

The impacts of COVID-19 on unpaid carers of adults with long-term care needs and measures to address these impacts: a rapid review of the available evidence

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Abstract

Context: Unpaid carers are the backbone of long-term care (LTC) systems around the world. The COVID-19 pandemic has further increased the pressure many unpaid carers experience, however, in contrast to people living in residential care settings, their experience has been largely absent from public reporting.

Objective: We aim to map the available evidence on the impact of COVID-19 on unpaid carers of adults with LTC needs to provide an overview of measures identified from the literature to address the impact.

Method: We conducted a rapid review of the academic and grey literature on unpaid carers of adults with LTC needs during the COVID-19 pandemic.

Findings: We identified five key themes that highlight the impact of COVID-19 on unpaid carers of people living in the community. These include, changes in care responsibilities, concerns around COVID-19 infections, changes in the availability of formal and informal support, financial as well as physical and mental health implications. Unpaid carers of people in residential care settings reported difficulties in communicating with residents, concerns about quality of care and COVID-19 entering the care home. We also showed that technology, financial assistance and support for working carers can help to mitigate these effects.

Limitations: The evidence reported in this review is based largely on cross-sectional data and some of the data reported relies on convenience samples.

Implications: We highlight the financial and health impact many unpaid carers experience. Given the vital support carers provide to adults with LTC needs policy makers should consider supporting unpaid carers to mitigate the negative impact on their lives.

Introduction

Unpaid carers represent the backbone of long-term care systems around the world. Already before the COVID-19 pandemic a large number of people around the world have been providing substantial amounts of unpaid care to relatives and friends with long-term care needs. In England and the United States, for example, there are an estimated 5 million and 40.4 million unpaid carers supporting older people, respectively (Brimblecombe et al. 2018; US Bureau of Labor Statistics 2019). In countries where community and residential long-term care services are less prevalent, almost all long-term care is provided by unpaid carers, most of whom are women (Wimo, Gauthier, and Prince 2018). Many provide personal care (activities of daily living) and/or help people with care needs with daily tasks and support (instrumental activities of daily living and supervision), such as help within the household and transportation (OECD/European Commission 2013, pp.9-10). There is substantial evidence that unpaid carers incur financial as well as physical and mental health consequences (e.g. Bom et al., 2019; Butrica & Karamcheva. 2014).

The COVID-19 pandemic has raised the profile of long-term care and made many of the issues the sector has been struggling with for years visible. However, most attention has been paid to people living and working in residential care settings who experienced disproportionate mortality (Comas-Herrera et al. 2020). So far there is limited knowledge on the impact of the COVID-19 pandemic on family and other unpaid carers, measures put in place to address this impact and evidence of their effect. We have brought together information from around the world to map the available evidence.

Methods

We conducted a rapid review of the literature to map the available evidence regarding the impacts of COVID-19 on unpaid carers and measures adopted to mitigate these impacts.

We included:

- publications in English and German that reported evidence collected from unpaid carers caring for adults with care needs.

We excluded publications that:

- were only based on the perspective of health and social care professionals and people with care needs without providing data from unpaid carers
- discussed issues concerning unpaid carers but did not report any data (e.g. letters, commentaries, editorials).
- focused on unpaid carers of children and young adults
- where the proportion of carers of adults with long-term care needs was substantially smaller (<20% of the sample) than that of carers of children and younger adults (aged 25 and under)
- did not allow for the impact on unpaid carers of the different groups to be distinguished.

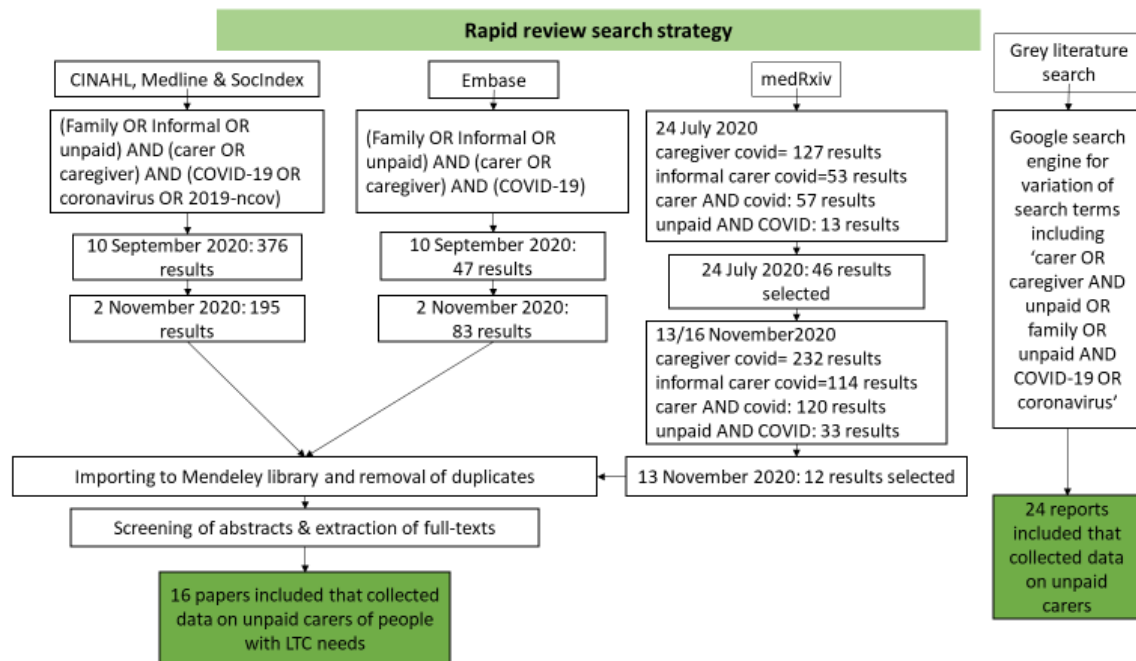
We decided to exclude young carers and the carers of children and younger adults as the impact on their lives and the need for support are likely to be different.

KLD initially searched the academic databases CINAHL, Medline, Socindex and Embase for articles focusing on informal, unpaid carers (i.e. caregivers) and COVID-19 on 3 July. The search was repeated on 21 July, 10 September and 2 November to reflect the rapid development of the literature. A also searched medRxiv, a preprint database for papers that have not yet completed the peer review process. The results from the academic databases as well as potentially relevant articles from medRxiv (based on title) were imported to the reference management software Mendeley, duplicates were removed, titles and were screened and relevant full texts were extracted in line with inclusion and exclusion criteria described above.

We included 16 academic papers in this review (see Table 2). Two papers identified through medRxiv had not completed the peer-review process at the time of writing. Both papers have since been published in academic journals (see Table 2). We were unable to assess the relevance of three academic papers where title and abstract met the inclusion criteria due to publisher access restrictions.

In addition, KLD searched the LTCcovid.org website for evidence on the impact of COVID-19 on unpaid carers and used the Google search engine to identify relevant studies in the grey literature using a mix of search terms. A detailed overview of the search strategy can be found in Figure 1. The review of the grey literature led to the inclusion of 24 reports. An overview of the reports included can be found in Table 3.

Figure 1: Overview of rapid review search strategy



KLD and ACH organized narratively the findings on impact of COVID-19 unpaid carers of people living in the community into five key themes. We developed these themes by organising findings by key words that were then iteratively grouped into bigger themes (e.g. key words, such as ‘time spent caring’, ‘new carers’, ‘carer characteristics’ were organised under the theme ‘care commitment’) .. These five themes that emerged are: care commitment, concerns related to COVID-19, availability of formal and informal support, financial implications and carer health. In addition, we summarised findings on the impact of COVID-19 on unpaid carers of people living in residential care settings. We also mapped the available information on measures used to address the impact on carers and evidence of how well this worked. This includes information on the use of technology, receipt of financial assistance and support to enable working carers to combine care and work commitments.

Results

In this rapid review we identified 40 studies (n=16 academic journal articles, n=24 reports) from 10 countries (Argentina (n=2), Australia (n=1), Canada (n=2), Germany (n=2), India (n=1), Italy (n=1), Japan (n=1), Taiwan (n=1), the UK(n=15) and the USA (n=14)) on the impacts of COVID-19 unpaid carers and measures to support them. The evidence presented is based on qualitative (n=8), quantitative (n=27) and mixed methods (n=5) research, conducted almost exclusively online or by phone (only Suzuki et al. (2020) explicitly reported the possibility of face-to-face interviews) using convenience samples (n=29) but also nationally representative datasets (n=11). Two thirds (n=26) were academic studies, but 13 reports were produced by voluntary sector organisations and one report was provided by a private health insurance provider (Blue Cross Blue Shield, 2020). An overview of the types of studies can be found in Table 1.

We organised findings on the impacts of COVID-10 on unpaid carers of people living in the community into five key themes that emerged from the literature. These are: care commitment, concerns related to COVID-19, availability of formal and informal support, financial implications and carer health. In addition, we summarised findings on the impacts of COVID-19 on unpaid carers of

people living in residential care settings. Detailed information on each of the themes by country and publication can be found in Table 4.

We also mapped the available information on measures used to address the impact on carers and evidence of how well this worked. This includes information on the use of technology, receipt of financial assistance and support to enable working carers to combine care and work commitments.

The impacts of COVID-19 on unpaid carers

Care commitment

Available evidence indicates that more people have become unpaid carers since the onset of the COVID-19 pandemic. The evidence shows that women continue to disproportionately take on unpaid care responsibilities and that carers who have taken on care responsibility since the onset of the COVID-19 pandemic are younger and often also have childcare responsibilities. Across countries, the care responsibility and commitment of most carers who were already providing care prior to the COVID-19 pandemic has increased. For a small proportion of carers, however, the amount of care they provided declined. This affected particularly carers supporting people outside their household who adhered to government distancing guidelines and travel restrictions (Office for National Statistics 2020; Carers UK 2020a, p.8)

Concerns related to COVID-19

We identified six key concerns. First, carers across countries were worried about catching COVID-19 and infecting the person they care for. Evidence from Germany and the US shows that carers report greater worry around infection than non-carers. Second, carers in the USA and the UK and carers of people with dementia in India and the USA worried about what would happen if they became unable to care if they or the person they care became ill or required hospitalisation. Third, adherence to movement restrictions and distancing guidelines posed challenges to carers and people with care needs. Fourth, particularly at the beginning of COVID-19 related public health measures unpaid carers reported difficulty in accessing relevant resources (e.g. food, hygiene products, PPE, medical items) due to shortages and movement restrictions. Fifth, government communication strategies affected carers' ability to respond to the pandemic. For example, while most unpaid carers (87%) in Germany felt they had access to good and comprehensible information and 81% of respondents felt they could adhere well to guidance, carers in the UK reported a lack of information, 'widespread confusion' about government advice, and challenges adhering to it (Carers UK 2020b, p.19; Eggert et al. 2020; Lariviere et al. 2020, p.11). Finally, while about half of carers surveyed in the UK felt they could manage their caring responsibilities at the moment, two-thirds worried how they would deal with further lockdowns and more than half about how they would manage during winter due to weather, limited opportunities to get out, seasonal illness and their own health (Carers UK 2020a, p.14).

Among carers of people with dementia, we identified a further theme: The impact of reduced social interaction and physical activity on the progression of dementia symptoms. Carers reported that since the onset of COVID-19 related public health measures the health and cognitive abilities of people with dementia had declined more rapidly and that people with dementia had developed more behaviours that carers found challenging to respond to. In Argentina, unpaid carers reported an increase in the use of psychotropic medication (Cohen et al., 2020a, p.4)

Availability of formal and informal support

Reduced availability of community services resulted in many carers having to increase their care commitment. For some carers, the unavailability of home help can create major challenges. We

identified three main reasons that led to the unavailability of home care. First, home care staff were unable of help to reach people's homes due to travel bans; second, reduced availability of services due to staff shortages and, third, people who use care and their families choosing to reduce services out of concerns about infection risk. We also identified a pattern where carers persisted with formal support, despite concerns around infection, as they were worried about not being able to access services again. Carers also voiced concerns whether previously established community support services would become available again at all (Giebel, Cannon, et al. 2020).

Carers of people with dementia faced particularly complex situations as studies report that many people with dementia find it difficult to follow public health restrictions and carers explain that reduced availability of support structures has an effect not just on behaviour that carers find challenging to respond to but also on their cognition (Eggert et al. 2020; Giebel, Cannon, et al. 2020; Roach et al. 2020; Vaitheswaran et al. 2020; Carers UK 2020b).

The support through informal networks, such as family, friends and neighbours was mixed. While many carers, including carers of people with dementia reported the receipt of continuous practical and emotional support, others reduced or stopped the involvement of their informal network due to infection risks and adherence to government guidelines.

Carers also reported experiencing reduced availability and delay in access to medical care for themselves and the person they provide care to. Others chose to avoid or delay medical care out of concerns about infection risk.

Financial implications

Prior to the COVID-19 pandemic, many carers were experiencing challenges in combining work and care and financial implications because their care responsibility prevents them from working (full-time) (Hosking, Maccora & McCallum 2020, p.13). The reduction of available community services, as discussed above, has created even greater challenges in combining paid work and unpaid care. While some carers who can work from home report experiencing greater flexibility to manage their responsibilities, this has been challenging for others. Those working in jobs that cannot be performed from home, expressed concerns around infection risk in their workplace.

Since the pandemic, carers across countries have reported financial concerns as a source of stress (Rosalynn Carter Institute for Caregiving 2020, p.3). For many US and UK carers financial implications posed a risk to people's ability to meet basic needs, including food. The financial impacts do not seem to have been as much of a concern in Germany (Eggert et al. 2020). Self-funded retirees in Australia have also been affected as they experienced a substantial drop in their finances 'when the Reserve Bank reduced cash interest to a record-low'.

Carer health

Some carers reported that that they gained positive feelings. Many others, however, reported a decrease in pleasant moments. Evidence from several countries shows that large proportions of carers have experienced increased burden and stress as well as other stress related symptoms, including difficulty concentrating, sleep loss, irritability and feelings of anguish. Unpaid carers also reported feeling more socially isolated and lonely than before the pandemic. This risk appeared greater among women, younger carers and those experiencing financial difficulties. Studies also report worsened mental health (e.g. depression, anxiety), mental well-being and physical health among carers.

Carers adapt

While this review highlights the disproportionate negative impact many carers incur, there is also important evidence of strength, resilience and adaptation. Carers have reported drawing strength from their informal support network (family, friends, online peer network) and emphasised the importance of making time for themselves and prioritising self-care.

Carers of people in residential care

Across countries, lockdown measures to protect vulnerable populations in care homes meant that unpaid carers were unable to visit their relatives over weeks and months. The inability to visit their relatives left many carers feeling stressed, angry, guilty and reliant on overstretched care home staff for updates and to facilitate virtual contact with their relatives. Carers reported difficulties in assessing the health status and well-being of their relatives as well as the quality of care they received. They also worried about how their relatives were treated without their ability to monitor the situation and the long-term implications of sustained isolation on their relative.

Measures to address the impact on carers and evidence on their impact

The use of technology

Carers reported that services and interventions using remote services have increased since the beginning of the COVID-19 pandemic. Five main purposes for the use of technology were described. First, to maintain social contacts; second, for peer support; third for contact with social services and care providers; fourth for the delivery of medical care and fifth, for ordering supplies.

Many carers have provided positive feedback on the experience of remote services and interventions. The evaluation of a remote peer support intervention for carers during the COVID-19 pandemic showed that over time carers developed friendships and experienced the virtual meeting as a safe space where they could take a break, relax and exchange experiences. The research emphasised that it took a coach to lead the group as well as time for these relationships to build and a sense of community to emerge (Lariviere et al. 2020). Other research, however, has pointed out issues around access, privacy and the ability of people with care needs to engage with the online tools as well as that the important recognition technological interventions cannot replace in-person practical support.

Receipt of financial assistance

Some carers received financial assistance. This included paid leave, the ability to flexibly spend funds that usually go towards day care and in-kind provision of protective equipment in Germany, as well as financial stimulus payments in USA. The UK government's introduction of the 'furlough scheme', which provided people whose jobs were temporarily suspended due to COVID-19 related public health measures with 80% of their income, initially ensured an income for approximately 13% of working carers, but many were worried about the future (Carers UK 2020b, p.13).

Support to enable working carers to combine care and paid work commitments

In Germany, government policy has enabled carers to take up to 10 days of paid leave during the COVID-19 pandemic. Even though carers participating in a study acknowledged difficulties in combining work and care, none of the respondents in the survey had taken up the opportunity for paid care leave (Eggert et al. 2020).

Discussion

Our review highlights that many carers have increased their care commitment and others have taken on new care responsibilities. There is great concern among carers that the person they care for could suffer consequences of a COVID-19 infection and carers have worked hard to prevent infections.

Where government advice was communicated clearly this helps carers to adhere to it. Reduced availability of formal and informal support structures has increased the responsibility of carers and challenged their ability to maintain employment. Many carers have also reported experiencing negative financial as well as physical and mental health implications. Women, younger carers, people with existing financial difficulties and BAME carers have been found to be at greater risk of negative outcomes (e.g. financial difficulties, health, loneliness). Carers of people living in residential care settings have found it difficult to remain in contact with their relative, have been worried about their health status, the quality of care they receive and feared negative long-term implications due to the prolonged social isolation experienced by their relatives.

Our review is based on data that has been collected since the beginning of the COVID-19 pandemic, but apart from the repeat surveys conducted by USagainstAlzheimer's and the two surveys by Carers UK, the studies rely only on cross-sectional data. The absence of longitudinal data means that it is not yet possible to observe patterns over time or establish causality, however, some data sources, such as the UK Understanding Society survey will enable comparisons to pre-COVID experiences. In addition, some of the reported data rely on convenience samples of people who either already have been in contact with services or who have responded to research advertisements. It is possible that the experiences of these groups differ from carers who are not in contact with services or not volunteering their participation. This may have affected results. Nevertheless, the information summarised in this review provides an important and up-to-date overview of the impact of the COVID-19 pandemic on unpaid carers. Our rapid review has also highlighted the importance of policy responses to mitigate and prevent the negative implications many unpaid carers experience.

Policy implications

For many carers the COVID-19 pandemic had an impact on their care responsibility, but also on their income and health

The provision of intensive unpaid care is generally associated with negative implications on carers' mental and physical health, their ability to engage in paid employment and ultimately, carers' income level leading to greater risk of 'vulnerability and poverty in old age' (World Health Organization 2020, 24). Our rapid review has shown that the COVID-19 pandemic is likely to have exacerbated all of these risks. Evidence from the UK and US show the fragile situations many carers live in worsened as everyday expenditure increased, leaving many reliant on foodbanks and vulnerable to hunger and even homelessness (Bennett, Zhang, and Yeandle 2020a, p.2; Rosalynn Carter Institute for Caregiving 2020, p.17). Labour market interventions, such as the British furlough scheme or the American stimulus cheque, even though not particularly targeted at carers have protected many working carers from economic hardship, while enabling them to compensate for the suspension of services (Carers UK 2020b, p.13; Rosalynn Carter Institute for Caregiving 2020). In countries, such as Germany, where informal carers are seen as a key component and are therefore offered access to a broader safety net of social protection mechanisms during "normal times", the impact appears to have been less severe (Zigante, 2018, p.18; Curry, Schlepper & Hemmings, 2019; Rothgang et al., 2020). This highlights the importance of social protection mechanisms. Other recommended measures include paid leave for unpaid carers, direct payments and unemployment benefits, including for those who voluntarily stopped working due to care responsibilities and/or infection risk. These measures should be universally available, easily accessible and not require administrative burden for the carer (Stokes and Patterson 2020, p.420-421).

Carers need support

Our review has further emphasised the importance of dedicated support structures for carers. The suspension of community services and voluntary reductions of informal support networks to reduce the risk of infection has not just increased the care load but also created considerable challenges for many working carers in combining work and care responsibilities. Even before the COVID-19 pandemic, access to long-term care services and benefits was difficult as their availability and funding is limited in most countries (World Health Organization 2020, 24). UK carers, for example, have reported persisting with domiciliary care support despite concerns around infections out of fear of not being able to access this support post COVID-19. Others who have lost their paid helpers struggle to sustain the care situation.

As outlined in the WHO policy brief on long-term care and by other organisations, it is crucial that in emergency situations carers (including paid and unpaid) receive permission to travel to respond to their care responsibilities, that they receive access to up-to-date information and actionable guidance for carers in different situations (e.g. for carers of people with dementia, for people providing end of life care), as well as protective equipment to enable them to protect themselves and the person they care for and support in developing contingency plans should they become unable to care (Carers UK 2020b, pp.23-24; World Health Organization 2020, 24). Carers also require timely access to health care for themselves and for the person with care needs (Vaitheswaran et al. 2020, p.1190).

Improved employment conditions for domiciliary care workers to increase the pool of available care staff could play a crucial role in supporting unpaid carers. Increased availability of trained domiciliary care workers would also help ensuring more consistent care with fewer changes of staff, which is likely to improve not just person-centred care but would also reduce the risk of infection as care staff would be in contact with a smaller group of people with care needs.

Demands for more practical and financial support have been voiced uniformly. Measures carers require include access to quality and affordable respite care so that carers can take breaks, resources and processes for contingency planning, mental health services, training, peer support as well as flexible employment and education policies (e.g. paid care leave, flexible hours, working from home), support with end of life care, death and bereavement and official recognition of carers in health records as key care partners and informant of the preferences and wishes of the person with care needs and in recovery plans (Carers UK 2020a, p.23, 2020b, p.23; Carers week 2020; Rosalynn Carter Institute for Caregiving 2020; World Health Organization 2020, p.25). In order for these services to be sustained it is crucial that the relevant authorities receive sufficient protected funding and implement monitoring mechanisms (Carers UK 2020b, p.23).

Technology has been recognised as having potential to enable the provision of some of the services and carers have welcomed that some community services have moved online to support carers with emotional support, advice and virtual interventions, however, it has been highlighted that not all carers can access these resources and many miss in-person contact and practical support (Carers UK 2020b, p.23; Rosalynn Carter Institute for Caregiving 2020, p.30). For the successful implementation it will be crucial that service providers address barriers to access. One suggestion for meaningful and accessible engagement of unpaid carers and people with care needs were weekly public broadcasting programmes of educational programmes or interventions, such as exercise in the home or sensory stimulation activities (O'Shea 2020, pp.3-4).

Carers of people living in residential care settings

The concerns of carers of people living in residential care settings received considerable attention in the media, however, they have largely remained unsolved as the trade-off between the risk of infection and residents' quality of life has proven difficult to address. The Alzheimer's Society in England has recommended that at least one unpaid carer per resident should receive the status of a key worker, receive training, access to COVID-19 testing, PPE and vaccination when possible (Alzheimer's Society 2020b, p.10). Where in person contact is not possible, it has been emphasised that carers should be able to regularly connect virtually with the person they care for to reduce the detrimental impact of isolation. Care settings should also ensure that family members are able to monitor the situation of their relatives. A possibility to facilitate this may be through assigning designated staff members as primary contacts for each family (Hado and Friss Feinberg 2020).

Women continue to carry the bulk of care

The provision of unpaid long-term care historically has fallen into the female realm. Despite a lot of progress around women's roles in society and strides towards equality, unpaid care continues to be disproportionately provided by women and has been identified as key driver of inequality (United Nations 2020). The UN estimates that women and girls on average provide 'three times the amount of unpaid care and domestic work' compared to men and boys (Nesbitt-Ahmed and Subrahmanian 2020; UN Women 2020). According to Oxfam, female unpaid care work globally 'contributes at least US\$10.8 trillion' per year to the economy (Coffey et al. 2020; Mercado, Naciri, and Mishra 2020). Our review has highlighted the heightened vulnerability of female carers. While it has long been reported that female carers experience worse mental and physical health, our review has shown that this pattern persists, and likely worsened, during the COVID-19 pandemic. In addition to health outcomes, women have also been found to report greater social isolation, loneliness and financial stress. With the number of older people with long-term care needs expected to be increasing, the role of women in the labour force will become increasingly important. Many women already provide care on top of other family and employment responsibility. The United Nations emphasise, the ability of women to carry multiple roles is not infinitely elastic (United Nations 2020). The COVID-19 pandemic widened and highlighted the gender inequality gap, but it also offers the opportunity to design gender-responsive and age-sensitive social protection mechanisms to mitigate and eventually eradicate these inequalities (Nesbitt-Ahmed and Subrahmanian 2020).

Table 1: Overview of type of studies

<i>Reference</i>	<i>Research methods</i>			<i>Data collection</i>	<i>Sampling</i>		<i>Sector</i>		
	<i>Qual</i>	<i>Quant</i>	<i>Mixed</i>		<i>Convenience</i>	<i>Representative</i>	<i>academic</i>	<i>voluntary</i>	<i>other</i>
Argentina									
Cohen et al., 2020a		✓		Online questionnaire	✓		✓		
Cohen et al., 2020b		✓		survey	✓		✓		
Australia									
Hosking, Maccora & McCallum, 2020	✓			text based online survey	✓			✓	
Canada									
Redquest et al., 2020			✓	Online survey	✓		✓		
Roach et al., 2020	✓			Remote interviews	✓		✓		
Germany									
Eggert et al., 2020		✓		Online survey		✓	✓		
Rothgang et al., 2020		✓		Online survey	✓		✓		
India									
Vaitheswaran et al., 2020	✓				✓		✓		
Italy									
Cagnin, A et al., 2020		✓		Telephone-based interview		✓	✓		
Japan									
Suzuki et al., 2020			✓	Face-to-face / virtual survey	✓		✓		
Taiwan									
Yeh et al., 2020		✓		Telephone interviews	✓		✓		

UK									
Alzheimer's Society, 2020		✓		survey	✓			✓	
Baxter, 2020	✓				✓		✓		
Bennett, Zhang & Yeandle, 2020a		✓		Web-survey		✓	✓		
Bennett, Zhang & Yeandle, 2020b		✓		Web-survey		✓	✓		
Bennett, Zhang & Yeandle, 2020c		✓		Web-survey		✓	✓		
Carers UK, 2020a			✓	Online survey	✓			✓	
Carers UK, 2020b			✓	Online survey	✓			✓	
Carers Week, 2020		✓		Poll	✓ ⁱ			✓	
Gallagher & Wetherell, 2020		✓		Web-survey		✓	✓		
Giebel, Cannon et al., 2020	✓			Telephone interviews	✓		✓		
Giebel, Hanna et al., 2020	✓			Telephone interviews	✓		✓		
Giebel, Lord et al., 2020		✓		Online and telephone survey	✓		✓		
Lariviere, M. et al., 2020	✓			Virtual data collection	✓		✓		
Office for National Statistics, 2020		✓		Web-survey		✓	✓		
Willner et al., 2020		✓		Online survey	✓		✓		
USA									
Blue Cross Blue Shield, 2020		✓		Survey	✓				✓
Czeisler, Lane et al., 2020		✓		Web-based survey		✓	✓		
Czeisler, Marynak et al., 2020		✓		Web-based survey		✓	✓		
Park, 2020		✓		Internet panel data		✓	✓		
Rosalynn Carter Institute for Caregiving, 2020			✓	Online survey	✓			✓	
Savla et al., 2020	✓			Telephone	✓		✓		

				interviews					
University Center for Social and Urban Studies, University of Pittsburgh, 2020		✓		Online survey	✓		✓		
UsAgainstAlzheimer's A-LIST survey 1, 2020		✓		Online survey	✓			✓	
UsAgainstAlzheimer's A-LIST survey 2, 2020		✓		Online survey	✓			✓	
UsAgainstAlzheimer's A-LIST survey 3, 2020		✓		Online survey	✓			✓	
UsAgainstAlzheimer's A-LIST survey 4, 2020		✓		Online survey	✓			✓	
UsAgainstAlzheimer's A-LIST survey 5, 2020		✓		Online survey	✓			✓	
UsAgainstAlzheimer's A-LIST survey 6, 2020		✓		Online survey	✓			✓	
UsAgainstAlzheimer's A-LIST survey 7, 2020		✓		Online survey	✓			✓	

Table 2: Overview of peer-reviewed papers

<i>Reference</i>	<i>Title</i>	<i>Journal</i>	<i>Study information</i>
Argentina			
Cohen et al., 2020a	Living with dementia: increased level of caregiver stress in times of COVID-19	International psychogeriatrics	Survey among (n=80) unpaid carers of people with Alzheimer's Disease and other dementia conducted through the Aging and Memory Center and FLENI in Buenos Aires, Argentina, in April 2020. The majority of the sample (69.23%) of carers were female with a mean age of 56.21 years.
Cohen et al., 2020b	COVID-19 Epidemic in Argentina: Worsening of Behavioral Symptoms in Elderly Subjects With Dementia Living in the Community.	Frontiers in psychiatry	Survey of (n=119) unpaid carers of people with Alzheimer's Disease and other dementias who were patients at the Aging and Memory Center of FLENI. Participants reported on carer experiences during the first eight weeks of the coronavirus quarantine in Argentina. Most carers were female (71.9%) and over half of the sample (56.1%) were aged 45 to 65 years.
Canada			
Redquest et al., 2020	Exploring the experiences of siblings of adults with intellectual/developmental disabilities during the COVID-19 pandemic.	Journal of intellectual disability research: JIDR	There were 91 members of 'Sibling Collaborative' who participated in an online survey 'exploring support and concerns of siblings of people with developmental disabilities during the COVID-19 pandemic in Canada. The survey opened in May 2020 and remained available for 10 weeks. Participants had to live in Canada, had to be 19 years or older and had to have at least one brother or sister with developmental learning disabilities. The majority of respondents were female (95%) and 43% were aged 30 to 49 years, while 22% were 50 to 69 years old.
Roach et al., 2020	Understanding the impact of the COVID-19 pandemic on well-being and virtual care for people living with dementia and care partners living in the community	MedRxiv (now published in Dementia)	In-depth telephone interviews (n=20) with family members and carers of people with dementia in Alberta, Canada between 23 April and 21 May 2020.
India			
Vaitheswaran et al., 2020	Experiences and needs of caregivers of persons with dementia in India during the COVID-19 pandemic - A qualitative study	Am J Geriatr Psychiatry	Carers (n=31) of people with dementia were recruited through the Schizophrenia Research Foundation (SCARF) in Chennai, India. Carers were invited to participate if they care for and live

			with the person with confirmed clinical diagnosis of dementia and are aged 18 years. Just over half of carers were female (51.6%) and on average 54.06 years old.
Italy			
Cagnin, A et al., 2020	Behavioral and Psychological Effects of Coronavirus Disease-19 Quarantine in Patients With Dementia.	Frontiers in Psychiatry	The article reports on data from a survey with unpaid carers (n=4.913) of people with dementia (people with Alzheimer's disease 69%; people with Vascular dementia (16%), people with frontotemporal dementia (8%), people with dementia with Lewy Bodies (7%) who are regularly supported at 87 Italian memory clinics. The information was collected 1 month following the COVID-19 related quarantine measures were put in place in Italy.
Japan			
Suzuki et al., 2020	The behavioral pattern of patients with frontotemporal dementia during the COVID-19 pandemic.	International Psychogeriatrics	The study is based on people with frontotemporal dementia and Alzheimer's disease living in the community as well as they carers. The participants with dementia were patients at Osaka University Hospital, Japan. To be eligible for the study people with dementia had to have 'relatively preserved basic activities of living', to be able 'to provide informed content' and to have a reliable information. The study included n=12 people with Frontotemporal dementia and their carers as well as n=12 people with Alzheimer's disease and their carers. The survey began in April, about two weeks following Japan's Emergency Declaration (7 April 2020) and remained open for about two weeks. Participants also engaged in semi-structured interviews.
Taiwan			
Yeh et al., 2020	Family members' concerns about relatives in long-term care facilities: Acceptance of visiting restriction policy amid the COVID-19 pandemic.	Geriatrics & gerontology international	Telephone interviews were conducted with 156 family members of people living in residential care settings in Taiwan between 13 and 17 April 2020. Just over half of respondents were male (53.2%). Respondents on average were 56.3 years old and children of care home residents (77.6%) who visited their relatives at least once a week prior to the lockdown (72.4%)
UK			

Baxter, 2020	A Hitchhiker's Guide to caring for an older person before and during coronavirus-19.	Feminist Frontiers	The article is based on the authors experience of supporting her father staying long-term care during the COVID-19 pandemic. The qualitative material was constructed from the authors' text dialogues, emails, diary entries and recollections.
Gallagher& Wetherell, 2020	Risk of Depression in Family Caregivers: Unintended Consequences of COVID-19	MedRxiv (now published in BJPsych Open)	Data from two waves of Understanding Society, a UK population level dataset. Wave 9 was collected between 2017 and 2019 and the specially commissioned COVID-19 Wave was collected in May 2020. The sample consisted of 1,349 carers and 7,527 non-carers. In comparison to non-carers carers were slightly older, more likely married/partners, female, unemployed/retired, living alone, and reported a health condition/disability.
Giebel, Cannon et al., 2020	Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study	Ageing & Mental Health	The study is based on (n=50) qualitative semi-structured interviews with unpaid carers (n=42) and people living with dementia (n=8) in England. The interviews were conducted during April 2020 by telephone. Carers had to be aged 18 or older and be current or former carers of people with dementia and currently accessing social care or social support services. The majority of respondents (carers) were white (92.9%), female (83%) and the spouses of people with dementia (55%). Carers were on average 60 years old. Five people with dementia lived in care homes.
Giebel, Hanna et al., 2020	Decision-making for receiving paid home care for dementia in the time of COVID-19: a qualitative study.	BMC geriatrics	The analysis for this research is based on interviews with (n=15) current unpaid carers of people with dementia with experience in accessing or trying to access paid home care during COVID-19 related restrictions in England between April and May 2020. Among the analysed sample 93.3% of carers were female, and over half (53.3%) were spouses of people living with dementia. Most (73.3%) lived with the person they care for.
Giebel, Lord et al., 2020	A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers	International Journal of Geriatric Psychiatry	The survey included unpaid carers (n=285), people with dementia (n=61) and older adults (n=223) across the UK to capture their social support service use before and after the implementation of COVID-19 related public health measures.

			The survey was conducted between April and May 2020. Most respondents were white (97%), female (68%), shared a household with others (74%) and were retired (71%).
Willner et al., 2020	Effect of the covid-19 pandemic on the mental health of carers of people with intellectual disabilities.	Journal of applied research in intellectual disabilities: JARID	Participants (n=244) were carers of children or adults with intellectual disabilities in the network of three intellectual disability charities. Participants had to be 18 or older, live in the UK, have internet access and be the primary carer for a child (under 18) (n=100) or adult (18 or over) (n=107) with intellectual disabilities. Data was collected in between 28 April and 5 June 2020 with the help of an online survey. A sample of participants was invited for interviews. The majority of respondents (91%) were female and parents of people with learning disabilities (93%). Carers of children were significantly younger than people caring for adults (42.1 years vs. 56.5 years). A small proportion (5%) have experienced COVID-19 (5%). Only results for carers of adults with disabilities were included in this review
USA			
Park, 2020	Caregivers' Mental Health and Somatic Symptoms During Covid-19	The journals of gerontology. Series B, Psychological science and social sciences	Data from the Understanding America Study ('a nationally representative internet panel of more than 8,500 adults). The analysis used data from a caregiving survey completed in January 2020 and a COVID-19 study completed in April/May 2020. The study investigates the responses of n=4,784 respondents. In the sample of non-caregivers, just over half of respondents were male (51.4%), while in both carer groups, the proportion of women was higher (short-term carers 59.6%; long-term carers 56.1%). More non-carers report no pre-existing chronic conditions (48.8%) than both carer groups (short-term carers 42.8%; long-term carers 40.8%). Fewer non-carers also report anxiety or depression prior to the pandemic (21.5%) (short-term carers 26.5%; long-term carers 31.6%).
Savla et al., 2020	Dementia Caregiving During the "Stay-at-Home" Phase of COVID-19 Pandemic.	The journals of gerontology. Series B,	The study is based on telephone interviews with (n=53) unpaid carers of people with dementia from rural Virginia, USA. The

		Psychological sciences and social sciences	interviews were undertaken two weeks after the governor enacted the COVID-19 related stay-at-home order (30 March 2020). Almost half of carers were the adult children of people with dementia (49.06%) or their spouse/partner (41.51%). Carers average age was 64.23 years. There was no information on carer gender.
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Table 3: Overview of reports

<i>Reference</i>	<i>Title</i>	<i>Study information</i>
Australia		
Hosking, Maccora & McCallum, 2020	Older Australians' life and care during the pandemic	National Seniors Australia invited their members to respond in text-based format to two questions. '1. What issues or concerns would you like to bring to the attention of the Government about the COVID-19 virus pandemic? 2. What resources do you need to deal with risks of COVID-19?' In total 1,100 members responded to these questions between 13 March and 21 April 2020 using a web link. The majority of respondents were aged 60 to 79 years (79.6%), most were female (60.9%) and 29.5% had a caring responsibility.
Germany		
Eggert et al., 2020	Pflegende Angehörige in der COVID-19 Krise Ergebnisse einer bundesweiten Befragung	The survey was conducted among 1,000 unpaid carers supporting a person aged 60 and older in their own home with registered care needs between 21 April and 20 May 2020. The online survey was conducted among a sub-sample of an offline-recruited online panel of 80,000 German speakers. The majority of unpaid carers were female and aged 40 to 85 years (61%). Almost half of the care recipients received domiciliary care 47%.
Rothgang et al., 2020	Zur Situation der hauslichen Pflege in Deutschland wahrend der Corona-Pandemic – Ergebnisse einer Online-Befragung von informellen Pflegepersonen im erwerbsfahinge Alter	The cross-sectional survey was conducted among people who have been officially identified as unpaid carers through the DAK (German Sickness Fund). The survey was also advertised through carer organisations and social media. A total of 1,296 unpaid carers aged 67 and younger responded to the survey between 8 June and 12 August 2020. Most respondents were female (86%) and have educational qualifications (completed apprenticeships, further qualifications. Degrees). Half of respondents are working (26% >20 hours per week; 24%<20 hours per week), 11% are retired, 7% unemployed and 22% identify as house-husbands/wives. 16% of the sample have a qualification (apprenticeship/degree) in the field of care. Respondents come from all 16 federal states in Germany. The proportion of respondents living in big, medium and small cities is relatively even (22-25%). A slightly larger group

		(29%) live in rural communities and most carers share the household with other people (95%). 74% of care recipients are aged 20 years and older and most live in together with the carer (81%).
UK		
Alzheimer's Society, 2020	Worst hit: dementia during coronavirus	The Alzheimer's Society surveyed 1,095 unpaid carers of people with dementia in England, Wales and Northern Ireland between 13 and 31 August 2020.
Bennett, Zhang & Yeandle, 2020a	Hunger and mental wellbeing	The report is based on analysis of the COVID-19 survey conducted in April and May 2020 and the 2017-2019 survey (Wave 9) of the UK Understanding Society dataset. The analysis only considers carers supporting a person outside the household.
Bennett, Zhang & Yeandle, 2020b	CARING and COVID-19 Financial Wellbeing	The report is based on analysis of the COVID-19 survey conducted in April and May 2020 and the 2017-2019 survey (Wave 9) of the UK Understanding Society dataset. The analysis only considers carers supporting a person outside the household.
Bennett, Zhang & Yeandle, 2020c	Loneliness and use of services	The report is based on analysis of the COVID-19 survey conducted in April and May 2020 and the 2017-2019 survey (Wave 9) of the UK Understanding Society dataset. The analysis only considers carers supporting a person outside the household.
Carers UK, 2020a	Caring behind closed doors: six months on – The continued impact of the coronavirus (COVID-19) pandemic on unpaid carers	The survey with 5,904 former (n=321) and current carers (n=5,583) was carried out by Carers UK from 11 to 28 September 2020. Respondents live in England (63%), Scotland (13%), Northern Ireland (14%) and Wales (10%). The majority are female (80%) and more than three quarter (79%) are aged between 45 and 74 years. Only 4% of the sample 'describe their ethnicity as black or minority ethnic. A proportion of carers (16%) also care for a child under 18. A quarter of carers (25%) 'consider themselves to have a disability'. Most carers have several years of care experience. Only 2% of the sample have been caring for less than one year and 1% started their caring responsibility when the COVID-19 pandemic began. Most carers (73%) care for one person, but 21% provide care to two people. A small proportion has care responsibilities for more people.
Carers UK, 2020b	Caring behind closed doors - forgotten families in the coronavirus outbreak	The survey with 5,047 former (n=217) and current carers (n=4,830) was carried out by Carers UK from 3 to 13 April 2020. Respondents live in

		England (67%), Scotland (19%), Northern Ireland (9%) and Wales (6%). The majority are female (81%) and more than three quarter (76%) are aged between 45 and 74 years. Only 4% of the sample 'describe their ethnicity as black or minority ethnic. A proportion of carers (18%) also care for a child under 18. Most carers have several years of care experience. Only 2% of the sample have been caring for less than one year and 1% started their caring responsibility when the COVID-19 pandemic began. Most carers (71%) care for one person, but 20% provide care to two people. A small proportion has care responsibilities for more people.
Carers Week, 2020	Carers week 2020 research report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak	The report is based on a polling survey conducted by YouGov with 4,556 people aged 18 and older living in the UK. The data collection took place in May 2020.
Lariviere, M. et al., 2020	Caring during lockdown: Challenges and opportunities for digitally supporting carers	The report draws on qualitative-longitudinal data based on 96 'virtual cuppas' delivered through Mobilise between 28 March and 28 July 2020. In total 118 participants took part in the virtual meetings. In addition (n=30) members of the 'Mobilise Virtual Cuppa community' participated in a short survey. The survey showed that participants joined from England, Wales and New York (United States). Most carers (70%) were 46-65 years old, white (83.3%) and provided care for more than year (90%) (pp.5-8).
Office for National Statistics, 2020	Coronavirus and the impact on caring	The report is based on data from the Understanding Society COVID-19 Study for which data was collected in April 2020. There are also comparative elements that compare the COVID-19 data to the Understanding Society 2017-18 data. In addition, the report presents data from the UK Opinions and Lifestyle Survey Pooled Datasets collected between 3 April 2020 and 10 May 2020.
USA		
Blue Cross Blue Shield, 2020	The impact of caregiving on mental and physical health – harnessing data, for the health of America	Data is based on the carer population that is commercially insured through Blue Cross and Blue Shield (BCBS) (p.1). At least half of carers are women and most carers aged 38-53 (45%) and aged 54-64 (38%). The majority of carers across all age groups cares for their spouse (>60%).
Czeisler, Lane et al., 2020	Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic -	Representative panel surveys were conducted across the United States with adults aged 18 year or older between 24 and 30 June 2020. The

	United States, June 24-30, 2020.	surveys investigated respondents' mental health, substance use and suicidal ideation.
Czeisler, Marynak et al., 2020	Delay or Avoidance of Medical Care Because of COVID-19 – Related Concerns – United States, June 2020	Representative panel surveys were conducted across the United States with adults aged 18 year or older between 24 and 30 June 2020. The surveys investigated respondents experience regarding 'delay or avoidance of urgent or emergency and routine medical care because of concerns about COVID-19' (p.1250).
Rosalynn Carter Institute for Caregiving, 2020	Caregivers in Crisis: Caregiving in the Time of COVID-19	Survey with N=422 participants (convenience sample recruited from carer groups), conducted between 2 June and 1 August 2020. Respondents are carers who have provided unpaid care 'at any time in the last 12 months to a relative or friend' (p.2). Carers from 46 states in the United States. More than half of participants from Georgia, Texas, Florida, California and New York' (p.10) 78% of respondents were primary carers, with 58% support their spouse and 31% caring for a (adult) child (no information on age). The majority (79%) live with the person they care for. Limitations: largest group were older white women (18%); only 1 Spanish speaker.
University Center for Social and Urban Studies, University of Pittsburgh, 2020	Effects of COVID-19 on Family Caregivers – A Community Survey from the University of Pittsburgh	Survey conducted between 15 April and 27 May 2020. There were n=3,552 participants of which 619 self-identified as unpaid carers. They were recruited through different strategies. The majority of carers were women (75.6%), white (> 80%) and highly educated (>60% had a Bachelor's degree or higher qualification). Most carers were (>80%) were 45 years and older. Out of all carers (>40%) were 65 years and older.
UsAgainstAlzheimer's A-LIST survey 1, 2020	UsAgainstAlzheimer's Survey on COVID-19 and Alzheimer's Community Summary of Findings for March 2020 (Survey #1)	Survey 1 was conducted by UsAgainstAlzheimer's A-LIST between 25 and 30 March 2020 among current and former carers of people with dementia and Alzheimer's disease (n=198) and survey among carers of people in assisted living facilities (n=52).
UsAgainstAlzheimer's A-LIST survey 2, 2020	UsAgainstAlzheimer's Survey on COVID-19 and Alzheimer's Community Summary of Findings for April 2020 (Survey #2)	Survey 2 was conducted by the UsAgainstAlzheimer's A-List between 17 and 21 April 17-21 among current carers of people with dementia and Alzheimer's disease (n=197) and among carers of people with dementia

		living in assisted living facilities (n=46).
UsAgainstAlzheimer's A-LIST survey 3, 2020	UsAgainstAlzheimer's Survey on COVID-19 and Alzheimer's Community Summary of Findings for May 2020 Survey (Survey #3)	Survey 3 was conducted by the UsAgainstAlzheimer's A-List between 8 and 13 May 2020 among current carers of people with dementia and Alzheimer's disease (n=176) and carers of people with dementia living in assisted living facility (n=36).
UsAgainstAlzheimer's A-LIST survey 4, 2020	UsAgainstAlzheimer's Survey on COVID-19 and Alzheimer's Community Summary of Findings for June 2020 Survey (Survey #4)	Survey 4 was conducted by the UsAgainstAlzheimer's A-List between 9 and 14 June 2020 among current carers of people with dementia and Alzheimer's disease (n=176) and carers of people with dementia living in assisted living facility (n=34) .
UsAgainstAlzheimer's A-LIST survey 5, 2020	UsAgainstAlzheimer's Survey on COVID-19 and Alzheimer's Community Summary of Findings for July 2020 Survey (Survey #5)	Survey 5 was conducted by the UsAgainstAlzheimer's A-List between 16 and 21 July 2020 among current carers of people with dementia and Alzheimer's disease (n=135) and carers of people with dementia living in assisted living facilities (n=31).
UsAgainstAlzheimer's A-LIST survey 6, 2020	UsAgainstAlzheimer's Survey #6 on COVID-19 and Alzheimer's Community Summary on Findings, September 2020	Survey 6 was conducted by the UsAgainstAlzheimer's A-List between 3 and 9 September 2020 among current carers of people with dementia and Alzheimer's disease (n=160) and carers of people with dementia living in assisted living facilities (n=29).
UsAgainstAlzheimer's A-LIST survey 7, 2020	UsAgainstAlzheimer's Survey #7 on COVID-19 and Alzheimer's Community Summary of Findings October 2020	Survey 7 was conducted by the UsAgainstAlzheimer's A-List between 8 and 14 October 2020 among current carers of people with dementia and Alzheimer's disease (n=118) and carers of people with dementia living in assisted living facilities (n=24).

Table 4: Results by country and theme

Country	Summary of key findings by country
Argentina	<p><i>Formal support</i></p> <ul style="list-style-type: none"> • While 28.6% of unpaid carers suspended visits from paid carers due to concerns around infection, the majority of carers, particularly carers of people with more advanced dementia, maintained their services (Cohen et al. 2020b, p.4). <p><i>Carer burden</i></p> <ul style="list-style-type: none"> • A study reported that prior to the epidemic 12% of carers of people with dementia experienced severe care burden. This increased to 42% during the pandemic (Cohen et al, 2020a, p.5). These findings were echoed by another Argentinian study reporting that while they could not detect a statistically significant difference in carer burden prior to the pandemic, burden increased significantly four weeks following the introduction of COVID-19 related measures, and especially for carers of people with advanced dementia (Cohen et al. 2020b, p.4). <p><i>Mental health and well-being</i></p> <ul style="list-style-type: none"> • Unpaid carers reported an increase in the use of psychotropic medication (Cohen et al., 2020a, p.4)
Australia	<p><i>Care commitment</i></p> <ul style="list-style-type: none"> • Increased care needs and reduced availability of paid services and informal support are reasons for increased care commitment (Hosking, Maccora & McCallum, 2020, p.7) <p><i>Concerns related to COVID-19</i></p> <ul style="list-style-type: none"> • Carers in Australia also found it difficult to interpret and apply government guidelines and to keep up with the amount of information circulated (Hosking, Maccora & McCallum, 2020, p.9). • Carers reported difficulties in accessing goods due to resource shortages and accessibility issues (Hosking, Maccora & McCallum, 2020, pp.16-17) <p><i>Financial implications</i></p> <ul style="list-style-type: none"> • Older carer reported to receive ‘very limited financial recognition’ (Hosking, Maccora & McCallum, 2020, p.13) • The report explained that many self-funded retirees had experienced a substantial drop in their finances ‘when the Reserve Bank reduced cash interest to a record-low’. In a survey among 1,110 seniors 20% reported financial stress due to COVID-19, particularly self-funders, unable to access support (Hosking, Maccora & McCallum, 2020, p.19). <p><i>Carers of people living in residential care settings</i></p> <ul style="list-style-type: none"> • Carers reported concerns about the ‘physical and emotional quality of life’ of their relatives as they were unable to see them. (Hosking, Maccora & McCallum, 2020, p.14) • Evidence indicated that carers worried about the quality of care and feared cover-ups of abuse without their ability to monitor the situation (Hosking, Maccora & McCallum, 2020, p.15) • Carers in Australia voiced the desire for regaining agency and participation in the care of their relative (Hosking, Maccora & McCallum,

	2020, p.15)
Canada	<p><i>Care commitment</i></p> <ul style="list-style-type: none"> • Research reported that sibling of people with intellectual/developmental disabilities expressed concern about their care responsibility if their family would become ill and unable to care (Redquest et al. 2020, p.4). <p><i>Concerns around COVID-19</i></p> <ul style="list-style-type: none"> • Carers reported that the cognitive abilities of their relatives with dementia had increased since the onset of the COVID-19 related public health measures. They linked this decreased to reduced opportunities for social interaction. Others reported that their relatives with dementia were frustrated as it was difficult for them to understand why they should not go out (Roach et al. 2020, p.10). <p><i>Formal and informal support structures</i></p> <ul style="list-style-type: none"> • Carers receiving family support emphasised the importance of this help. (Roach et al. 2020, p.6) • Reduced availability of domiciliary support played a role in carers increased stress levels (Roach et al. 2020, p.6) • Carers of people with dementia in Canada appreciated continued support with service providers, even if the amount and type of services had changed. (Roach et al. 2020, p.8) • While carers preferred in person contact, some carers of people with dementia in Canada reported advantages, such a feeling less rushed, being able to choose tools (e.g. telephone vs. zoom) and being able to speak more candidly if the person with dementia was not part of the call. Others, however, experienced greater difficulty discussing issues in front of the person they care for and experiencing technical barriers (Roach et al. 2020, p.8). • Some carers also reported technological barriers (Roach et al. 2020, p.9). • Carers were worried about services that supported them prior to COVID-19 may not become available again (Roach et al. 2020, p.10). <p><i>Health and well-being</i></p> <ul style="list-style-type: none"> • Carers reported anxiety and feelings of burnout as support services are limited (Roach et al. 2020, pp.9-10). <p><i>Technology</i></p> <ul style="list-style-type: none"> • Some carers of people with dementia in Canada reported advantages, such a feeling less rushed, being able to choose tools (e.g. telephone vs. zoom) and being able to speak more candidly if the person with dementia was not part of the call. Others, however, experienced greater difficulty discussing issues in front of the person they care for and experiencing technical barriers (Roach et al. 2020). • Some carers reported that formal service providers and community programmes remained in contact with the families they supported using innovative ways. Carers were appreciative of the continued contact. (Roach et al. 2020, p.8)
Germany	<p><i>Care commitment</i></p> <ul style="list-style-type: none"> • Increased care needs and reduced availability of paid services and information support are reasons for increased care commitment (Rothgang et al, 2020) • In Germany, almost twice as many carers of people with dementia (35%) compared to other carers said that they won't be able to

sustain the level of care (Eggert et al. 2020, p.12)

Concerns related to COVID-19

- While in Germany the majority of unpaid carers felt they had access to good and comprehensible information and most respondents felt they could adhere well to guidance. (Eggert 2020; Rothgang et al., 2020). However, only 19% of respondents in one survey felt that COVID-19 related measures sufficiently recognised unpaid carers (Rothgang et al., 2020, p.28)
- Even though only a very small proportion of respondents (<1%) had been infected with COVID-19, a considerable proportion reported being very (36%) or “somewhat” (49%) concerned about an infection (Rothgang et al., p.30). Another study found that older carers were less concerned about an infection than younger carers (Eggert et al. 2020, p.5).

Formal and informal support structures

- In comparison to other carers (27%), carers of people with dementia (41%) significantly more often reported a worsening of the overall care situation. The disproportionate impact on carers of people with dementia was also shown in the ratings of carers agreeing that they are concerned that they won't be able to manage domiciliary care for longer (35% of carers of people with dementia vs. 19% of other carers) (Eggert et al. 2020, pp.6, 13).
- In Germany, the use of day care stopped for 81%, domiciliary care stopped for 7% and declined for 13% (Eggert et al. 2020). In addition, carers reported reduced quality of care since the onset of the pandemic (Rothgang et al. 2020).
- More than 40% of survey respondents said that they have started to use technology to maintain social contact (Rothgang et al. 2020, p.37)
- In Germany, the impact of COVID-19 as a challenge on carer's financial situation was least reported (Eggert et al. 2020).
- Many carers have both work and caring responsibilities. While some reported no difference in their ability to combine work and care (64% of respondents, Eggert et al., 2020), others stated to experience even greater challenges in combining paid work and unpaid care for carers in Germany (45% of respondents, (Eggert et al., 2020); 71% of respondents (Rothgang et al. 2020, p.38). However, none of the respondents in the survey has taken up the government policy enabling carers to take up to 10 days of paid leave during the COVID-19 pandemic (Eggert et al. 2020). Furthermore, most carers were not concerned about their future employment (70%). These worries, however, were higher among carers with a monthly household net-income of less than 2000€ (44%) while carers with a household income of 4000€ or more were less concerned (7%) (Eggert et al. 2020).
- German carers were generally satisfied with the COVID-19 related measures. Carers particularly valued being able to take paid leave to respond to a care situation and the ability to choose what they spend the support payment on. Carers also welcomed being provided with protective equipment, being able to freely use the budget that would usually go towards day or respite care, flexible working hours, expansion of COVID-19 testing and the ability to work from home (Rothgang et al. 2020).

Health and well-being

- The health status of more than half of carers (52%) and self-reported quality of life had declined (Rothgang et al. 2020, p.7).
- The proportion of carers reporting loneliness increased from 33% prior to the COVID-19 pandemic to 51.4% during the pandemic (Rothgang et al. 2020, p.43).

	<ul style="list-style-type: none"> ○ Carers reported that negative feelings, such as helplessness (29%), emotional impact of conflicts (24%), despair (22%), and anger (20%) had increased, while nice moment with the person with care needs had declined (23%). However, 12% also reported an increase in nice moments. Consistently, a greater proportion of carers of people with dementia than carers of people with other care needs reported negative feelings. (Eggert et al., 2020, pp.9-10). • In Germany average burden scores increased from 13.94 to 15.73 (Rothgang et al. 2020, pp.43-44) <p><i>Technology</i></p> <ul style="list-style-type: none"> • In Germany 40% of respondents of a cross-sectional survey have started using new technological approaches to maintain social contacts (Rothgang et al., 2020, p.37). <p><i>Receipt of financial assistance</i></p> <ul style="list-style-type: none"> • German carers were generally satisfied with the COVID-19 related measures. Carers particularly valued being able to take paid leave to respond to a care situation. Carers also welcomed being provided with protective equipment, being able to freely use the budget that would usually go towards day or respite care, flexible working hours, expansion of COVID-19 testing and the ability to work from home (Rothgang et al. 2020). <p><i>Support to enable working carers to combine care and paid work commitments</i></p> <ul style="list-style-type: none"> • Many carers have both work and caring responsibilities. The reduction of available community services has created even greater challenges for carers in Germany (Rothgang et al. 2020). However, none of the respondents in the survey has taken up the government policy enabling carers to take up to 10 days of paid leave during the COVID-19 pandemic. Most German carers were not concerned about their future employment (70%). These worries, however, were higher among carers with a monthly household net-income of less than 2000€ (44%) while carers with a household income of 4000€ or more were less concerned (7%) (Eggert et al. 2020).
India	<p><i>Concerns related to COVID-19</i></p> <ul style="list-style-type: none"> • Carers worried about how to protect their relative with dementia from getting a COVID-19 infection (Vaitheswaran et al. 2020, p.1187). • Carers worried what would happen if they were no longer able to support their relative with dementia (Vaitheswaran et al. 2020, p.1187). • Carers reported challenges in engaging the person with dementia in activities inside the house and to prevent them from going out (Vaitheswaran et al. 2020, pp.1187-1188). • Carers reported challenging behaviour as their relatives with dementia experienced difficulties in adhering to hygiene measures (Vaitheswaran et al. 2020, p.1189). • Carers experienced difficulties in combining working and caring from home and were worried ‘about the financial impact of the lockdown’ (Vaitheswaran et al. 2020, p.1189). <p><i>Formal and informal support structures</i></p> <ul style="list-style-type: none"> • Research from India described how an older lady previously managed to support her husband with dementia and to manage their household with the help of paid help. The paid helpers inability to get to the house led to a collapse of this situation (Vaitheswaran et al. 2020, p.1189).

	<ul style="list-style-type: none"> • Carer responsibility increased substantially as their usual formal and informal support networks can no longer be accessed' (Vaitheswaran et al. 2020, p.1189), • Carers reported several barriers around accessing remote services. These include, limited experience with technology, lack of access, difficulties for people with dementia to engage in remote conversations, practical needs that cannot be met through online services (Vaitheswaran et al. 2020, p.1191). <p><i>Health and well-being</i></p> <ul style="list-style-type: none"> • Carers reported the development of health problems and difficulty in accessing medical care for these. (Vaitheswaran et al. 2020, p.1189) <p><i>Technology</i></p> <ul style="list-style-type: none"> • Some carers expressed a need for use technologically supported services, such as medical video or telephone consultations. Other, however, identified several barriers that would prevent them from using of technology. They include a 'lack of experience and knowledge', limited access, inability of people with dementia to participate in virtual conversation, limited need for services that could only be provided using remote technology (Vaitheswaran et al. 2020, p.1191).
Italy	<p><i>Concerns related to COVID-19</i></p> <ul style="list-style-type: none"> • Carers of people with dementia reported an increase in behaviour (e.g. irritability (40.2%), apathy (34.5%), agitation (30.7%), anxiety (29%), depression (25.1%) and sleep disorder (24%)) they found challenging to respond to after one month of quarantine measures. (Cagnin et al. 2020, p.3). <p><i>Health and well-being</i></p> <ul style="list-style-type: none"> • Italian carers of people with dementia also reported high stress levels (65.9%, n=3,240), anxiety (almost 46%), helplessness (34.2%), anguish (29.3%), irritability (26.4%), abandonment (22%) and depression (18.6%) while strict public health measures were in place. Women were at greater risk to develop anxiety, anguish and to feel helpless (Cagnin et al. 2020, pp.4-5).
Taiwan	<p><i>Carers of people in residential care</i></p> <ul style="list-style-type: none"> • In Taiwan the majority of carers (84.6%) accepted and supported the decision to suspend visits (Yeh et al. 2020, p.941). • Carers in Taiwan reported being especially concerned about their relative's psychological stress (38.5%, n=60), the clinical nursing (36.9%, n=42) they received and their relative's access to daily activities (21.1%, n=33) (Yeh et al. 2020, pp.940-941) • The survey in Taiwan showed that those who accepted the restriction were also more likely to give the care facility a five-star rating. These relatives would also prefer for their relative to stay in the care home even if a COVID-19 infection would occur (79.7%) (Yeh et al. 2020, p.941).
UK	<p><i>Care commitment</i></p> <ul style="list-style-type: none"> • The Carers week report estimates (2020, p.4) that 4.5 million people have taken on new caring responsibilities since COVID-19 related public health measures were put in place. This suggests an almost 50% increase in the number of unpaid carers. • A substantial increase (32% in April 2020) of carers helping people outside their own household were helping someone they had not

provided support to prior to the pandemic was reported by the Office for National Statistics (ONS) (2020).

- Evidence from the UK suggests that more than half of new carers were female (Carers week polling: 59%; ONS report: 51%) and that that new carers were more likely to be working (62%), to be younger and to have children under 18 (35%) (Carers week 2020, pp..10, 17; Office for National Statistics 2020). UK evidence also shows (Carers week 2020, p.10).
- UK data suggest that carers spend, on average, 10 more hours per week, taking the average time spent caring per week to 65 hours (Carers UK 2020b, pp.6-7).
- Increased care needs and reduced availability of paid services and information support are reasons for increased care commitment (Carers UK, 2020a, p.6)
- In the UK, 45% of survey respondents reported that they felt unable 'to provide the level of care needed by the person with dementia [they] care for (Alzheimer's Society 2020a). This was due to adherence to government distancing guidelines and travel restrictions and affected particularly carers supporting people outside their household (Carers UK estimate: 5%) (Carers UK 2020a, p.8; Office for National Statistics 2020).

Concerns around COVID-19

- A large proportion of carers (87%) were worried what would happen to the person they support if they became unable to care for them (Carers UK 2020b, p.6).
- Carers worried about the risk of infection through health and social care staff (Carers UK 2020b, p.7; Carers UK 2020a, p.7)
- A small proportion of carers in the UK reported difficulty in adhering to shielding advice due to their caring responsibility (Carers UK 2020a).
- UK carers reported difficulty in accessing basic needs (e.g. food, hygiene products) during the early part of the pandemic (Carers UK 2020b, p.18) and carers of people with dementia complaint that people with dementia were not recognised as 'vulnerable', which led to difficulties in accessing priority shopping slots and home delivery (Giebel, Hanna, et al. 2020).
- carers in the UK reported a lack of information, 'widespread confusion' about government advice, and challenges adhering to it (Carers UK 2020b, p.19; Lariviere et al. 2020, p.11).
- Finally, while about half of carers surveyed in the UK felt they could manage their caring responsibilities at the moment, 67% worried how they would deal with further lockdowns and how they will manage during winter (63%) due to weather, limited opportunities to get out, seasonal illness and their own health. Both concerns were even higher among BAME carers (73% and 72%, respectively) (Carers UK 2020a, p.14).

Formal and informal support structures

- Carers in the UK, including carers of people with dementia reported reduced services, which impacted on carers ability take breaks (Carers UK 2020b, 2020a). This impact was particularly pronounced among BAME carers (Carers UK 2020a, p.8). Carers report reduced availability of day care, activities provided by local carers organisations, sitting services and other services enabling breaks, while domiciliary care and the delivery of meals remaining more widely available (Alzheimer's Society 2020b; Carers UK 2020a, p.12; Giebel, Cannon, et al. 2020; Giebel, Lord, et al. 2020). A report on carers supporting people outside their household showed that 25% of carers

in need of support initially did not get the help they needed. The situation improved in May 2020. The report also identified issues with carers access psychotherapy and pharmacy services (Bennett, Zhang, and Yeandle 2020c, p.2).

- Research from the UK showed that it was a difficult decision for many families whether or not to accept the risk of many changing carers entering their home. Carers of people with dementia relied on domiciliary care to support their care situation, but some also worried that they would lose financial support for paid care or to encounter significant barriers in re-obtaining care package if they stopped them (Giebel, Cannon, et al. 2020; Giebel, Hanna, et al. 2020). Carers also voiced concerns whether community support services would become available again in future and whether the person with dementia would still be able to benefit from these services (Giebel, Cannon, et al. 2020).
- Carers reported that their own medical treatment (38%) or that of the person the care for (57%) (90% of health and social care services of people with dementia) had been delayed and many carers (65%) stated that they had put off seeing health service providers out of concerns over infection. A considerable proportion of carers (70%) were worried what would happen if the person they care for requires hospitalisation (Carers UK 2020a, p.14) (Alzheimer's Society 2020b, p.34).
- However, the provision of remote support for carers of people with dementia was limited and hampered by difficulties in accessing the online tools and some people with dementia experiencing difficulties in engaging with virtual programmes (Giebel, Cannon, et al. 2020). Furthermore, while carers appreciated a call from their social worker, it did not replace the practical support many carers needed (Giebel, Hanna, et al. 2020, p.6).
- On the other hand, a study accompanying the virtual cuppa project, an interventions which offered carers to meet virtually for half an hour showed that over time carers developed friendship and experienced the virtual meeting as a safe space where they could take a break, relax and exchange experiences. The research made clear that while it is possible to facilitate such a programme remotely, it took a coach to lead the group as well as time for these relationships to build and a sense of community to emerge (Lariviere et al. 2020).
- A small proportion of UK carers have used technology to access GP and other health and long-term care related services (16%), support groups (13%) and online mental health services (5%) (Carers UK 2020a, p.19). A proportion of carers (10%) reported difficulty in accessing technological tools. This was higher among carers experiencing financial difficulties (18%) (Carers UK 2020a, p.19)
- A study on carers of people with dementia found that losing informal support increased carers' feeling of sole responsibility as well as 'feelings of stress and fatigue' (Giebel, Hanna, et al. 2020, p.6)

Financial impact

- A study on UK carers supporting people outside their household showed that carers had lower financial well-being than non-carers in May 2020, this was greater among women, younger carers (31-45 years) and carers in paid work. Interestingly, the announcement of the furlough scheme improved financial well-being across the population, including for carers (Bennett, Zhang, and Yeandle 2020b, p.2).
- Carers reported greater spending (81%), including on food (72%) and household bills (38%) leading to concerns about their financial situation (Carers UK 2020b, p.6). Carers reported incurring additional costs due to the need for specialist care equipment and home

adaptations as well as increased food bills, as own-brand products often were unavailable (Carers UK 2020b, p.11; Carers week 2020, p.5). A study investigating carers supporting people outside their household found that in the households of 228,625 carers someone had gone hungry in the previous week. The risk of hunger was greater for women and younger carers (17-30 years). Furthermore, 106,450 carers reported using of a foodbank in the last month. Again this were more women and younger carers (17-30 years) (Bennett, Zhang, and Yeandle 2020a, p.2).

- A large proportion of UK carers (40%) also reported that they were able to work from home, while others had to return to their workplace (14%) or were key workers (27%). Many carers who were able to work from home welcomed not having to commute and to be able to work more flexibly, while others found it more challenging to combine working from home with caring (Carers UK 2020a, p.17, 2020b, p.13).
- Research among UK carers providing support outside their own household found that working carers spent fewer hours working than non-carers. Female carers worked fewer hours than males (Bennett, Zhang, and Yeandle 2020b, p.10).
- UK carers reported that they would benefit from an increase in government funding for long-term care services and a rise in carer's allowance (Carers UK 2020a, p.21). Despite these employment policies, 11% of carers reduced their hours and 9% gave up their jobs to provide care (Carers UK 2020a, p.17). Carers reported that affordable and accessible replacement care (48%), flexibility in working hours and days (43%), the ability to take paid care leave (42%), to work part-time (33%) or full-time (25%) from home as well as effective communication with and understanding from the employer would have enable them to maintain employment (Carers UK 2020a, p.18)

Health and well-being

- UK carers reported strain on personal relationships, lack of opportunities to take breaks, the inability to talk about their concerns, feeling worried about the future, feeling less motivated and tired, experiencing daily routines as challenging and feeling more caught up between their relationship role and being a carer (Carers UK 2020a; Lariviere et al. 2020, p.12; Office for National Statistics 2020). Increased stress (58%), feeling exhausted and worn out (74%) was reported among UK carers. A considerable proportion (44%) of carers reported reaching breaking point (Carers UK 2020a, pp.6-7; Lariviere et al. 2020).
- Large proportion of carers (ranging from 58%-71%) also reported heightened levels of stress (Carers week 2020, p.5) (Carers UK 2020a, p.6)
- A survey among 800 carers of people with dementia reported heightened feelings of exhaustion (69%), anxiety (63%), sleeping problems (50%) and depression (49%) (Alzheimer's Society 2020a)
- Many unpaid carers reported feeling socially isolated and lonely (48% of respondents of the Carers UK survey) (Lariviere et al. 2020, p.12). People experiencing financial difficulties experienced a greater risk (62% of respondents of the Carers UK survey). (Carers UK 2020a, p.13). It was also reported that carers supporting people outside their home experienced greater loneliness among than non-carers and younger carers, women and working carers were more likely to feel lonely. (Bennett, Zhang, and Yeandle 2020c, p.2)
- UK Research showed that carers experiencing financial difficulties were also at greater risk of feeling 'lonely and cut-off from people (62%) (Carers UK 2020a, p.13). Carer loneliness was also identified as important predictor of depression (Gallagher and Wetherell

2020a).

- In the UK studies younger carers supporting a person outside their household reported more loneliness than older carers (Bennett, Zhang, and Yeandle 2020c, p.2). It further reported that more women and working carers experienced loneliness (Bennett, Zhang, and Yeandle 2020c, p.2). The findings described above stand in sharp contrast to the report by ONS. Their results on chronic loneliness suggest that there was no difference to pre-COVID levels (8% of carers) (Office for National Statistics 2020).
- UK evidence shows that a large proportion of carer consistently reports poor mental health and well-being during the pandemic. In comparison, a greater proportion of women and carers experiencing financial difficulties reported worse mental health (Carers UK 2020a, p.13). There was also evidence that younger working carers experiencing lower mental health (Bennett, Zhang, and Yeandle 2020a, p.2; Gallagher and Wetherell 2020b; Giebel, Lord, et al. 2020, p.6;)
- A UK report showed that women and people with financial difficulties were more likely to report worsened mental health due to COVID-19 related measures (Carers UK 2020a, p.13). Three UK studies uniformly report that access to social and psychological support can reduce the risk poor mental health outcomes (Gallagher and Wetherell 2020a; Giebel, Lord, et al. 2020; Willner et al. 2020, p.1527). While acknowledging consistently poorer health among women providing care before and during the COVID-19 pandemic, a study investigating carers supporting people outside their home did not observe a significant difference in mental health between carers and non-carers and before and during the COVID-19 pandemic (Office for National Statistics 2020).
- Carers have also reported worsened physical health (58%) (Carers UK 2020a, p.130). Again, more female (58%), BAME carers (74%) and carers experiencing financial difficulties (74%) reported a greater impact since the onset of COVID-19 related measures (Carers UK 2020a, p.13).
- Carers who participated in the 'virtual cuppa' project reported that the virtual peer support network help them in developing 'individual resilience' and supportive relationships (Lariviere et al. 2020, p.19)

Carers of people living in residential care settings

- Carers were unable to visit people they support in residential care settings (Carers UK 2020b, p.8).
- Carers worried about the long-term impact of COVID-19 related restrictions on their relatives and the level of activity and social engagement that takes place to keep residents engaged (Carers UK 2020b, p.8; Giebel, Cannon, et al. 2020).
- Carers reported feelings of anger about the situation of people in residential care settings and guilt about not being able to support their relative in person (Baxter 2020, p.766)
- UK carers reported relying on care home staff for updates and enabling contact with their relatives through virtual platforms (Giebel, Cannon, et al. 2020). The use of remote communication technologies can be challenging for residents (Baxter 2020, p.766).

Technology

- In the UK (58%) carers have started to use technology to maintain social contact (Carers UK 2020a; Rothgang et al. 2020). However, the provision of remote support for carers of people with dementia was limited and hampered by difficulties in accessing the online tools and some people with dementia experiencing difficulties in engaging with virtual programmes (Giebel, Cannon, et al. 2020). Furthermore, while carers appreciated a call from their social worker, it did not replace the practical support many carers needed

(Giebel, Hanna, et al. 2020, p.6).

- A study accompanying the virtual cuppa project, which offered carers to meet virtually for half an hour showed that over time carers developed friendship and experienced the virtual meeting as a safe space where they could take a break, relax and exchange experiences. The research made clear that while it is possible to facilitate such a programme remotely, it took a coach to lead the group as well as time for these relationships to build and a sense of community to emerge (Lariviere et al. 2020).
- A smaller proportion of UK carers have used technology to access GP and other health and long-term care related services (16%), support groups (13%) and online mental health services (5%) (Carers UK 2020a, p.19). A proportion of carers (10%) reported difficulty in accessing technological tools. This was higher among carers experiencing financial difficulties (18%) (Carers UK 2020a, p.19)

Receipt of financial assistance

- The UK government's introduction of the furlough scheme has initially ensured an income for approximately 13% of working carers, but many were worried about the future (Carers UK 2020b, p.13). Despite these employment policies, 11% of carers reduced their hours and 9% gave up their jobs to provide care (Carers UK 2020a, p.17). Carers reported that affordable and accessible replacement care (48%), flexibility in working hours and days (43%), the ability to take paid care leave (42%), to work part-time (33%) or full-time (25%) from home as well as effective communication with and understanding from the employer would have enable them to maintain employment (Carers UK 2020a, p.18)
- UK carers reported that they would benefit from an increase in government funding for long-term care services and a rise in carer's allowance (Carers UK 2020a, p.21).

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ⁱ This an assumption by the authors as no details are provided in the report