family members, friends, or neighbours. Sometimes, their **ability to care could be limited**, for example if care needs were so complex that they required special training or if care needs persisted over a long time, leading to the loss of informal support if members of the care network moved to a different place, became too old to provide care or died. Some carers experienced their **informal support as unreliable**, predominantly where siblings cared for their ageing parents [see C1B]. This could lead to difficulties in distributing care-related information and conflict over how best to provide care and share responsibilities.

Formal services were either privately funded or provided by the community (e.g. home care services, day-care centres, meals-on-wheels and transportation services). Schools played an important part in the support of children with special needs. Carers often found that **information on availability, accessibility and entitlement was hard to obtain**. This and the fact that service provision was often fragmented made it very **difficult and time intensive for them to organise and coordinate** the support they required. *Providing easily understandable information and signposting or referring* to available services was highly valued support. Some employers provided these services on their company intranets, organised information and networking events, provided carer-specific assistance through their EAPs (employee assistance programme), or employed case

managers who provided personalised assistance and information. Charities or publicly accessible websites too could help carers to identify and coordinate services by informing them directly or connecting carers to peers and enabling them to share information online. Carers often found that formal services, where they lived, were **inadequate for their needs** or unavailable. This problem appeared to be particularly prevalent for carers living in rural areas and carers of children with special needs, especially if they suffered from rare or 'invisible' conditions that affected behaviour (e.g. autism, attention deficit hyperactivity disorder). Cultural norms could also determine the availability of support and societies that traditionally saw caring as a personal matter made it harder for carers to receive help. Services which had been sought to enable carers to work could thus create additional demands as carers were often contacted at work when problems arose that these services were not qualified to handle. Some services were **unaffordable** or could increase financial pressure [see C1F] and publicly funded services were **not always accessible** due to strict eligibility criteria. Many carers also found services **did not consider their own needs** and were **not flexible** enough, specifically regarding business hours, which often conflicted with carers' work hours. This meant that they had to come to work late or leave early, especially if there was no suitable transport available to bring the cared-for person to services and back home. Carers who were themselves health-care professionals (double-duty carers) often felt that they were viewed as a resource by service providers rather than someone seeking support. Even if carers finally found adequate help with caring, they might find that the **cared-for person did not accept** any outside help. Equally, some carers did not trust anyone else with caring for their loved one or thought it would take too much time to delegate. Carers of terminally ill people, especially children, sometimes did not seek help with caring and decided to quit their job or take an extended leave of absence as they wanted to spend as much of the time they had left with their loved one as possible.

Technology helped carers in different ways. Monitoring technology could reassure people needing care that help would be readily available, thus increasing their confidence to be more active and take care of their own needs. This could decrease the demand on carers. Additionally, monitoring the cared-for person while at work could offer peace of mind, allowing carers to concentrate on their work in the knowledge that they would be notified if necessary. It was also used to communicate with their loved-one and to coordinate their care arrangement. Technologies could create additional challenges too, as carers and cared-for people were **required to have the necessary abilities and skills** to use them and it could **take a lot of time and effort** to operate them properly. Some carers found that technology, often offered to them by local authorities or healthcare professionals, was **unsuitable** for their needs, was too **expensive** or was **not accepted by the cared-for person**, highlighting the need to **ensure the suitability** of technologies and to **personalise** them for individual needs and preferences. Some carers found that technology created problems at work, for example, repeated phone calls could cause work interruptions.

Some **employers did not allow their use** at work. *Training line managers and raising their awareness* as to why it is important for carers to have access to technology helped in some cases. Enabling carers to take **short breaks** from work to check on the person they cared for could also help carers to worry less and focus more on their work.

In some cases, **adjusting their work situation** was the only option carers had. Flexibility regarding their work hours, workplace and the ability to take leave when necessary without having to fear for their job were highly valued solutions. **Flexible work hours and the option to work from home** were of course **not always possible**. In some cases, employers found a different task or role for carers which allowed for more flexibility. Having no access to flexible work meant that some carers had to use sick or annual leave to be able to provide care. This could create or exacerbate health problems in the long run if carers could not use this time for their own needs [see C1D]. Working from home to tend to the cared-for person could be challenging as carers could find themselves distracted, **work interruptions** could occur, and they could feel guilty that they did not pay more attention to their loved-one. Some organisations developed different models and policies regarding flexi-time and **carer leave**, (e.g. paid or unpaid, emergency leave, differences in the number of days a carer can take leave). Due to the unpredictable nature of caring however, carers found it **difficult to plan ahead** and predict how long they would need leave for. Long-term leaves could make it **difficult to return to work** [see C1E] and unpaid leave could cause **financial difficulties** [see C1F]. Some workplaces, typically larger companies, had formal policies in place which regulated eligibility for flexible work and leave. Although these ensured equal access, **formal policies were often inadequate** or too rigid to address the needs of carers, especially if they were universal policies originally designed for parents of healthy children. *Raising awareness* of the diversity of caring situations and having a carer's champion in the workplace to lobby for the interests of carers was found to help improve these policies. An **un-supportive workplace** and the view that caring is a private rather than a public issue had an impact on the availability of support and meant that **carers often did not openly self-identify** and request support for fear of negative career consequences. They were also reluctant to talk about their caring role because they did not want to be seen as a 'shirker' or getting special treatment or did not want to be labelled, particularly in male-dominated workplaces. *Creating a supportive work culture* could enable carers to access the practical and emotional support they needed. Some carers worked hard to build up good relationships with co-workers so that they would **help them at work** and cover for them in case they needed to take time off to care. Smaller companies often preferred to make individual arrangements. While these could ensure greater flexibility and a better fit for the needs of the carer, these **individual arrangements were also highly dependent on the line-manager/ employer**. Line-managers were often described as gatekeepers to workplace support and carers could feel indebted or obliged to work extra hard to reciprocate. Some carers experienced a loss of

the support they had individually arranged with their line-manager if they had to change departments inside the company or if they got a new line-manager. Thus, some companies developed a *carer's passport* (which lists the support a carer had been able to negotiate) and provided line-manager training to sensitise them to carer issues. Some carers found that the only way for them to reconcile work and care was to **change their task, workplace or job**. Having to change job was challenging for carers as they often had no time for the job search or feared that future employers might not offer the flexibility they required. Restricted employment opportunities were particularly problematic for rural carers. **Self-employment** theoretically provided a maximum of flexibility and autonomy. However, it could mean **financial uncertainty** and increased pressure to work as they had no access to many employment rights and benefits. They were thus particularly vulnerable to care-related work interruptions which could harm their business development.

Low-level domestic support, for example, help with shopping, housework or looking after their children while they were at work or caring was a big help for some carers. In some countries, carers employed migrant care workers to help them with looking after the cared-for person. This could be considered semi-formal help with caring as these care workers were paid but often not officially employed or adequately trained. This form of support was **not affordable** for everyone as care workers lived with the cared-for person 24 hr a day. These care workers were not always officially employed or even registered which **could be illegal** in some countries.

4.2 | C1B) Psychosocial/-emotional stressors (Figure 5)

Carers often faced several **psychosocial/-emotional stressors**. Caring could be very distressing, especially when carers had to deal with their loved-one being in pain or displaying difficult behaviour (e.g. children with behavioural disorders or older people with dementia). Some people described the gradual decline of their ageing parents and the reversed parent-child roles as very confusing and distressing. Fluctuating care needs too caused stress as carers found it difficult to plan ahead. End-of-life care was upsetting not only because of the loss of their loved-one but also because it could mean the sudden loss of state support and benefits, which could push carers into an existential crisis on top of an emotional one [see C1F]. Apart from financial difficulties, cultural or familial expectations limited carers' perceived choice whether they wanted to be more involved in caring or work and was strongly related to gender and the relationship with the cared-for person. Filial piety in many Asian countries expects children to care for their parents when they age. There was generally a greater expectation of women to provide care which could make it difficult for male carers to talk about their caring role and get the support they needed. Family and personal expectations played an important part in determining roles and responsibilities and often depended on the type and quality of the relationship with

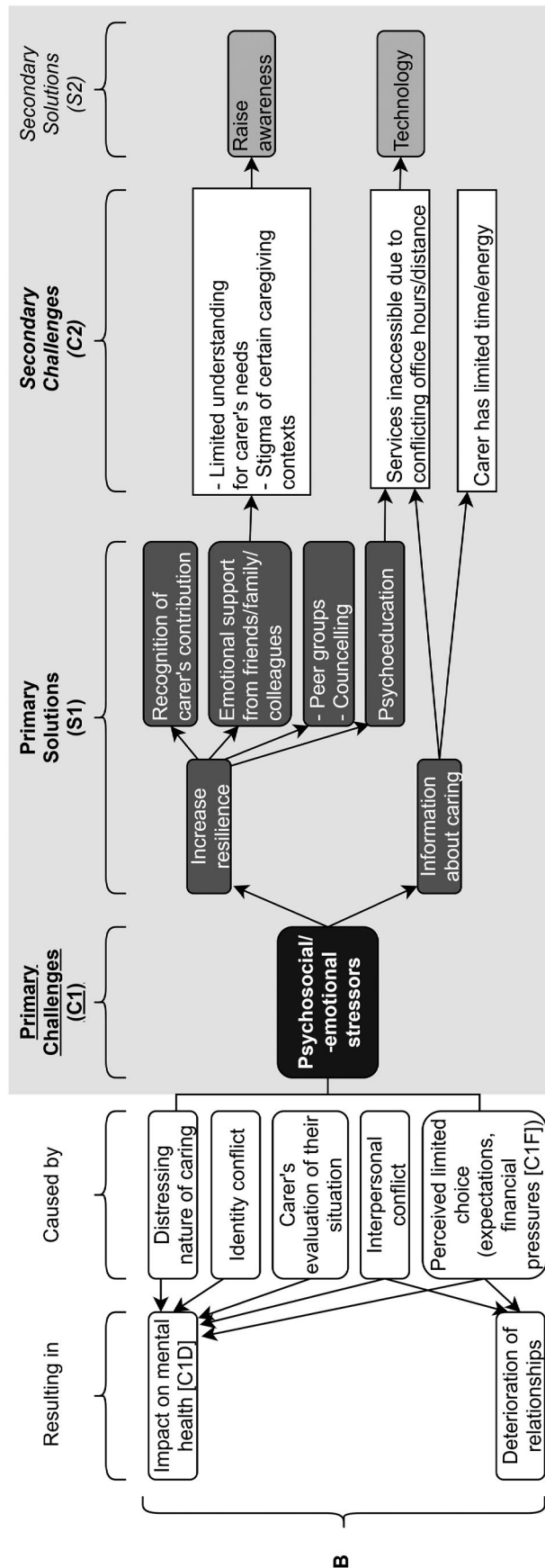


FIGURE 5 Application of the framework for Primary Challenge C1B 'Psychosocial/-emotional stressors' (PRC, person receiving care)

the cared-for person. While spouses typically assumed the caring role without question, decisions regarding involvement with caring for a parent were often not straightforward for siblings. Proximity, both emotional and locational, was a factor in this, as was employment status. Those with no job or greater opportunities for flexibility were expected to take on the role of main carer. This was also the case for siblings who worked in the (health-) care sector (double-duty carers). Parents of children with special needs usually negotiated roles and responsibilities, some finding more rigid role assignments and some sharing them more equally. Some, particularly double-duty carers, had difficulties with their identity. They were unsure whether they were primarily carers or workers and had trouble prioritising one role or the other, although women, especially mothers often prioritised caring. Double-duty carers additionally had trouble separating their professional carer role from their informal one, causing confusion and uncertainty. Conflict was an additional source of distress. Relationships with friends and family, which could be an important source of emotional and instrumental support, often suffered due to the carer's lack of time and attention. Family members who were only peripherally engaged with caring could create conflict when they criticised the carer or tried to interfere with the care arrangement. Caring could sometimes exacerbate underlying family conflicts. The cared-for person could create conflict if they rejected the care arrangement, made additional demands on the carer's time, were unappreciative or generally had a difficult relationship with the carer. Conflict at work could arise from negative attitudes of employers and co-workers with a limited understanding of the carer's situation. Carers' own evaluation of their situation could further impact their psycho-emotional well-being. They often described feeling guilty for having to prioritise work over care and vice versa. Many also expressed resentment for the situation they were in and feelings of being abandoned and not appreciated for what they contributed. Carers sometimes struggled with their confidence, many doubting their ability to successfully combine work and care, feeling that they were unprepared and did not know enough about caring, or perceiving themselves as unreliable at work.

Increasing carers' resilience was seen as very helpful and several strategies have been identified to that end, such as **emotional support**, often provided informally by friends, family and colleagues. A supportive culture at work had a massive impact on carers' well-being. Often, however, carers found **limited understanding for their needs** and concerns and the **stigma associated with some caregiving contexts** meant that this form of support was not always very effective. **Raising awareness** on a societal level could lead to greater understanding for carers and eliminate stigma. **Peer groups** in the community and at work, both online and in the physical world, created a safe space and helped carers share their experience and get support from people in similar situations. **Counselling**, either privately organised or provided at the workplace, also helped people get emotional support and increase their resilience. On top of enabling them to access required support, **recognition of their contributions** by their families and society made carers feel better about their situation.

Psychoeducation by professionals or specifically developed programmes helped carers to increase their resilience, confidence and self-efficacy, develop organising and coping skills, and deal with personality traits such as perfectionism. These programmes could help carers change their attitude towards their situation and focus on the positive aspects of caring, improving their well-being. Some found that caring gave them a purpose and were proud and grateful that they were able to support their loved-one. Others found strength in their faith or culture. Psychoeducational programmes delivered in a community peer group setting were often **inaccessible due to conflicting office-hours or distance**. *Technology* was a solution, delivering these programmes via web-based platforms.

Receiving personalised **information about caring** and targeted advice could increase carers' confidence in their abilities. This information was provided directly by healthcare professionals, case managers employed by their workplace, information events organised by employers, or peers. Getting the required information could be challenging for carers due to **limited available time and energy** and some services were **inaccessible due to conflicting office-hours or distance**. *Technology*, dedicated websites and discussion fora, can provide these services independent of time and location.

4.3 | C1C) Distance (Figure 6)

Challenges arose from the physical **distance** between the workplace and place of residence of the cared-for person. Having to travel between these places and their own home could take up a lot of time and travel costs could start to add up [see C1F]. If services were used to help with caring, for example, day care centres, the distance between those, workplace and place of residence could also create difficulties, especially if there was no adequate transportation for the cared-for person and business-hours conflicted with carers' work hours. This meant that they were often late for work or had to leave early. Distance was an important aspect to consider regarding carers' ability to respond to emergencies at home. Carers who worked and lived at a substantial distance from the person they cared for found that commuting daily was not possible. Caring at a distance, their role was

primarily the management of any care arrangement they had organised. This could be very time-intensive and difficult, as they were not able to solve arising issues or respond in person to emergencies. Carers experienced feelings of guilt as they were not able to be more present for their loved-one. Constantly worrying and investing a lot of time in care management could result in presenteeism. Many carers saved up their vacation or weekends, which they might have needed for recreation, to travel to the cared-for person.

Help with caring could be a solution for carers, as were **work adjustments** [see S1A]. Some long-distance carers found that they had to **move** so that they lived closer to either the person they cared for, the services they needed to help with caring or their workplace. **Relocating the cared-for person** into their own home could present another solution, but **they could reject** this idea, and even if they did not, cohabitation could mean greater potential for interpersonal conflict [see C1B].

4.4 | C1D) Carer's health (Figure 7)

Carers' health, physical and mental, had a big impact on their ability to work and care. Health problems might have already existed before they started caring or developed because of chronic physical and emotional exhaustion. Carers often described having trouble to get enough sleep. Being unhappy with their current situation or worrying about their future and their loved-one caused them sleepless nights. Caring could also disrupt sleep, for example, some carers of people with dementia reported continuous calls as their loved-one was disoriented or lonely or monitoring equipment they used kept them awake (e.g. bed sensor alarms). This chronic exhaustion could lead to decreased productivity at work and increase the risk of accidents or mistakes. It could also result in carers having to take sick leave.

Seeking medical or **professional help** would be important but many carers **did not prioritise their personal health** as caring for their loved-one did not leave them enough time. **Conflicting office hours** of professionals posed an additional access restriction. The *workplace could be a valuable source of healthcare* through occupational health services and initiatives which aimed to increase the well-being of workers, such as yoga or relaxation classes. Some carers also made

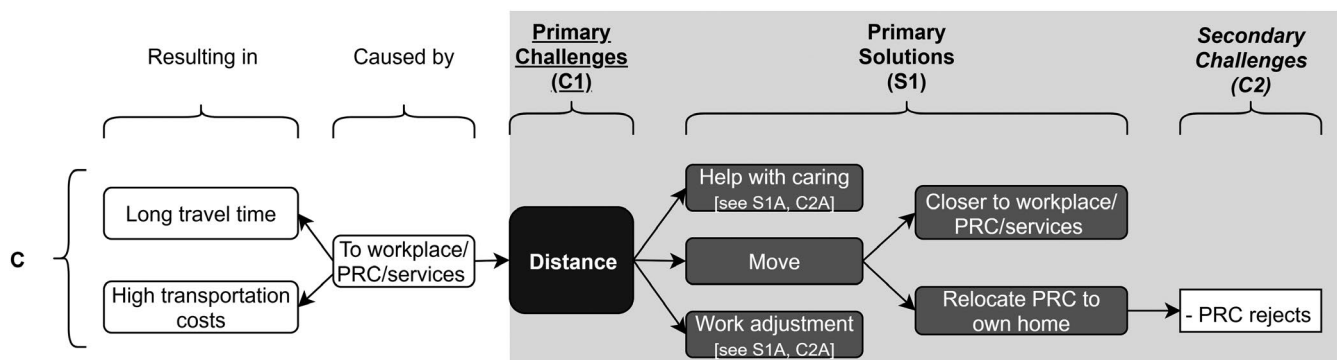


FIGURE 6 Application of the framework for Primary Challenge C1C 'Distance' (PRC, person receiving care)

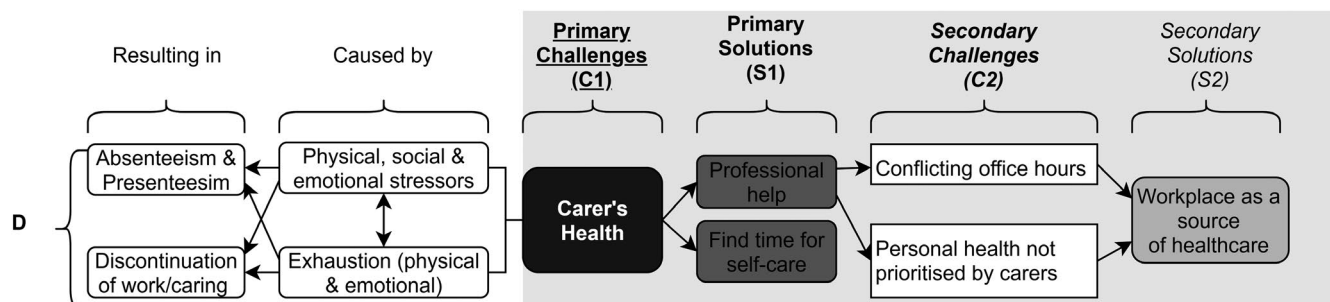


FIGURE 7 Application of the framework for Primary Challenge C1D 'Carer's Health' (PRC, person receiving care)

an effort to **find time for self-care** which could range from spending time with friends to 'pampering' or even just a few minutes every day for themselves.

4.5 | C1E) Returning to work (Figure 8)

Returning to work or finding a job was difficult for carers who had had to leave work or had never had a job due to their caring responsibilities. Carers expressed concerns about the gap in their career and that their skills had become outdated. People who had become carers early in life might have experienced opportunity costs regarding their education. This could have long-term consequences on their careers as well as their confidence. Some carers expressed dismay that caring was not recognised as a skill in the job market. Additionally, returning to work might only be possible when caring ends, which might mean the death of the cared-for person. This could be a very distressing time and the sudden loss of benefits received to support caring could create enormous additional pressure for carers in mourning to find work quickly.

Creating opportunities for training and education, sensitive to the interests, needs and resources of carers, as well as the needs of the job market, were very helpful for carers looking for work. Access to further and higher education and support in developing ambitions and perspectives for their careers and lives were important for young carers. Work placements specifically designed for carers helped people gain valuable job experience and on-the-job training which could be organised around their caring responsibilities. Some employers, particularly

in markets where qualified labour was in short supply, played a crucial part in enabling carers to return to work by maintaining close contact to their (former) employees and including them in job training. Many carers desired the **recognition of caring skills** (e.g. social skills, management skills) on the job market and valued support to identify their skills. Carers looking for work after a long absence might profit from **support with the job search**, building up skills, confidence and self-efficacy, helping with CV writing and job interview training. Supporting carers to develop business ideas and transition into self-employment was also mentioned as a potential solution.

4.6 | C1F) Financial pressure (Figure 9)

Financial pressure was a frequently mentioned problem. Travel costs for long-distance carers, therapies and especially care services could add up substantially. Some carers had to reduce their work hours to meet the needs of the cared-for person, which meant a reduction of income. Having to take unpaid leave or exit the job market meant that carers often had no income at all. This could also impact on their pension entitlements and insurance protection. Many carers thus felt that they had no choice but to work even though they needed more time to care which could affect their health [see C1B&D]. Some carers had to use up their **private funds or take out loans** to meet the costs and often incurred **debt**.

Some **workplaces provided financial assistance** in the form of benefits, special insurance schemes or subsidised care services. An **unsupportive workplace culture or line-manager** limited the accessibility of these solutions as carers did not feel confident to ask for

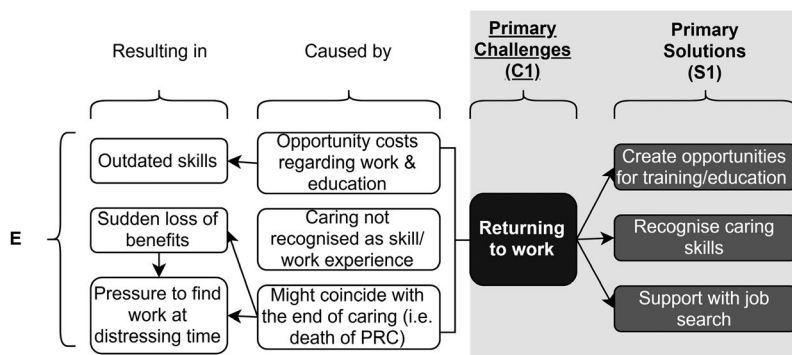


FIGURE 8 Application of the framework for Primary Challenge C1E 'Returning to work' (PRC, person receiving care)

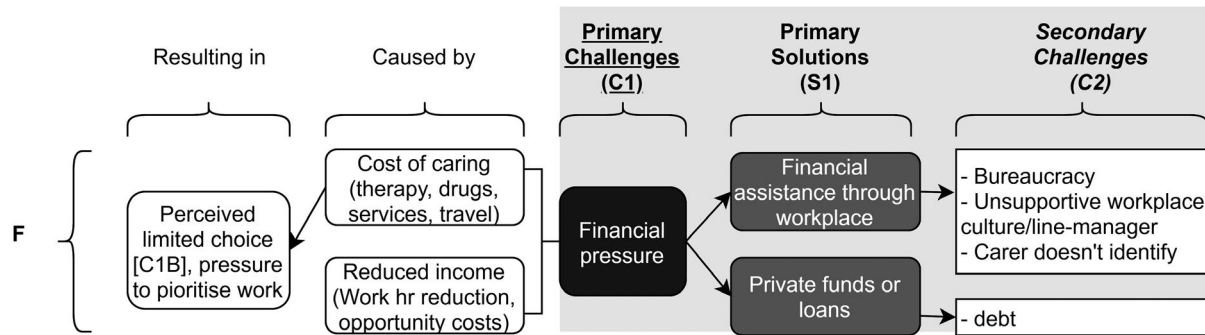


FIGURE 9 Application of the framework for Primary Challenge C1F 'Financial pressure' (PRC, person receiving care)

them or *did not identify as carers*. *Bureaucracy* also restricted access to financial assistance.

5 | DISCUSSION

This paper comprehensively reviewed the challenges of combining work and care and solutions described in the literature to address these challenges. The outcome is a conceptual framework which serves to better understand the complexity of work-care reconciliation. The framework links challenges to potential solutions while also highlighting any consecutive challenges which can potentially arise from these solutions. The framework can thus be used by those supporting or developing support for working carers to better understand their needs and potential shortcomings or barriers to solutions.

The analysis revealed that the workplace as a source of both challenges and support appears to be relatively well researched and understood. Flexibility regarding work hours and workplace, as well as the ability to take leave when required, were essential for carers. This reflects findings from a recent Carers UK (2019) report which identified flexible work and paid care leave as the second and third most desired solutions for working carers. However, flexible work was not always possible or accessible if the organisational culture or line-managers were unsupportive. Many carers were unwilling to self-identify at work because they feared negative career repercussions, making workplace carer support inaccessible. Ireson et al. (2018) investigated available workplace carer support in different sectors and found organisational values an important factor, determining availability and accessibility. Similarly, a supportive line-manager/employer was the most desired solution identified by Carers UK (2019). The importance of autonomy and social support at work to mediate the effects of high job demand on emotional well-being has been described in the job demand-control and job demand-control-support models (Johnson & Hall, 1988; Karasek, 1979). There is a gap in the literature regarding different levels of autonomy at work—particularly regarding work schedule, working from home and taking breaks—and how these impact on the challenges carers face and the solutions and support they can access. Flexible work does not automatically mean autonomy over one's work schedule. Working from

home too warrants closer examination. Kossek, Lautsch, and Eaton (2006) found that teleworking could decrease work–family conflict if workers employed adequate boundary management, but their study did not focus on carers who might find boundary management more difficult. Additionally, more research is needed to understand the challenges of self-employed or gig-working carers and those on zero-hour contracts.

High caring demands, taking up too much time and energy and impacting on productivity, and unpredictable care needs, making it difficult to plan ahead, were identified as important challenges by many working carers, irrespective of the age or condition of the cared-for person. It appeared that the kind of care need (e.g. constant monitoring, challenging behaviour) and the amount of time spent caring had a substantial impact on carers' ability to remain in work. Pickard et al. (2018) too established a connection between time spent caring and security of employment, stating that providing ten hours of care or more per week put carers' employment at risk. In the reviewed publications, a significant difference between caring for a child with special needs and caring for an adult was the availability of adequate formal and informal help with care. Parents of children with special needs, especially mothers, appeared to find it more difficult to find suitable help and were often faced with stigma (Bourke-Taylor et al., 2011; Brennan, Rosenzweig, Jivanjee, & Stewart, 2016; Bruns & Schrey, 2012; Chou & Kröger, 2014; Home, 2008). It is likely that cultural context influences the availability of support, particularly cultural assumptions regarding the role of a mother and family in general, the responsibilities of the state, and the visibility and acceptance of illness and disability in society. The degree to which societies see care as a public or private issue reflects cultural norms and attitudes regarding family and is manifested in their arrangements and legislation regarding social care. Accordingly, countries which view care as a family issue tend to have low public involvement whereas countries which see it as a public responsibility provide either financial support, which can be used to finance privately organised care or publicly funded services (Bettio & Plantenga, 2004). A closer investigation of potential differences when combining work and care for a child or adult with special needs in different cultural contexts could contribute to a greater awareness for the necessity of solutions to be sensitive to different caring situations.

Carers' health, appraisal of their situation, and coping strategies were important in their ability to manage work and care. Cultural norms and expectations as well as interfamilial and -personal dynamics impacted on this. Interventions that aimed to increase carers' resilience and improve management and coping strategies were seen as beneficial to increase carers' psycho-emotional well-being. Carers often described a lack of care-related knowledge. Despite potentially positive impacts of increased knowledge on caring, Alzheimer's Research UK (2015) found that, sometimes, knowing more about the condition of their loved-one and their prognosis can interfere with carers' coping strategies. It might be helpful in such cases to provide information in connection with professional or peer support. Additionally, a cultural shift would be required that no longer views carers as a resource but acknowledges their contribution and enables them to access the solutions and support they need to care, work, return to work and fulfil their own life goals. Finally, technology has been mentioned by many publications as playing a part in support for working carers, although often only as a side-note. More research is needed to understand which and how technology can help people to better combine work and care.

This review has several strengths and limitations. The search was not limited regarding work and care context and includes publications from different cultural settings, providing a broad view on challenges and solutions of combining work and care. Limiting the search to English, however, could have limited further understanding. Influential carer support organisations such as Carers UK produce research which is not published in peer-reviewed journals but provides invaluable insight into issues relevant for working carers. Including grey literature in the analysis is thus a distinct strength of this review. However, it comes at the price of not being able to assess the quality of included publications due to their diversity, although this is not necessarily required for a scoping review (Pham et al., 2014). Another limitation of the scoping review methodology is that it does not allow the measurement of effect sizes and provides limited opportunities for direct comparison of findings of different studies. Thus, although including diverse work and care contexts in this review provides a more inclusive view on working carers' challenges, statements regarding the specific nature of the challenges which arise from these different care giving contexts are limited. The feedback from stakeholder consultations on content and design was invaluable in constructing the conceptual framework from very complex data.

6 | CONCLUSION

This review provides a framework which links challenges of combining work and care with potential solutions and serves to highlight additional challenges resulting from these solutions. Owing to the diversity of care giving contexts and available solutions, reconciling work and care is often a very complex effort. When aiming to support working carers it should be considered whether the offered solution is accessible to carers, whether it could create additional challenges for carers and whether and how other stakeholders such

as the cared-for person, employers and members of the care network are impacted.

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CONFLICT OF INTEREST

All of the authors confirm that they have no competing interests.

AUTHORS' CONTRIBUTIONS

AS took the lead in developing the review protocol. MH and LdW reviewed and approved the protocol. AS and JV screened and selected the relevant articles and resolved disagreements by discussion and seeking opinion from CA, MH, MS and LdW. AS extracted and analysed the data and drafted the manuscript. MH, MS and LdW contributed significantly to the subsequent drafts and the final manuscript. All authors reviewed and approved the final manuscript.

STATEMENT OF ETHICS APPROVAL

N/A.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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