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RESEARCH

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 Evidence up to November 2020

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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, their experience has been largely absent from public reporting.
Objective: We aim to map the available evidence of the impacts of COVID-19 on unpaid carers of adults (>18 years) with LTC needs as well as of measures implemented to mitigate these effects and how well they have worked.
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, covering the period until November 2020.
Findings: We identified six key themes that highlight the impacts of COVID-19 on unpaid carers of people living in the community. These are: care commitment, concerns related to COVID-19, availability of formal and informal support, financial implications, carer health and well-being, and carers' adaptability. In addition, we captured aspects identified by unpaid carers supporting people in residential care settings under the theme 'carers of people in residential settings'. Finally, we reported evidence of measures implemented to mitigate the impacts on carers. This included the use of technology and the receipt of financial assistance and support for working carers.
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 impacts that 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 impacts on their lives.

Keywords: unpaid; informal; carer; dementia; COVID-19; policy

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Introduction

Unpaid carers represent the backbone of long-term care systems around the world. Even before the COVID-19 pandemic, as many as 9% (5 million) of all adults in the UK and nearly 16% (40 million) of adults in the US were estimated to provide unpaid care to people with care needs (own calculations using data from Gov.uk [2018] and US Census Bureau [n.d.]) (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, & 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: 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 more visible many of the issues the sector has been struggling with for years. However, most attention has been paid to people living and working in residential care settings, who experienced disproportionate mortality (Comas-Herrera et al., 2021). So far there is limited knowledge on the impacts of the COVID-19 pandemic on family and other unpaid carers, on the measures put in place to address these impacts and on evidence of their effect. We have brought together information from around the world to map the available evidence for unpaid carers, focusing on adult carers who provide care for other

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adults. We excluded evidence on 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.

Methods

We conducted a rapid review of the literature to map the available evidence regarding the impacts of COVID-19 on adult unpaid carers and measures adopted to mitigate these impacts. There is no agreed definition of how a rapid review should be conducted (Haby et al., 2016). In the interest of timeliness, rapid reviews take a number of methodological shortcuts compared to systematic reviews including 'not using a protocol, limiting the literature search, limiting inclusion criteria, only having one person screen the literature search results, not conducting quality appraisal, and not conducting a meta-analysis' (Tricco et al., 2015: 9).

Our rapid review approach differed from a systematic review in that i) we did not register/provide a protocol, ii) only one researcher assessed inclusion/exclusion of articles, ii) we did not conduct a risk of bias/quality appraisal, iii) we did not contact authors for further information, iv) we limited the languages to those the researcher conducting the search and extracting the data was fluent in, v) we did not fully adhere to 'A Measurement Tool to Assess Systematic Reviews' (AMSTAR) or 'Preferred Reporting Items for Systematic Reviews and Meta-Analysis' (PRISMA) guidelines.

We included:

- publications in English and German that reported evidence collected from unpaid carers caring for adults with care needs. Languages were chosen pragmatically as the languages the first author is fluent in.

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 mostly on unpaid carers of children and young adults (we used the criteria of carers of adults with long-term care needs representing <20% of the sample compared to 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.

KLD initially searched the four academic databases CINAHL, Medline, Socindex, and Embase for articles focusing on informal, unpaid carers (i.e., caregivers) and COVID-19. The databases selected were among those also used in other reviews focusing on unpaid care (Bom et al., 2019; Greenwood & Smith, 2015). The search was first conducted on 3 July 2020 and then repeated on 21 July 2020, 10 September 2020, and 2 November 2020 to reflect the rapid development of the literature. KLD also searched medRxiv, a preprint database for papers that have not yet completed the peer-review process to ensure the inclusion of emerging evidence that had not yet been published in academic journals.

The search terms included:

- For CINAHL, Medline, and SocIndex: (Family OR Informal OR unpaid) AND (carer OR caregiver) AND COVID-19 OR coronavirus OR 2019-ncov)
- For Embase: (Family OR Informal OR unpaid) AND (carer OR caregiver) AND (COVID-19)
- For medRxiv: caregiver covid, informal carer covid, carer AND covid, unpaid AND COVID

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 abstracts 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, but 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. These papers were excluded in the interest of a rapid turnaround of the available evidence. The authors did not pursue other routes, such as contacting the authors directly to access the papers, in the interest of time.

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. Search terms used for the Google search engine included:

- carer OR caregiver AND unpaid OR family OR unpaid AND COVID-19 OR coronavirus.

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**. A detailed overview of the review process can be found in **Figure 1**.

KLD and ACH organized the findings on the impacts of COVID-19 on unpaid carers of people living in the community into six key themes. We developed these themes iteratively: 1) We organised our summary notes by keywords based on the sub-headings in the articles and reports included in the review. Where no sub-headings were used in the original articles and where the notes did not fit with existing keywords, we created new keywords. 2) We then grouped related concepts. 3) Finally, we organised related concepts together into overarching themes (e.g., keywords such as 'time spent caring', 'new carers', and 'carer characteristics' were organised under the theme 'care commitment'). In total, we identified seven themes that describe the range and diversity of findings reported in the included articles and reports, six of which relate to carers of people living in the community. These are: care

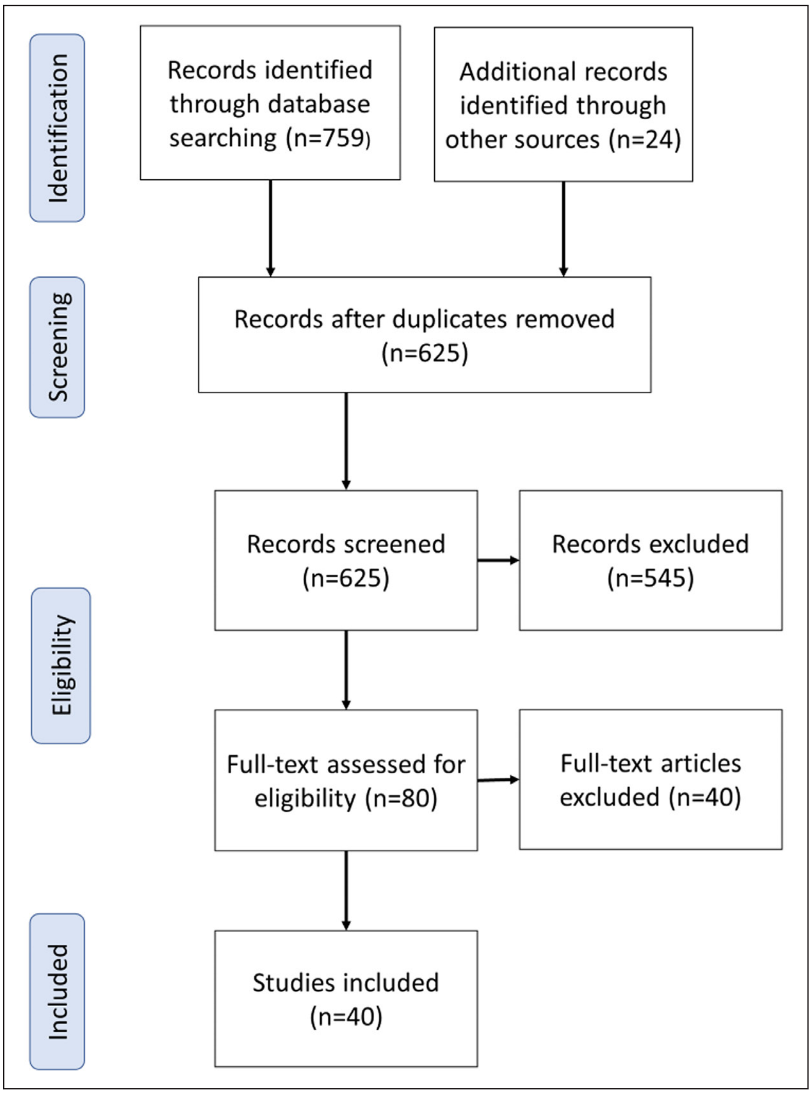

Figure 1: Overview of review process.
Adapted from: (Moher D et al., 2009; Peters et al., 2017).

commitment, concerns related to COVID-19, availability of formal and informal support, financial implications, carer health and well-being, and carer adaptability. We also identified one additional theme for carers of people living in residential care settings.

We also provided an overview of the interventions put in place to support carers during the pandemic and available evidence of how well they worked. We identified technology-based interventions as well as financial assistance and other support for working carers.

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). The studies focus on the impacts of COVID-19 on unpaid carers and on measures implemented to mitigate these effects. The evidence presented is based on qualitative (n = 8), quantitative (n = 27), and mixed methods (n = 5) research. Studies have been conducted almost exclusively online or by phone (only Suzuki et al. [2020] explicitly reported the possibility of face-to-face interviews). Most studies used convenience samples (n = 29), but some analyzed nationally representative datasets (n = 11). Two thirds (n = 26) were academic studies, 13 reports were produced by voluntary sector organisations, and one report was provided by a private health insurance provider. An overview of the types of studies can be found in **Table 1**.

We organised the findings on the impacts of COVID-19 on unpaid carers of people living in the community into six key themes that emerged from the literature. These are: care commitment, concerns related to COVID-19, availability of formal and informal support, financial implications, carer health and well-being, and carer adaptability. In addition, one theme covered the impacts of COVID-19 on carers of people living in residential care settings.

The detailed findings for each theme, by country, are provided in **Table 4**, which also includes the references for all the studies. In this section we provide a broad overview of the key findings by each of the seven themes, with some specific country examples.

Table 1: Overview of type of studies.

Reference	**Research methods**			**Data collection**	**Sampling**		**Sector**		
	Qualitative	**Quantitative**	**Mixed methods**		**Convenience**	**Representative**	**academic**	**voluntary**	**other**
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		✓	✓		

(Contd.)

Reference	Research methods			Data collection	Sampling		Sector		
	Qualitative	Quantitative	Mixed methods		Convenience	Representative	academic	voluntary	other
Carers UK, 2020a			✓	Online survey	✓			✓	
Carers UK, 2020b			✓	Online survey	✓			✓	
Carers Week, 2020		✓		Poll	✓[1]			✓	
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	✓			✓	

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Reference	Research methods			Data collection	Sampling		Sector		
	Qualitative	Quantitative	Mixed methods		Convenience	Representative	academic	voluntary	other
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.

Reference	Title	Journal	Study information
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 Cent of 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 and older. 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 one month after the COVID-19-related quarantine measures were put in place in Italy.

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Reference	Title	Journal	Study information
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 their 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' consent and to have a reliable informant. 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, were children of care home residents (77.6%), and 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 in different care settings before and 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/partnered, female, unemployed/retired, living alone, and reporting 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 cares 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.

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Reference	Title	Journal	Study information
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 reported 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 reported 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, Psychological sciences and social sciences	The study is based on telephone interviews with (n = 53) unpaid carers of people with dementia from rural Virginia, USA. The 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.

Table 3: Overview of reports.

Reference	**Title**	**Study information**
Australia		
Hosking, Maccora, & McCallum, 2020	COVID-19: 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 häuslichen Pflege in Deutschland während der Corona-Pandemic – Ergebnisse einer Online-Befragung von informellen Pflegepersonen im erwerbsfähigen 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 were working (26% >20 hours per week; 24% < 20 hours per week), 11% were retired, 7% unemployed and 22% identified 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	Caring and COVID-19: 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.

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Reference	**Title**	**Study information**
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	Caring and COVID-19: 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, Asian 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 quarters (76%) are aged between 45 and 74 years. Only 4% of the sample 'described 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 one year (90%).
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.

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Reference	Title	Study information
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). At least half of carers were women and most carers were aged 38–53 (45%) and 54–64 (38%). The majority of carers across all age groups cared for their spouse (>60%).
Czeisler, Lane, et al., 2020	Mental health, substance use, and suicidal ideation during the COVID-19 pandemic – United States, June 24–30, 2020.	Representative panel surveys were conducted across the United States with adults aged 18 years or older between 24 and 30 June 2020. The 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 years 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'.
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'. Carers came from 46 states in the United States. More than half of participants from Georgia, Texas, Florida, California, and New York. 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; only one 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%) 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 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 2020 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).

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Reference	**Title**	**Study information**
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	*Availability of formal and informal support* · 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., 2020a: 1380). *Carer health and well-being* · 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 epidemic' (Cohen et al., 2020b: 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., 2020a: 1380). · Unpaid carers reported an increase in the use of psychotropic medication 'to control behavioural symptoms' of the person with dementia they care for; however, this was not statistically significant (Cohen et al., 2020b: 4).
Australia	*Care commitment* · Increased care needs and reduced availability of paid services and informal support are reasons for increased care commitment (Hosking, Maccora, & McCallum, 2020: 7). *Concerns related to COVID-19* · Carers in Australia found it difficult to interpret and apply government guidelines and to keep up with the amount of information circulated (Hosking, Maccora, & McCallum, 2020: 9). · Carers reported difficulties in accessing goods due to resource shortages and accessibility issues (Hosking, Maccora, & McCallum, 2020: 16–17). *Financial implications* · Older carers reported to receive 'very limited financial recognition' (Hosking, Maccora, & McCallum, 2020: 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 found themselves unable to access support (Hosking, Maccora, & McCallum, 2020: 19). *Carers of people living in residential care settings* · 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: 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: 15). · Carers in Australia voiced the desire for regaining agency and participation in the care of their relative (Hosking, Maccora, & McCallum, 2020: 15).
Canada	*Care commitment* · 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: 4). *Concerns related to COVID-19* · Carers reported that the cognitive abilities of their relatives with dementia had decreased since the onset of the COVID-19 related public health measures. They linked this decrease 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: 10). *Availability of formal and informal support structures* · Carers receiving family support emphasised the importance of this help (Roach et al., 2020: 6). · Reduced availability of domiciliary support played a role in carers increased stress levels (Roach et al., 2020: 6). · Carers of people with dementia in Canada appreciated continued support from service providers, even if the amount and type of services had changed (Roach et al., 2020: 8). · Carers were worried about services that supported them prior to COVID-19 may not become available again (Roach et al., 2020: 10).

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Country	Summary of key findings by country
	Carer health and well-being · Carers reported anxiety and feelings of burnout as support services are limited (Roach et al., 2020: 9–10). *Carers' adaptability* · Carers also reported ways of looking after themselves by prioritising self-care, drawing strength from relationships and supporting their brother/sister' (Redquest et al., 2020: 4).
Germany	*Care commitment* · Reduced availability as well as uptake of paid and unpaid support are among reasons for increased care commitment (more time spent caring). Working carers also reported more difficulty in combining their care and work responsibility. Nevertheless, about two thirds report that they are happy with their employer in this situation (Rothgang et al., 2020: 32, 38). · Almost twice as many carers of people with dementia (35%) compared to other carers said that they will not be able to sustain the level of care (Eggert et al., 2020: 12). *Concerns related to COVID-19* · 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 et al., 2020: 15; Rothgang et al., 2020: 29). · Only 19% of respondents in one survey felt that COVID-19 related measures sufficiently recognised unpaid carers (Rothgang et al., 2020: 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., 2020: 30). Another study found that older carers were less concerned about an infection than younger carers (Eggert et al., 2020: 5). *Availability of formal and informal support* · Almost 60% of carers reported that their support situation had changed (Rothgang et al., 2020: 31). · 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 will not be able to manage domiciliary care for longer (35% of carers of people with dementia vs. 19% of other carers) (Eggert et al., 2020: 6, 13). · The use of day care stopped for 81% of people with care needs, domiciliary care stopped for 7% and declined for 13% (Eggert et al., 2020: 14). In addition, carers reported reduced perceived quality of care since the onset of the pandemic (Rothgang et al., 2020: 44). *Financial implications* · The impact of COVID-19 as a challenge on carer's financial situation was the item least reported out of a list of potential concerns (Eggert et al., 2020: 12). · 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 2,000€ (44%) while carers with a household income of 4,000€ or more were less concerned (7%) (Eggert et al., 2020: 17). *Carer 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: 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: 43). · 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: 9–10). · Average burden scores increased from 13.94 to 15.73 (Rothgang et al., 2020: 43-44).
India	*Concerns related to COVID-19* · Carers worried about how to protect their relative with dementia from getting a COVID-19 infection (Vaitheswaran et al., 2020: 1187). · Carers worried what would happen if they were no longer able to support their relative with dementia (Vaitheswaran et al., 2020: 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: 1187–1188). · Carers reported challenging behaviour as their relatives with dementia experienced difficulties in adhering to hygiene measures (Vaitheswaran et al., 2020: 1189).

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Country	Summary of key findings by country
	Availability of formal and informal support structures · 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: 1189). · Carer responsibility increased substantially as usual formal and informal support networks can no longer be accessed (Vaitheswaran et al., 2020: 1189). *Financial implications* · Carers experienced difficulties in combining working and caring from home and were worried 'about the financial impact of the lockdown' (Vaitheswaran et al., 2020: 1189). *Carer health and well-being* · Carers reported the development of health problems and difficulty in accessing medical care for these (Vaitheswaran et al., 2020: 1189).
Italy	*Care commitment* · 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: 3). *Carers health and well-being* · 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 feelings of helplessness (Cagnin et al., 2020: 4–5).
Taiwan	*Carers of people in residential care* · The majority of carers (84.6%) accepted and supported the decision to suspend visits (Yeh et al., 2020: 941). · Carers 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: 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: 941).
UK	*Care commitment* · The Carers Week report (2020: 4) estimates 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) in carers helping people outside their own household who were supporting someone they had not looked after prior to the pandemic (Office for National Statistics, 2020). · Evidence suggests that more than half of new carers were female (Carers Week polling: 59%; ONS report: 51%) and that new carers were more likely to be working (62%), to be younger and to have children under 18 (35%) (Carers Week, 2020: 10, 17; Office for National Statistics, 2020). · UK data suggest that carers spend, on average, 10 more hours per week, taking the average time spent caring to 65 hours per week (Carers UK, 2020b: 6–7). · Increased care needs and reduced availability of paid services and information support are reasons for increased care commitment (Carers UK, 2020a: 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: 35). · Reduced ability to support people with care needs have affected particularly carers supporting people outside their household (Carers UK estimate: 5%) (Carers UK, 2020a: 8; Office for National Statistics, 2020). This may have at least in part been due to Government distancing guidelines and travel restrictions. *Concerns related to 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: 6). · Carers worried about the risk of infection through health and social care staff (Carers UK, 2020b: 7; 2020a: 7). · A small proportion of carers in the UK reported difficulty in adhering to shielding advice due to their caring responsibility (Carers UK, 2020a: 19).

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Country	Summary of key findings by country
	· UK carers reported difficulty in accessing basic needs (e.g., food, hygiene products) during the early part of the pandemic (Carers UK, 2020b: 18), and carers of people with dementia complained 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: 19; Lariviere et al., 2020: 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 Black, Asian, and Minority Ethnic (BAME) carers (73% and 72%, respectively) (Carers UK, 2020a: 14). · A considerable proportion of carers (70%) were worried what would happen if the person they care for requires hospitalisation (Carers UK, 2020a: 15) *Availability of formal and informal support* · Carers in the UK, including carers of people with dementia reported reduced services, which impacted on carers ability to take breaks (Carers UK, 2020b, 2020a). This impact was particularly pronounced among BAME carers (Carers UK, 2020a: 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 remain more widely available (Alzheimer's Society, 2020b; Carers UK, 2020a: 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 (April 2020) did not get the help they needed. The situation improved in May 2020 (Bennett, Zhang, & Yeandle, 2020c: 2). · Research from the UK showed that, for many families, whether or not to accept the risk of many changing carers entering their home was a difficult decision. 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 that they would 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). · A study on carers of people with dementia found that losing informal support increased carers' feelings of sole responsibility as well as 'feelings of stress and fatigue' (Giebel, Hanna, et al., 2020: 6). *Financial implications* · 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, & Yeandle, 2020b: 2). · Carers reported greater spending (81%), including on food (72%) and household bills (50%). Among carers surveyed, 38% agreed with a statement expressing concerns about their financial situation (Carers UK, 2020b: 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 were often unavailable (Carers UK, 2020b: 11; Carers Week, 2020: 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, & Yeandle, 2020a: 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: 17). · 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, & Yeandle, 2020b: 10). *Carer health and well-being* · A report also identified issues with carers access to psychotherapy and pharmacy services (Bennett, Zhang, & Yeandle, 2020c: 3). · Carers reported that their own medical treatment (38%) or that of the person they care for (57%) (90% of health and social care services of people with dementia (Alzheimer's Society, 2020b: 34)) had been delayed and many carers (65%) stated that they had put off seeing health service providers out of concerns over infection (Carers UK, 2020a: 15).

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Country	Summary of key findings by country
	· 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: 12; Office for National Statistics, 2020). · UK carers reported increased stress (ranging from 58%–71%), feeling exhausted and worn out (74%). A considerable proportion (44%) of carers reported reaching breaking point (Carers UK, 2020a: 6–7; Carers Week, 2020: 5). · A survey among 800 carers of people with dementia reported heightened feelings of exhaustion (69%), anxiety (64%), sleeping problems (50%), and depression (49%) (Alzheimer's Society, 2020a: 30) · Many unpaid carers reported feeling socially isolated and lonely (48% of respondents of the Carers UK survey) (Lariviere et al., 2020: 12; Carers UK, 2020a: 13). Research showed that carers experiencing financial difficulties were also at greater risk of feeling 'lonely and cut-off from people' (62%) (Carers UK, 2020a: 13). Carer loneliness was identified as an important predictor of depression (Gallagher & Wetherell, 2020). It was also reported that carers supporting people outside their home experienced greater loneliness than non-carers and younger carers, women and working carers were also more likely to feel lonely (Bennett, Zhang, & Yeandle, 2020c: 2). 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 carers consistently reports poor mental health and well-being during the pandemic. This was found to be worse for women and carers experiencing financial difficulties (Carers UK, 2020a: 13). There was also evidence that younger working carers experience lower mental health (Bennett, Zhang, & Yeandle, 2020a: 2). While acknowledging consistently poorer mental health among women than men, as well as among people during the pandemic compared to before, a study investigating carers supporting people outside their home did not observe a significant difference in mental health between carers and non-carers (Office for National Statistics, 2020). · Three UK studies uniformly report that access to social and psychological support can reduce the risk of poor mental health outcomes and well-being (Gallagher & Wetherell, 2020; Giebel, Lord, et al., 2020; Willner et al., 2020: 1527). · Carers have also reported worsened physical health (58%). 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: 13). *Carers' adaptability* · The analysis of the virtual cuppa intervention showed that carers started to change their views and perspective, to set up new routines, to engage in self-care, such as practising relaxation techniques, going out for a walk or spending time in their garden and to engage in virtual peer support activities (Lariviere et al., 2020: 14–15). *Carers of people in residential care* · Carers were unable to visit people they support in residential care settings (Carers UK, 2020b: 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: 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: 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: 766).
USA	*Care commitment* · Many carers (63% (University Center for Social and Urban Studies 2020: 16) reported increasing their care commitment due to the COVID-19 pandemic or an increase (55% [Rosalynn Carter Institute for Caregiving, 2020: 20]) 'in the frequency of contact' with the person with care needs. · A survey among members of an insurance fund in the USA showed that 55% of those identifying as current carers would not have done so prior to the COVID-19 pandemic (BlueCross BlueShield, 2020: 2). · A repeat survey among carers of people with dementia in the US showed that between March and October 2020 on average more than 30% of carers reported additional tension about keeping the person with dementia they care for at home and an increasing proportion of carers (24% in March; 36% in July; 35% in October 2020) found it difficult to be around the person with dementia for 24 hours per day (USAgainstAlzheimer's, 2020). · In one study, 11.3% of carers found benefits in the COVID-19 pandemic. These included the ability to spend more time with the person with dementia (when the carer was unable to work) and that the person with dementia appeared at greater ease with the carer being around (Savla et al., 2020: 3).

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Country	Summary of key findings by country
	· Carers stated that their care responsibility had become more difficult, both physically (22%) and emotionally (56%) (University Center for Social and Urban Studies, 2020: 17). US carers of people with dementia 47% (n = 53) reported high role overload (Savla et al., 2020: 4).
	Concerns related to COVID-19
	· Many US carers worried about becoming infected, infecting their relative with care needs and becoming unable to care (Rosalynn Carter Institute for Caregiving, 2020: 3; USAgainstAlzheimer's, 2020). More carers (28.6%) than non-carers (20.0%) worried about a family member contracting COVID-19 (University Center for Social and Urban Studies, 2020: 9).
	· The repeat survey among carers of people with dementia in the US showed that the concern around the ability to care persisted throughout the pandemic. A greater proportion of carers worried what would happen if they became unable to care (71% March, 58% July, 75% October 2020) than if the person with dementia became ill (42% March, 38% June, 29% October 2020) (USAgainstAlzheimer's, 2020).
	· Carers reported difficulties in accessing everyday goods due to shortages, public health measures, and financial issues (Rosalynn Carter Institute for Caregiving 2020, 16).
	· In the US, 64% of carers of people with dementia reported in March 2020 that they got the information they needed, while 31% found that the level of information was insufficient (USAgainstAlzheimer's 2020, Survey 1).
	· Carers of people with dementia in the US reported lowering their expectations for the festive season, with 90% of carers expecting reduced social interaction having a negative impact (October 2020) (USAgainstAlzheimer's, 2020).
	Availability of formal and informal support
	· US carers, including carers of people with dementia report reduced availability of respite/day care, coaching or counselling for carers, support groups and in-home health aid (USAgainstAlzheimer's 2020). On the other hand, it appears that food and medicine delivery services have increased while in-home nursing care remained stable (Rosalynn Carter Institute for Caregiving 2020: 4).
	· Even though almost 60% of carers of people with dementia found available domiciliary care sufficient, 41% reported weariness as the amount of support from care aides had reduced (Savla et al., 2020: e243).
	· While some carers were able to maintain their unpaid/informal support structures or to receive additional support, many carers reported to have lost these (just over half) or that the support they receive has been reduced (27%–39% of carers of people with dementia) (Rosalynn Carter Institute for Caregiving, 2020: 4; USAgainstAlzheimer's, 2020)
	Financial implications
	· The repeat survey among carers of people with dementia in the US showed that in the early period, 74% of carers reported being more concerned about their own and their family's financial health than before COVID-19 (March 2020). Over time these concerns decreased to 43% (May 2020) to then increase again to 52% (September 2020) (USAgainstAlzheimer's, 2020).
	· In a survey contrasting US unpaid carers with non-carers, a greater proportion consistently expressed financial concerns, including being able to afford food (29%), not having the money to buy additional food when needed (13.6%), and worrying about food running out before they could afford more (20%) (University Center for Social and Urban Studies, 2020: 9–10). Even carers becoming homeless during the pandemic were mentioned (Rosalynn Carter Institute for Caregiving, 2020: 17).
	Carer health and well-being
	· A greater proportion of carers than non-carers reported to have cancelled medical appointments (57% vs. 43%) and fewer have seen a doctor (5% vs. 64%) (University Center for Social and Urban Studies, 2020: 9).
	· Carers (17%) in the US reported an increase in family disagreement or conflict around caring since the onset of the COVID-19 pandemic (University Center for Social and Urban Studies, 2020: 19).
	· US carers reported increased care-related stress (25%: BlueCross BlueShield, 2020: 2; 83%: Rosalynn Carter Institute for Caregiving 2020: 3).
	· The repeat survey among carers of people with dementia showed that stress levels fluctuated a bit over time. In April 2020, 92% of carers reported higher stress due to COVID-19. This declined to 62% by July but then increased again to 77% in October 2020 (USAgainstAlzheimer's 2020). By October 2020, a considerable proportion of carers of people with dementia reported several key stressors, such as vigilance/being 'super alert' (45%), sleep problems (40%), loss of interest in activities (34%), difficulty concentrating (31%), trouble experiencing positive feelings (29%), [and] irritable/angry behaviour (25%) (USAgainstAlzheimer's, 2020).

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Country	Summary of key findings by country
	· Carers of people with dementia reported increased isolation. The repeat survey conducted between March and October 2020 showed the lowest value in June (69%) and the highest in October (75%) (USAgainstAlzheimer's, 2020). · The survey among members of an insurance company showed that younger carers experienced more loneliness or isolation than older carers (56% Millienials; 54% GenXers; 42% baby boomers) (BlueCross BlueShield, 2020: 2) · Research found that US carers showed consistently worse burden and stress as well as mental health outcomes (anxiety, depression) since the COVID-19 pandemic. Research also found that mental health, physical health, and loneliness were rated worse by carers than among non-carers (Rosalynn Carter Institute for Caregiving, 2020: 3; University Center for Social and Urban Studies, 2020: 12). · A US study found that 'adverse conditions', including substance use (32.9% carers vs. 6.3% non-carers) and suicidal ideation (30.7% carers vs. 3.6% non-carers) were more prevalent among unpaid carers (Czeisler, Lane, et al., 2020: 1051). Stress levels were found to be more pronounced among female carers (Rosalynn Carter Institute for Caregiving, 2020: 10). · US evidence identified a difference in somatic symptoms, such as headaches, body aches, and abdominal discomfort between long-term and short-term carers. Long-term carers were also more likely to report more somatic symptoms (Park, 2020: 4). · US carers also reported a delay in access to medical care for their relative with care needs (37%; 55% carers of people with dementia) and for their own needs (21%; 62% of carers of people with dementia) (USagainstAlzheimer's, 2020). In comparison to non-carers (25%), a greater proportion of carers (30.8%) rated their ability to access health-care 'a little/lot worse'. (University Center for Social and Urban Studies, 2020: 10, 18). Avoidance of urgent or emergency care was significantly higher among carers than non-carers. (Czeisler, Marynak, et al., 2020: 1250) *Carers' adaptability* · Carers (about 57%) reported active coping strategies (Savla et al., 2020: e244). The included contact with friends, meditation, music, gardening (USAgainstAlzheimer's, 2020; Savla et al.: e244). · 81% of current caregivers have felt negative emotions in their caregiver role, which is managed by speaking with friends, prayer/meditation, listening to music, and a host of other strategies. (USAgainstAlzheimer's, 2020, Survey 7). *Carers of people in residential care* · A survey among US carers of people with dementia showed how visitor restrictions were in place in March 2020 (74% of carers unable to visit) and remained in place wide-spread before restrictions slowly started to be lifted (68% unable to visit in July, 62% in September; 42% in October) (USAgainstAlzheimer's, 2020). · The proportion of carers feeling less confident about the level of care their relative received increased from 35% in March to 44% in June, but then dropped to 21% in October. Across all months a consistently larger proportion of carers expressed concern about the 'facility's ability to adequately care' for their relative with dementia (ranging from 47% in June to 37% in September) (USAgainstAlzheimer's, 2020). · The US survey among carers of people with dementia showed that most carers (ranging from 100% in March to 92% in October) were in favour of 'testing all nursing home residents and staff'. It is interesting that agreement with testing slightly declined as the proportion of carers who had heard of cases in their relatives' care facility increased (from 50% in June to 67% in September 2020) (USAgainstAlzheimer's, 2020). · Overall, US carers expressed willingness to wear personal protective equipment (93–94%), to have socially distanced visits (70–90%), to be tested prior to their visit (59%–67%), to pay for these tests (32–41%) or to use video visits instead of in-person visits (41–59%) (USAgainstAlzheimer's, 2020).

We also mapped the available information on measures used to address the impacts on carers and evidence of how well they worked. The measures were grouped as use of technology, receipt of financial assistance and support to enable working carers to combine care and work commitments. Details of the evidence for these measures, by country, can be found in **Table 5**.

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 beginning 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 was typically the case for carers supporting people outside their household who adhered to government distancing guidelines and travel restrictions (see **Table 4** for detailed information by country).

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 cared for. Evidence from Germany and the US shows that carers report greater worry around infection than non-carers (Eggert et al., 2020; Rosalynn Carter Institute for Caregiving, 2020; Rothgang et al., 2020; University Center for Social and Urban Studies, 2020). Second, carers in the US and the UK and carers of people with dementia in India and the US worried about what would happen if they became unable to care, if they or the person they care for became ill or required hospitalisation (Carers UK, 2020b; USAgainstAlzheimer's, 2020; Vaitheswaran et al., 2020). 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, personal protective equipment [PPE], medical items) due to shortages and movement restrictions. Fifth, government communication strategies affected carers' ability to respond to the pandemic. For example, 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. On the other hand, carers in the UK reported a lack of information, 'widespread confusion' about government advice, and challenges adhering to it (Carers UK, 2020b; Eggert et al., 2020; Lariviere et al., 2020). Finally, while about half of carers surveyed in the UK felt they could manage their caring responsibilities at that moment, two thirds worried how they would deal with further lockdowns and more than half were concerned about how they would manage during winter due to weather, limited opportunities to get out, seasonal illness, and their own health (Carers UK, 2020a: 14).

Among carers of people with dementia, we identified a further aspect: The impact of reduced social interaction and physical activity on the progression of dementia symptoms. Carers reported that since COVID-19-related public health measures were implemented, 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.

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 created major challenges. We identified three main reasons that led to the unavailability of home care. First, home care staff were unable to reach people's homes due to travel bans; second, there was reduced availability of services due to staff shortages; and, third, people using paid care and their families chose to reduce services out of concerns about a COVID-19 infection. We also identified a pattern where carers persisted with formal support, despite concerns around infection, as they were worried about not being able to regain access to services. Carers also voiced concerns about 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. Carers also explained that reduced availability of support structures had an effect on behaviour that carers find challenging to respond to as well as on the cognition of people living with dementia (Carers UK 2020b; Eggert et al., 2020; Giebel, Cannon, et al. 2020; Roach et al. 2020; Vaitheswaran et al. 2020).

The availability of support through informal networks, such as family, friends, and neighbours, was mixed. While many carers, including carers of people with dementia, reported that practical and emotional support from their informal networks continued, others reduced or stopped their network's involvement due to concerns around infection risks and adherence to government guidelines.

Carers also experienced reduced availability of, as well as delays in access to, medical care, both for themselves and the person they provide care to. Some reported avoiding or delaying medical care out of concerns about infection risk.

Financial implications

Prior to the COVID-19 pandemic, many carers were already experiencing challenges in combining work and care, as well as financial implications because their care responsibility prevents them from working full-time (Hosking, Maccora & McCallum, 2020). The reduction of available community services during the pandemic, as discussed above, has created even greater challenges in combining paid work and unpaid care. While some carers who can

Table 5: Results of intervention by country and theme.

Canada	*The use of technology* · 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: 9).
Germany	*The use of technology* · In Germany 40% of respondents of a cross-sectional survey have started using new technological approaches to maintain social contacts (Rothgang et al., 2020: 37). *Receipt of financial assistance and support for working carers* · German carers were generally satisfied with the COVID-19 related measures. Carers would particularly value being able to take paid leave to respond to a care situation. Carers would also welcome 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: 45, 48). · Many carers have both work and caring responsibilities. While some reported no difference in their ability to combine work and care (54% of respondents [Eggert et al., 2020: 17]; 26% of respondents [Rothgang et al., 2020: 38]), others stated that they experience even greater challenges (45% of respondents, [Eggert et al., 2020: 17]; 71% of respondents [Rothgang et al., 2020: 38]). However, none of the respondents in one of surveys have made use of the government policy enabling carers to take up to 10 days of paid leave during the COVID-19 pandemic (Eggert et al., 2020: 17).
India	*The use of technology* · Some carers expressed a need to use technologically supported services, such as medical video or telephone consultations. Others, however, identified several barriers that would prevent them from using technology. They include a 'lack of experience and knowledge', limited access, inability of people with dementia to participate in remote conversation, limited need for services that could only be provided using remote technology, and the issue that practical needs remain unmet (Vaitheswaran et al., 2020: 1191).
UK	*The use of technology* · In the UK, one survey found that 58% of carers have started to use technology to maintain social contact (Carers UK, 2020a). 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 experienced 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: 6). · 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: 19). · A proportion of carers (10%) reported difficulty in accessing technological tools. This was higher among carers experiencing financial difficulties (18%) (Carers UK, 2020a: 19). · 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 help with technical issues, to lead the group as well as time for these relationships to build and a sense of community to emerge (Lariviere et al., 2020). · 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: 19) *Receipt of financial assistance and support for working carers* · 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: 13). Despite these employment policies, 11% of carers reduced their hours and 9% gave up their jobs to provide care (Carers UK, 2020a: 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 enabled them to maintain employment (Carers UK, 2020a: 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: 21).

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USA	*The use of technology* · Carers in the US reported using technology for social contacts (85.9%), self-care (22.8%), health monitoring (43.8%), and e-visits (17.0%), care coordination (37.8%), and ordering of supplies (53.6%) (University Center for Social and Urban Studies, 2020: 21). Most US carers found telehealth, tele-mental health, remote counselling, training, and coaching very helpful, while some reported difficulty in adapting to online services (Rosalynn Carter Institute for Caregiving 2020: 26–28). Carers of people with dementia in the US reported that local area agencies contacted them more frequently and that access to telehealth had been enabled (Savla et al., 2020: e243). Receipt of financial assistance and support for working carers · US carers most commonly reported receiving a check from the federal government (CARES Act in March 2020). Some also received temporary rent and housing assistance or gift cards to help with household expenses. Many carers expressed the need for further assistance, such as a caregiver stipend or a second stimulus check (Rosalynn Carter Institute for Caregiving, 2020: 26, 28). · The wish for government support, such as food stamps or unemployment benefit among carers of people with dementia declined from 32% in March 2020 to 7% in June 2020 (USAgainstAlzheimer's, 2020).

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 about infection risk in their workplace.

Since the pandemic, carers have reported financial concerns as a source of stress (Rosalynn Carter Institute for Caregiving, 2020). For many US and UK carers, financial implications posed a risk to people's ability to meet basic needs, including food (Bennett, Zhang, & Yeandle, 2020a, 2020b; Rosalynn Carter Institute for Caregiving, 2020; University Center for Social and Urban Studies, 2020). 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' (Hosking, Maccora & McCallum, 2020).

Carers' health and well-being

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 wellbeing, and physical health among carers (Please see **Table 4** for detailed information by country).

Carers' adaptability

While this review highlights negative impacts on many carers, there is also important evidence of strength, resilience, and adaptation. Carers have reported drawing strength from their informal support networks (family, friends, online peer network) and emphasised the importance of making time for themselves and prioritising self-care (See **Table 4** for detailed information by country).

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. Detailed information of evidence from Australia, Taiwan, the UK, and the USA can be found in **Table 4**.

Measures to address the impact on carers and evidence of how well this worked

The use of technology

Carers reported that services and interventions using technology 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 for 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 the important recognition that technological interventions cannot replace in-person practical support. Detailed information on research findings from Canada, Germany, India, the UK, and the USA can be found in **Table 5**.

Receipt of financial assistance and support for working carers

Some carers received financial assistance. In Germany, for instance, this included paid leave, the ability to spend flexibly the funds that usually go towards day care, as well as in-kind provision of protective equipment. In addition, German government policy enabled carers to take up to 10 days of paid leave during the COVID-19 pandemic. In practice, 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). While measures in the UK and the US were not specifically targeted at carers, they contributed to supporting carers' financial situation. The UK government's introduction of the 'furlough scheme' provided people whose jobs were temporarily suspended due to COVID-19 with 80% of their income. According to a survey, this intervention initially ensured an income for approximately 13% of working carers, but many were worried about the future (Carers UK, 2020b). In the United States, carers benefited from general financial stimulus payments (Rosalynn Carter Institute for Caregiving, 2020). Please see **Table 5** for more information by country.

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 this. Where government advice was communicated clearly, this helped carers to adhere to it. Reduced availability of formal and informal support structures 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 Black, Asian, and minority ethnic (BAME) carers have been found to be at greater risk of negative outcomes (e.g., financial difficulties, health, loneliness) (Bennett, Zhang, & Yeandle, 2020a, 2020b, 2020c; BlueCross BlueShield 2020; Cagnin et al., 2020; Carers UK, 2020a; Rosalynn Carter Institute for Caregiving, 2020). Carers of people living in residential care settings have found it difficult to remain in contact with their relatives, have been worried about their health status and the quality of care they receive, and have feared negative long-term implications due to the prolonged social isolation experienced by their relatives (Baxter, 2020; Carers UK, 2020b; Giebel, Cannon, et al., 2020; Hosking, Maccora, & McCallum, 2020; USAgainstAlzheimer's, 2020; Yeh et al., 2020).

Policy implications

For many carers, the COVID-19 pandemic had an impact on their care responsibilities, 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 that the fragile situations many carers live in has worsened. As everyday expenditure increased, many were left vulnerable to hunger and even homelessness and reliant on foodbanks (Bennett, Zhang, & Yeandle, 2020a: 2; Rosalynn Carter Institute for Caregiving, 2020: 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: 13; Rosalynn Carter Institute for Caregiving, 2020). In countries such as Germany, where unpaid carers are seen as a key part of the care system and have access to a broader safety net of social protection mechanisms during 'normal times', the impact appears to have been less severe (Curry, Schlepper & Hemmings, 2019; Rothgang et al., 2020; Zigante, 2018: 18). This highlights the importance of social protection mechanisms. Other recommended measures included 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 (Stokes & Patterson, 2020: 420–421).

Carers need support

Our review has 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, as well as increasing the care load, 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 again post COVID-19 (Giebel, Cannon, et al., 2020; Giebel, Hanna, et al., 2020). Others who have lost their paid helpers struggled 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 (paid and unpaid) carers receive permission to travel to attend to their care responsibilities and 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). In addition, carers need access to PPE and to vaccination to enable them to protect themselves and the person they care for as well as support with developing contingency plans to prepare for situations when they may be unable to care (Carers UK, 2020b: 23–24; Lauter et al., 2021; 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: 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 as informants of the preferences and wishes of the person with care needs and in recovery plans (Carers UK, 2020a: 23, 2020b: 23; Carers Week, 2020; Rosalynn Carter Institute for Caregiving, 2020; World Health Organization, 2020: 25).

Technology has been recognised as having potential to enable the provision of some of the services and carers have welcomed that some community services were moved online to provide carers with emotional support, advice, and virtual interventions. However, it has also been highlighted that not all carers can access these resources and many miss in-person contact and practical support (Carers UK, 2020b: 23; Rosalynn Carter Institute for Caregiving, 2020: 30). For 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: 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, the trade-off between the risk of infection and residents' quality of life has proven difficult to address (Low et al., 2021). The Alzheimer's Society in England 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: 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 & Friss Feinberg, 2020).

Women continue to carry the bulk of care

Historically, the provision of unpaid long-term care has fallen into the female realm. Even though in many countries (e.g., United Kingdom [ONS, 2013], Germany [Robert Koch-Institute, 2015]), the number of older men caring for their wives is increasing, globally women continue to provide three times times the amount of unpaid care and domestic work compared to men and boys (Nesbitt-Ahmed & 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, & Mishra, 2020). Our review has highlighted the heightened vulnerability of female carers. While it has long been reported that female carers experience worsened mental and physical health, our review has shown that this pattern persists, and is likely to have worsened, during the COVID-19 pandemic. In addition to health outcomes, women have also reported greater social isolation, loneliness, and financial stress. Expected demographic change means that the number of older people with long-term care needs is likely to increase over the next decades while the share of the population at working age decreases. This will make the role of women in the labour force increasingly important (European Commission, 2020). Many women already provide care on top of other family and employment responsibilities. The UN emphasises that 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 & Subrahmanian, 2020).

Conclusion

Our review is based on data that has been collected since the beginning of the COVID-19 pandemic and up to November 2020, but, apart from the repeat surveys conducted by USagainstAlzheimer's and the two surveys by Carers UK, the studies so far rely only on cross-sectional data. The absence of longitudinal data means that it is not yet possible to observe patterns over time or to 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 (see **Tables 2** and **3**). 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. It shows that increasing numbers of unpaid carers continue to provide many hours of care and support for people with care needs, that carers are concerned about their ability to protect the person they care for from a COVID-19 infection and that they are worried about the consequences. Our review also found that the availability of formal and informal support has been affected, that being an unpaid carer can have implications on carers finances, health, and well-being and that many carers have responded and adapted to the changes created through the pandemic. In addition, our review has highlighted the concerns of carers supporting people in residential care settings and their concerns about residents' social contacts and the quality of care they receive. It has also emphasised the importance of policy responses, such as the use of technology, direct and indirect financial support, as well as measures that enable carers to maintain employment, to mitigate and prevent the negative implications many unpaid carers experience.

Note

[1] This an assumption by the authors as no details are provided in the report.

Competing Interests

The authors have no competing interests to declare.

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