

# The early impacts of COVID-19 on unpaid carers of people living with dementia: Part II of a mixed-methods systematic review

Clarissa Giebel (✉ [clarissa.giebel@liverpool.ac.uk](mailto:clarissa.giebel@liverpool.ac.uk))

University of Liverpool

Catherine V Talbot

Bournemouth University

Emily Wharton

LJMU

Klara Lorenz-Dant

Aida Suarez-Gonzalez

Jacqueline Cannon

Hilary Tetlow

Katarzyna M Lion

Jochen Rene Thyrian

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## Research Article

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## Abstract

## Background

With a lack of existing comprehensive reviews, the aim of this mixed-methods systematic review was to synthesise the evidence on the early impacts of the pandemic on unpaid dementia carers across the globe.

## Methods

This review was registered on PROSPERO [CDR42021248050]. PubMed, CINAHL, Embase, Scopus and Web of Science were searched from 2020 to July 2021. Studies were included if they reported on the different impacts of the pandemic on unpaid dementia carers aged 18+, with papers published in English, German, Polish, or Spanish. A number of research team members were involved in the selection of studies following PRISMA guidance.

## Results

Thirty-six studies (43 papers) from 18 countries reported on the early impact of the pandemic on unpaid dementia carers. Impacts were noted on accessing care and support; carer burden; and well-being. Studies found that carers had limited access to care and support services, increased workload, enhanced feelings of isolation, and reduced wellbeing. All these negative impacts were interlinked, with reductions in access to care and support increased carer's unpaid caring tasks, removing any opportunities for temporary respite, and thus increasing carer burden and reducing mental well-being in many.

## Conclusions

The needs of unpaid dementia carers appear to have increased during the pandemic, without adequate support provided. Policy initiatives need to enable better mental health support and formal care provision for unpaid carers and their relatives with dementia, whilst future research needs to explore the long-term implications of carer needs in light of care home restrictions and care delivery.

## Introduction

Of the estimated 55 million people living with dementia worldwide (WHO, 2021), many receive support from family members or friends, who are providing free and unpaid care to their relatives with dementia. Whilst providing a great deal of support for their relatives, unpaid carers are often overlooked in receiving support themselves (Clemmensen et al., 2021). Already before the COVID-19 pandemic, many unpaid carers experienced high levels of burden and poor mental well-being as a result (Sutcliffe et al., 2017). This increases as dementia advances, due to higher care needs of the person with dementia, and can often be a contributor for people with the condition to utilise more formal care including entering a care home (Kerpershoek et al., 2020).

People living with dementia have been particularly vulnerable and susceptible to the COVID-19 in this ongoing pandemic, due to their predominantly increased age (Banerjee et al., 2020) and frequent lack of understanding public health restrictions (Giebel et al., 2021a; Tuijt et al., 2021a). This has not only affected the person living with the condition, but also their support network which tries to keep them safe.

The COVID-19 pandemic has provided new care challenges and additional care needs for people with dementia, with social care and social support services primarily closed or operating at reduced levels (Giebel et al., 2021b). Early evidence seems to indicate that these reductions in external care support have led unpaid carers to take on additional care roles, on top of their previous caring roles (Rising et al., 2021; Sririam et al., 2021). Additional caring duties and hours without any respite appear to be linked to poorer mental health and well-being in carers, with a growing body of evidence reporting on the wider exacerbated mental health needs of unpaid carers since the pandemic (Rainero et al., 2021; Vaitheswaran et al., 2021).

Despite a burgeoning evidence base into the impacts of the pandemic on unpaid dementia carers, to date, it appears that no single systematic review has evaluated and synthesised the existing literature on the wider impacts of the pandemic on these unpaid carers. Instead, a rapid systematic review from early 2021 has looked at the psychological impact only, reporting negative effects of the pandemic on unpaid carers' mental health, including depression and anxiety (Hughes et al., 2021). The review failed to explore the wider impacts of the pandemic, however, on carers' access to care, which may be linked to reductions in health and well-being. Other systematic reviews on COVID-19 and dementia have solely focused on people with dementia and specific outcomes, such as cognition and mental health (Suarez-Gonzalez et al., 2021), or included non-primary research very early in the pandemic (Bacsu et al., 2021), providing little insights into the wider impacts on unpaid carers.

Therefore, the aim of this mixed-methods systematic review was to understand the impact of the COVID-19 pandemic on unpaid dementia carers, focusing on carers' health and well-being as well as health and social care access in the early stages of the pandemic. There is a continued need for understanding how the pandemic is impacting on unpaid carers, not just for dementia, but also for other conditions. COVID-19 is still affecting people's lives, so that knowledge from the early stages of the pandemic can help shaping care and support from Governments and care services to meet the needs of the unpaid workforce of some of the most vulnerable populations of our societies during the current pandemic as well as moving forward.

## Methods

The protocol of this systematic review was registered on PROSPERO [ID: CRD42021248050]. Two unpaid carers (JC, HT) advised on the development of this review, were interpreting the findings jointly with other team members, read through drafts of the manuscript, and provided feedback. Due to the high number

of included studies, the results are presented in two parts: Part I focusing on people living with dementia and Part II focusing on unpaid carers. A full report of the methods for this review is presented in Part I (see Giebel et al., submitted). Only empirical studies were included in this review, both quantitative and qualitative. Studies for Part I and II were included if they focused on people living with dementia aged 18+ and/or unpaid carers of people living with dementia aged 18+. Studies of people without a dementia diagnosis, formal or paid carers, or people aged 17 and younger were excluded. The data bases PubMed, CINAHL, Embase, Scopus and Web of Science were searched from 2020 to July 2021, using the search term 'Covid-19' and search terms relating to dementia. Each title and abstract were screened by one reviewer (with the task divided amongst three reviewers due to citation size), and a 10% check was performed by a fourth reviewer as part of Stage 1. For Stage 2, each full-text paper was then screened by two reviewers each, with the task divided among four reviewers in total due to the large number of inclusions. Included studies were assessed using QualSyst (Kmet et al., 2004) by two researchers independently.

## Results

### Overview of included studies and data selection

159 full texts were read through for inclusion for the overarching review (Part I and II), with 36 studies reported in 43 papers specifically reporting on the impact of the pandemic on unpaid dementia carers. Studies were conducted across 18 countries, including Greece, Italy, Singapore, India, Poland, and the UK. The majority of studies (n=25) were quantitative, including retrospective surveys enquiring about changes since the pandemic (Carpinelli-Mazzo et al., 2021; Pongan et al., 2021) and assessments of mental health and carer burden (i.e., Hwang et al., 2021; Losada et al., 2021). Qualitative studies (n=8) reported on remote interviews with unpaid carers about their experiences of providing care during the pandemic and their concerns (i.e., Rising et al., 2021; Sririram et al., 2021). Three mixed-methods studies reported on different impacts, including carer burden and access to care (Dassel et al., 2021; Rajagopalan et al., 2021; Savla et al., 2021). All studies focused on unpaid carers of community-residing people living with dementia, with Borg et al. (2021) focusing on both community and care homes.

**[Figure 1; Tables 1-3]**

Table 1  
Overview of included studies

Authors	Country	Population (people with dementia/carers/ sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period data collected
Alexopoulo et al.	Greece	Carers of people with mild (N =13) and major (N =54) neurocognitive disorder (about carers)	Care burden, mental health, cognition	Quantitative	Telephone survey was based on items of the neuropsychiatric inventory questionnaire, the AD8 Dementia Screening Instrument, and the Bristol Activities of Daily Living Scale. Generalized Anxiety Disorder 7-Item (GAD-7) and the 22-item Impact of Event Scale-revised (IES-R).	Caregiver distress severity during the confinement period was influenced by memory deficits, neuropsychiatric symptoms of people with dementia, caregiver hyperarousal and avoidance symptoms and worries directly linked to the COVID-19 crisis.	Community	N/A
Altieri; Santangelo	Italy	84 carers of people with dementia (about carers)	Carer burden, mental health	Quantitative	Online survey, a sociodemographic questionnaire, the Italian version of Hospital Anxiety and Depression Scale (HADS), the Italian version of the Resilience Scale for Adults (RSA), the Italian version of Caregiver Burden Inventory (CBI).	Produced psychological consequences in carers of people with dementia, with an increase of levels of depression. High resilience had a negative effect on anxiety levels.	Community	April and May 2020
Azevedo et al.	Argentina, Brazil, Chile	321 family carers of people with dementia (about people with dementia and carers)	Care Burden, Mental health, Behaviour	Quantitative cross-sectional study	Questionnaires were applied via telephone - age, sex, education level, socioeconomic status (through appropriate instruments for each Country), kinship, medical diagnosis, and severity of dementia.	Individuals with dementia felt sadder and had increased anxiety symptoms. Compulsive-obsessive behaviour, hallucinations, increased forgetfulness, altered appetite, and increased difficulty in activities of daily living were reported more frequently. Carers reported feeling more tired and overwhelmed.	Community	May to July 2020
Borelli et al.	Brazil	58 people and carers (about people with dementia and carers)	Care burden, mental health, cognition	Quantitative cross-sectional study	The Neuropsychiatric Inventory Questionnaire (NPI-Q), Zarit Burden Interview (ZBI), Beck Depression (BDI) and Anxiety (BAI)	Cognitive decline was shown, as well as behavioural symptoms especially apathy/depression and functional decline. Increased carers' psychological distress.	Community	May to June 2020

Authors	Country	Population (people with dementia/carers/ sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period data collected
Borg et al.	France	398 carers accompanying a people with dementia living at home (HC) and 159 accompanying a people with dementia living in a nursing home (NHC) (about people with dementia and carers)	Care burden, Mental health	Quantitative cross-sectional study	Online survey - Anxiety was assessed with the GAD-7 scale, Depressive symptoms were assessed with the CES-D scale, caregiver's burden was assessed using the validated short version of the Zarit Burden Interview, and level of self-rated stress was assessed with a visual analog scale ranging from 0 (no stress at all) to 10 (highest stress you can imagine).	Half of the carers exhibited poor mental health, including depression, anxiety, or self-reported stress. 126 PWD (34%) went to day care facilities before lockdown, this type of professional support was totally suspended during the lockdown.	Community and nursing home	17th Marc 11th 2020
Borges-Machado et al.	Portugal	36 carers (about people with dementia and carers)	Care burden, mental health	Quantitative	Survey - Barthel Index (BI), The NPI 30 was used to analyse the BPSD, CarerQol was used to address Carer-Qol-7D, and CarerQol-VAS.	Increased caregiving burden and a decline in their well-being. People with dementia decreased their volume of physical activity, and conversely increased their sitting time, decreased well-being.	Community	Nove 2019 June
Boutoleau-Bretonnière et al. (2 papers)	France	38 carers (about people with Alzheimer's disease and carers)  38 behavioural variant frontotemporal dementia (bvftd) and 38 Alzheimer disease (AD) carers (about carers)	Cognition, Mental Health, care burden  Behaviour, Care burden	Quantitative	The Neuropsychiatric Inventory-Questionnaire  Standardised surveys,  The Neuropsychiatric Inventory (NPI)  Questionnaire	Only 10 had neuropsychiatric changes. Confinement seems to impact neuropsychiatric symptomatology in people with AD with low baseline cognitive function. The duration of confinement significantly correlated with both the severity of their neuropsychiatric symptoms, as well as with the distress experienced by their carers  Bvftd carers - increased burden regardless of behavioural changes. AD carers -increased burden related to changes in people with AD neuropsychiatric symptoms.	Community	26th Marc 9th N 2020
Carcavilla et al.	Spain	106 family carers of people with dementia (about carers)	Care burden, mental health	Quantitative descriptive cross-sectional study	Online survey - Caregiver's profile, main problems for the caregiver and consequences for both people with dementia and their carers during COVID,	Family carers of people with dementia experienced psychological problems, like anxiety, mood, sleep, or eating disorders during confinement.	Community	May June

Authors	Country	Population (people with dementia/carers/ sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period data collected
Carpinelli Mazzi et al.	Italy	239 carers of people with dementia (about people with dementia and carers)	Access to care, Mental health, Care burden	Quantitative	Telephone survey: Italian versions of Zung's depression and anxiety assessment  Scales (ZDAAS), the Perceived Stress Scale (PSS), The ZBI (Zarit Burden Interview)	people with dementia were deprived of care services and time of isolation had a significant negative effect on anxiety and depression in carers.	Community	N/A
Cohen et al.	Argentina	119 family carers of persons with AD or related dementia  Living at home (about people with dementia and carers)	Behaviour, mental health, health	Quantitative	Questionnaire survey: designed a visual analog scale to study the burden of care that  family members or paid caregivers experienced before and during the epidemic, demographics of family members, paid caregivers, and dementia subjects	Increased anxiety (43% of the sample), insomnia (28% of the subjects), depression (29%), worsening gait disturbance (41%), and increase use of psychotropics to control behavioural symptoms. Social isolation, lack of outpatient rehabilitation services, and increased stress of family carers	Community	N/A
Cohen et al.	Argentina	80 family carers of persons with Alzheimer's disease (about people with dementia and carers)	Mental health, care burden, access to care	Quantitative	Questionnaire survey: Items included demographic characteristics of  both subjects with dementia and family members  and problems of management, rehabilitation, and  care that subjects experienced during the first 4 weeks of the coronavirus quarantine in our setting, anxiety, burnout and stress  that a family caregiver experienced.	Increased stress caregiver, half of the subjects with dementia experienced increased anxiety and that most family members discontinued all sort of cognitive and physical therapies	Community	April
Dassel et al.	USA	82 carers (about carers)	Access to care	Mixed	Quantitative survey and semi-structured qualitative telephone interviews	Some of family carers revisited or updated advance directives of care recipients and/or had some type of contingency plan if they were to become ill 3 themes: Interruption of  Care Plans, focused on the present, navigating without a compass	Community	Survey May - June  2020 telephonic interview  July - September  2020

Authors	Country	Population (people with dementia/carers/ sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period data collected
Giebel et al.	UK	14 unpaid carers, 7 people with dementia (about people with dementia and carers)	Service usage	Qualitative interviews	Co-produced questions about inequalities in accessing post-diagnostic care	4 themes: (1) Getting the ball rolling: the process of diagnosis; (2) Balancing the support needs of people with dementia and carers; (3) Barriers to accessing support; and (4) Facilitators to accessing support.	Community	Janu Marc 2020
Giebel et al. (2 papers)	UK	569 participants, 61 people with dementia, 285 unpaid carers, and 223 older adults (about people with dementia and carers)	Mental wellbeing, Service usage	Quantitative 3-time point survey	Co-produced survey on service usage, General Health Questionnaire, Short version of the Warwick-Edinburgh Mental Wellbeing Scale, Patient Health Questionnaire	Social support service use significantly reduced since pandemic;  Higher variations in service usage linked to increased levels of anxiety in people with dementia, and lower levels of mental well-being in unpaid carers.	Community	April Augu 2020
Giebel et al./ Hanna et al. (5 papers)	UK	50 baseline participants (42 unpaid carers, 8 people with dementia), 20 follow-up interviews (16 unpaid carers, 4 people with dementia) (about people with dementia and carers)	Service usage, Cognition, Everyday functioning, Mental wellbeing	Qualitative interviews	Co-produced questions about service usage before and since the pandemic	People with dementia were reported to deteriorate faster, struggled accessing social support services, and experienced difficulties deciding about whether to receive paid home care. Inequalities in accessing care noted. Mental health issues noted for people with dementia and unpaid carers.	Community	April July :
Helvaci Yilmaz et al.	Turkey	54 individuals diagnosed with AD and carers (about people with dementia and carers)	Carer burden, cognition, mental health	Quantitative	Survey prepared by the neurology department of Medipol University Istanbul	AD worsening symptom was forgetfulness and agitation. The carers thought that something terrible would happen to the patient and felt they could not find time for themselves. Drug rejection increased the burden twofold	Community	April May : 2020
Hwang et al.	USA	34 carers (about carers)	Mental health, care burden	Quantitative	Questions were developed by the authors based on the previous literature, generalized Anxiety Disorder-7, Center for Epidemiologic Studies Depression Scale, Clinical Dementia Rating (CDR), Barthel Activities of Daily Living Index, Neuropsychiatric Inventory (NPI).	Worrying about spreading covid-19 to the people with dementia, taken on additional caregiving duties for others in their family since covid-19, and reported one or more anxiety symptoms	Community	June 2020 Augu 28th, 2020

Authors	Country	Population (people with dementia/carers/ sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period data collected
Kostyal et al.	Hungary	370 family carers of people with dementia (about carers)	Access to care, care burden, mental health	Quantitative	Online survey - socio-demographic background, caregiver-care recipient relationship, caregiver's responsibilities: caregiver's self-reported physical, general and mental health status, difficulties posed by the pandemic	A deterioration in their financial status. A decline in general and mental health, family carers' burden increased	Community	May-2020
Losada et al.	Spain	88 family carers (about family caregiver)	Care burden, Cognition, Mental health	Quantitative	Telephone survey - Spanish version of GDS and Barthel Index-Behavioural and psychological symptoms, Carers' depressive and anxiety symptomatology, carers' emotions, family and economy during COVID	Increased negative emotions, conflicts, and thoughts on giving up on caregiving. Some carers had increased positive emotions.	Community	June – Mid of May 2021
Ng et al.	Singapore	50 people with Mild FTD and 50 people with mild AD dementia (about people with dementia and carers)	Access to care, behaviour	Quantitative	Phone based Survey - to identify major themes of particular concern to patient-carers dyads of FTD.	Preliminary findings  Demonstrate that people with FTD have significant worsening in behaviour and social cognition, as well as suffer greater negative consequences from disruption to healthcare services compared to people with AD.	Community	N/A
Panerai et al.	Italy	128 carers of people with dementia (about people with dementia and carers)	Care burden, cognition, mental health	Quantitative	The Neuropsychiatric Inventory Questionnaire (NPI-Q) and the Caregiver Burden Inventory (CBI)	Increased risk for burning out of carers, Neuropsychiatric symptoms in people with dementia significantly increased as well.	Community	April and May 16th
Pongan et al.	France	Carers of people with dementia (about people with dementia and carers)	Care burden, behaviour, Mental health	Quantitative	Cross-sectional online survey, The Checklist for Reporting Results of Internet E-Surveys (CHERRIES), the GAD-7 scale (The General Anxiety Disorder-7), The CES-D scale (Center for Epidemiologic Studies-Depression)	Impact on behavioural disorders in people with dementia and these disorders are associated with poorer mental health of carers.	Community	15th – 15th June
Rainero et al.	Italy	97 dementia centers, 4913 people with dementia (about people with dementia and carers)	Care burden, mental health	Quantitative	Survey, Clinical Dementia Rating (CDR)	Carers reported a high increase in anxiety, depression, and distress. Acute worsening of clinical symptoms in people with dementia	Community	April
Rajagopalan et al.	India	104 dementia and their carers (about people with dementia and carers)	Care burden, behaviour, mental health, access to care	Mixed method	Validated instruments and a semi-structured interview guide	Worsening of behaviour, problems in accessing care, disruptions in functional activities and struggles in enforcing infection prevention contributing to caregiver distress.	Community	15 May and 2 June 2020

Authors	Country	Population (people with dementia/carers/sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period data collected
Rising et al.	USA	25 people with dementia and Caregiver (about people with dementia and carers)	Care burden, cognition, mental health	Qualitative	Semi-structured interviews	Four themes emerging: disruption of socialization, fear and risk mitigation, coping strategies, and caregiver burden	Community	Augu Nove 2020
Rusowicz et al.	Poland	85 carers (about caregiver)	Care burden, mental health	Quantitative	Questionnaire; 10-item Perceived Stress Scale (PSS-10)	High levels of stress, PSS-10 correlated with the deterioration of illness during Covid-19, changes in daily functioning, and concerns about both the health of the charge and caregiver	Community	N/A
Savla et al.	USA	53 family carers of persons with dementia (about caregiver)	Cognition, Care burden, access to care	Mixed	Structured survey and open-ended questions - people with dementia's living arrangement and cgs' relationship with people with dementia, age, perception of income adequacy, and race/ethnicity, people with dementia's memory-related behaviour problems, cgs rated three items exhausted, more things to do than can handle, didn't have time for self) on a 4-point Likert scale from 0 (not at all) to 3 (extremely)	Carers who were more concerned about the COVID-19 pandemic were at greater odds of experiencing high role overload than those who recognized positive aspects of the pandemic. Home care services had reduced.	Community	April and M
Sriram et al.	UK	23 carers (about carers)	Care burden, access to care, mental health	Qualitative	Semi-structured Interview	Three main themes—Changes to daily life, impact on carer health and wellbeing and reduced support from health and social support networks.	Community	N/A
Tam et al.	Canada	498 participants carers and people with dementia (about people with dementia and carers)	Carer burden, health services, mental health	Quantitative	Survey - themes: 1) information and resource needs, 2) Caring for someone living with dementia during the COVID-19 pandemic (specific to care partner surveys), 3) mental health and well-being needs, 4) the use of technology for social connection during the pandemic.	Reported several serious concerns, inability to visit the person that they care for in long-term or palliative care. Reported that the pandemic increased their levels of stress overall and that they felt lonelier and more isolated than they did before the pandemic.	Community	June 2020 Augu 2020
Tsapanou et al.	Greece	339 carers (about carers and people with dementia)	Carer burden	Quantitative, Exploratory sequential mixed-methods design – Quantitative	Online questionnaire was created regarding both changes of the patient they take care of, and changes to their own burden	Significant decline, both in an overall aspect of the people with dementia, and in specific domains (mostly communication and mood). carers-significantly increased physical and psychological burden	Community	Nove 2020 April

Authors	Country	Population (people with dementia/carers/ sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period data collected
Tuijt et al. (2 papers)	UK	30 people living with dementia, 31 Family carer (about people with dementia and carers)	Cognition, care burden Access to care	Qualitative	Interviews were semi structured Semi-structured interviews	1) awareness of restrictions, 2) restructuring caring relationships to manage covid-19 risk, 3) protective factors, 4) the psychological and cognitive impact of restrictions, and 5) the importance of social engagement.  Three main themes were derived relating to: proactive care at the onset of covid-19 restrictions; avoidance of healthcare settings and services; and difficulties with remote healthcare encounters.	Community	May - August 2020
Tulloch et al.	Australia	26 carers of people with dementia (about carers)	Access to care, positive caregiver experiences	Qualitative	Semi-structured interviews	Pre-pandemic care: (1) focusing on the people with dementia and (2) working together during-pandemic care: (1) respecting personhood; (2) connecting with virtues and values; (3) improving relationships; (4) seeking and receiving support; (5) prioritizing self-care; (6) being protective and proactive; (7) making practical changes. Moving forward from COVID-19: (1) strengthening commitment to the people with dementia (2) looking after my own needs, and (3) considering practical requirements.	Community	June and August 2020
Vaitheswaran et al.	India	31 carers (about carers)	Care burden, carers need	Qualitative	Semi structured interviews	Themes: unique to the carers that directly related to their caregiving role, while the second set did not relate directly to their caregiving role, needs, provision of support to meet needs	Community	1st Sept 2019 - 29th Febr 2020

Authors	Country	Population (people with dementia/carers/ sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period data collected
Werner et al.	Israel	73 Israeli family carers of  Persons with dementia (about carers)	Behaviour, access to care	Quantitative cross-sectional study	Online survey - Problematic Behaviour Scale, loneliness, cognitive function, fear	Feelings of burden  Were associated with carers' forgone care and feelings of loneliness and perceptions of the care-receiver's cognitive functioning were associated with care-receivers' forgone care.	Community	25 Jun 2020  And close 25 Jun 2020
West et al.	UK	15 participants (people with dementia and Carers)	Health, access to care, Mental health, care burden	Qualitative	Semi structured qualitative Interviews.	8 key themes, with subthemes: Fear and anxiety, food and eating (encompassing food  Shopping and eating patterns), isolation and identity,  Community and social relationships, adapting to covid-19, social isolation and support structures, and medical interactions.	Community	N/A
Zucca et al.	Italy	87 dementia centres, 4710 caregiver – people with dementia pairs (about carers)	Care burden, Mental Health	Quantitative	Survey: six  Questions tapping the following stress symptoms:  (1) depression, (2) anxiety, (3) anguish, (4) irritability, (5) overwhelmed/helplessness (OH), and (6) isolation/abandonment  (IA).	Increased stress, anxiety, concerned for people with dementia' health, sense of isolation and abandonment.	Community	April 14 to 24, 2020

Table 2  
Quality assessment ratings for quantitative studies

Research Paper	Overall Score
Alexopoulo et al.	1.00
Altieri; Santangelo	0.89
Azevedo et al.	0.94
Borelli et al.	1.00
Borg et al.	0.94
Borges-Machado et al.	0.94
Boutoleau-Bretonnière et al.	1.00
Carcavilla et al.	0.67
Carpinelli Mazzi et al.	0.78
Cohen et al.	1.00
Cohen et al.	0.89
Dassel et al.	0.71
El haj et al.	0.83
El haj et al.	0.83
Giebel et al. (2 papers)	1.00
Helvacı yilmaz et al.	0.94
Hwang et al.	1.00
Kostyal et al.	0.89
Losada et al.	1.00
Ng et al.	0.78
Panerai et al.	1.00
Pongan et al.	0.94
Rainero et al.	1.00
Rajagopalan et al.	0.94
Rusowicz et al.	0.94
Savla et al.	0.82
Tam et al.	0.89
Tsapanou et al.	0.89
Werner et al.	0.94
Zucca et al.	0.94

Table 3  
Quality assessment ratings for qualitative studies

Research Paper	Overall Score
Dassel et al.	0.70
Giebel et al.	0.95
Giebel et al./ Hanna et al. (5 papers)	0.90
Rajagopalan et al.	0.85
Rising et al.	0.65
Savla et al.	0.75
Sriram et al.	1.00
Talbot, Briggs	0.90
Tuijt et al. (2 papers)	0.90
Tulloch et al.	0.85
Vaitheswaran et al.	0.65
West et al.	0.90

## Impact on access to care and support

The impact of the pandemic on access to health or social care was reported in 14 studies, all of which identified reductions in access for unpaid carers, leaving many people without access to vital support. The availability of support services also appeared to be location-dependent, with level of support services varying greatly between areas, based on UK reports (Giebel, Hanna et al., 2021; West et al., 2021). Carers reported reduced access to all areas of support services, including local day centres, memory cafes, support groups and respite care worldwide (Carpinelle-Mazi et al., 2021a; Cohen et al., 2021a; Rajagopalan et al., 2021). Most of those support the person with dementia directly and the unpaid carer indirectly, whilst peer support groups can support either (e.g., Giebel et al., 2020; Sriram et al., 2021). Following up with carers at two subsequent time points, Giebel et al. (2021b) identified a small upward trend in access to social support services again in the months following the first nationwide lockdown in the UK, with access to paid carers being the least affected by the pandemic. Paid home care may have been the least impacted service because of the difficult decisions carers needed to make during the pandemic, whereby some carers suspended paid care visits due to fears of transmitting COVID-19, while others felt they could not cope without paid care and were fearful of reobtaining it post-pandemic (Giebel et al., 2020). Similar findings in access to care during the pandemic were reported in other studies (e.g., Cohen et al., 2020a; Dassel et al., 2021; Rajagopalan et al., 2021; Sriram et al., 2021; Tuijt et al., 2021b). However, there were some reports of local area agencies on ageing checking in on carers more frequently than before COVID-19 and nutrition services delivering extra meals (e.g., Savla et al., 2020).

Difficulties with accessing care homes due to the increased care needs of the care-recipient was reported in one study (Giebel et al., 2021c). In this UK study, carers expressed that finding care home places was challenging due to inflated fees and care home closures, with some carers opting for a care home place far away.

Access to healthcare services was explored in some studies. In Israel, Werner et al. (2021) found that 50% of the carers who needed to see a GP or specialist had forgone at least one of these services. In Argentina, carers reported to have discontinued all sorts of cognitive and physical therapies (Cohen et al., 2020a). Similarly, in an interview study by Tuijt et al. (2021b), carers reported avoiding healthcare settings and services due to the risk of coronavirus transmission and fears of overburdening the NHS. However, they also reported proactive care on the onset of COVID-19, whereby a variety of healthcare professionals would telephone to enquire how the person living with dementia and their family were managing, although this was not the case for all participants.

Some studies reported that few care services had adapted by providing remote support during the early stages of the pandemic. However, even when remote support was provided, carers felt it was not a direct replacement for the in-person contact and care that was offered and utilised pre-pandemic (Giebel et al., 2021d; Sriram et al., 2021). Similar issues were reported for remote healthcare consultations, which were often organised and handled by the carer (Tuijt et al., 2021b). There were also reports of digital barriers or exclusion from accessing remote healthcare and support services (e.g., Giebel et al., 2021d; Tuijt et al., 2021b).

## Impact on carer burden

Twenty-eight studies documented the impacts of the COVID-19 pandemic on carer burden, with many noting increases in caring responsibilities or time dedicated to care (e.g., Borges-Machardo et al., 2020; Tam et al., 2021; Tsapanou et al., 2021). A range of tools were used to measure carer burden in quantitative studies (n=20); however, most relied on self-reports rather than validated measures (e.g., Boutoleau-Bretonniere et al., 2020; Cohen et al., 2021; Helvacı Yilmaz et al., 2021; Tsapanou et al., 2021). Two studies utilised the Zarit Burden Interview (Borg et al., 2021; Borelli et al., 2021). These studies reported high levels of burden, with Borg et al. (2021) noting 32.4% of carers' scores indicated severe burden. Two studies used the Caregiver Burden Inventory (CBI; Altieri & Santangelo, 2020; Penerai et al., 2020). In a pre-post study on the impact of confinement during the pandemic on carers in Italy, Penerai et al (2020) found statistically significant changes in CBI scores pre- and during lockdown, with an increase of approximately 10% of carers at risk for burning out. Large

effect sizes were reported for total CBI scores and physical burden, and a medium effect size in time dependence and developmental burden. One study used the Care-related Quality of Life Instrument, reporting significant increases in subjective burden (Borges-Machado et al., 2020).

Impacts on carer burden have been associated with stage of dementia across quantitative studies, with Cohen et al. (2021a) noting levels of carer burden being particularly high for carers of people with advanced dementia after four weeks of quarantine. Significant differences in the influence of diagnostic type of dementia on levels of burden have not been observed (Altieri et al., 2021; Boutoleau-Betonniere et al., 2020). However, Boutoleau-Betonniere et al. (2020) did report that increases in burden occurred among carers of people living with behavioural variant frontotemporal dementia regardless of changes in neuropsychiatric symptoms, whereas increases in burden among carers of people living with Alzheimer's disease was related to changes in neuropsychiatric symptoms.

Findings from qualitative (n=5) and mixed-methods (n=1) studies show that carers attributed increases in burden to the suspension of care services, a lack of usual support from other family members, heightened feelings of responsibility and a need to take extra precautions to avoid infection (Rising et al., 2021; Srirani et al., 2021; Tuijt et al., 2021; Vaitheswaran et al., 2020; Rajagopalan et al., 2021; West et al., 2021). Some quantitative studies reported that carer burden was amplified by changes in the care needs of the person living with dementia due to symptom advancement during lockdown periods (see Part I). In Brazil, Borelli et al. (2021) found carers of people living with dementia whose cognition had worsened since March 2020 reporting significantly increased burden.

The ongoing nature of the COVID-19 pandemic and possibility of future lockdown periods have implications for carer burden. In Greece, Tsapanou et al. (2021) reported high levels of physical and psychological burden, which increased significantly from an initial lockdown to a second prolonged lockdown period.

## Impact on well-being

Twenty-six studies reported on the impact of the pandemic on the wellbeing of carers, focusing specifically upon mental well-being and social wellbeing.

## Impact on mental wellbeing

All 26 studies described the negative impact of the pandemic on carers' mental well-being. In a survey in Italy, Rainero et al. (2020) found 45.9% of carers reported increases in anxiety and 18.6% reported increases in depression since quarantine. Similarly, in France, Borg et al. (2021) found half of carers exhibited poor mental health, including depression, anxiety, or self-reported stress. Studies typically focused upon anxiety, depression and stress among carers (e.g., Altieri & Santangelo, 2021; Carpinelli & Mazzi et al., 2020; Hwang et al., 2021; Rainero et al., 2020; Zucca et al., 2021); however, some studies also reported negative effects upon sleep and eating disorders during home confinement (e.g., Carcavilla et al., 2021; Cohen et al., 2020). Validated measures of depression and anxiety included the GAD-7 (Alexopoulou et al., 2021; Hwang et al., 2021; Pongan et al., 2021), Italian version of the Hospital Anxiety and Depression Scale (HADS; Altieri & Santangelo, 2021), the Center for Epidemiologic Studies Depression Scale (Hwang et al., 2021), Zung's depression and anxiety assessment scales (ZDAAS; Carpinelli Mazzi et al., 2020). Stress was primarily measured using the Perceived Stress Scale (Carpinelli Mazzi et al., 2020; Rusowicz et al., 2021).

The negative impact of the pandemic on carer's wellbeing and mental health was also noticed in qualitative (n=4) and mixed-methods studies (n=1). Many studies reported on the increased anxiety, fear, depression or stress levels (eg., Sriram et al., 2021; Rising et al., 2021; West et al., 2021; Rajagopalan et al., 2021). Most commonly the anxiety/fear was related to becoming infected with COVID-19 and/or infecting of a person with dementia (e.g., Sriram et al., 2021; Rising et al., 2021). The increased anxiety of carers was related to managing following the restrictions by person with dementia or other member of family/society (e.g., Sriram et al., 2021); worry about the condition of the person with dementia after pandemic (Giebel et al., 2021d) or ongoing fear for future (Hanna et al., 2021). In the UK, some carers have reported feeling of being strained and losing their freedom (West et al., 2021) or loss of hope (Hanna et al., 2021) and loss of control feelings (Giebel et al., 2021d). Carers from India have been also reporting increased negative feelings, including feeling lost (Rajagopalan et al., 2021). Carers in the USA reported putting their own needs on hold due to the increased demands of caregiving (Rising et al., 2021).

Several studies have also reported on coping with providing care during the pandemic, used strategies and self-protective factors. Losada et al. (2021) study presented that majority of carers considered that they coped well whereas Salva et al. (2021) reported that active coping strategies were used by 57% of carers. The frequently used coping strategies were related to self-care or described, i.e., by taking up some new or creative activities (e.g., Tulloch et al., 2021; West et al., 2021); reading, doing house chores (e.g., Rising et al., 2021), maintaining social connections or being able to get out (Tuijt et al., 2021). Factors including effective communication during pandemic, existing support networks, coping mechanisms and lifestyle factors including exercises or access to green spaces were reported as factors contributing to resilience of carers by Hanna et al. (2022).

A few studies focussed on positive aspects of providing care during the pandemic. In an Australian study, carers noted that providing care during the pandemic revealed their inner strength as well as their priorities and values having changed, whilst the relationship between them and care recipients deepened (Tulloch et al., 2021). Being close and spending more time with loved ones was also presented in other studies (Rising et al., 2021; Sriram et al., 2021). Similarly, some carers in the Losada et al. (2021) study reported an increase in positive emotions such as hope and happiness during the pandemic. The pandemic has also offered an opportunity to rest to some carers (West et al., 2021).

## Impact on social health

The impact of the pandemic on social health was reported in six studies. These studies reported enhanced levels of social isolation and loneliness among carers during the pandemic. In a survey of 395 carers in Canada, Tam et al. (2021) found that most carers felt isolated, left out, and lacking companionship some of the time or often, with 89% also feeling more or somewhat more isolated since the pandemic. A sense of isolation and abandonment was also

reported in an Italian study, but less frequently than other symptoms of stress (Zucca et al., 2021). There was a notable lack of studies using validated measures of social health.

Social isolation and loneliness were also documented in qualitative studies. In the USA, participants reported that the inability to socialise with their community, travel for leisure, and see family members were primary issues (Rising et al., 2021). In an interview study in the UK, carers expressed feelings of loneliness during a period of lockdown which they attributed to their main social contact being the person living with dementia whom they cared for (Hanna et al., 2021). Research with carers from minority ethnic backgrounds in the UK indicated that social interaction was also widely reduced, often due to fears of contracting COVID-19 and transmitting it to loved ones (West et al., 2021). These carers also discussed being unable to attend communal culturally relevant events as a negative impact of the pandemic, such as church or temple.

In one study, the majority of carers reported turning to technology to connect with others (Tam et al., 2021). However, only 19% of carers reported that using technology to connect with others felt the same as interacting with them in-person.

## Quality ratings

All but three studies were of good quality (see Tables 2 and 3), with scores ranging from 0.65 to 1.00.

## Discussion

This appears to be the first comprehensive systematic review on the early impacts of the pandemic on unpaid dementia carers. Whilst a previous systematic review has explored the impacts on health only (Hughes et al., 2021), this review purposefully synthesised the evidence into different aspects of the lives of unpaid carers, including mental health and well-being, as well as access to care for themselves and their relatives, and the impacts this in turn had on their health and mental health. Substantial evidence generated in the early stages of the pandemic has shown the negative effects of the pandemic on accessing dementia-related care and support (Dassel et al., 2021; Werner et al., 2021), which led to increased caring duties for family members and friends (Giebel et al., 2020), subsequently perniciously affecting carers' mental health and well-being (Carpinelli Mazzi et al., 2020; Tam et al., 2021).

Accessing care and support is not only vital for the person living with the condition, but also for the unpaid carer – both of whom have experienced increased barriers in doing so since the pandemic (also see Part I). The majority of research has highlighted social care and social support reductions since the pandemic, primarily focusing on community care, with some research indicating early care home access issues (Giebel et al., 2021c) and health care utilisation barriers (Tuijt et al., 2021). Being unable to access care, either for themselves via peer support groups for example, or predominantly for their relative with dementia to gain some temporary respite from caring duties (Tretteteig et al., 2017), has wide-ranging implications for the carer. Without any respite or time off from caring, carers have been found to be more likely to be burned out (Cohen et al., 2021b). Whilst evidence reported in this review has already highlighted increased burden for many early on, the continuing nature of the pandemic is likely having long-term repercussions on carers leading to burnout. Future research needs to follow up carers and explore the long-term effects, however, early evidence from this review strongly indicates a greater need to adequately and equitably support unpaid carers in their roles, and as individuals themselves.

These effects have not only been noted regarding carer burden, but also more widely for mental well-being. All studies but one (Tulloch et al., 2021) noted at least some aspects of negative impacts on the mental and social health of unpaid carers, particularly focusing on depression, anxiety, and stress, as well as social isolation and loneliness. Tulloch et al. (2021) purposefully only analysed positive experiences however, clearly producing biased findings. For many carers, engaging with the person with dementia was their only point of face-to-face social contact during the pandemic, generating feelings of loneliness (Hanna et al., 2021; Tam et al., 2021). This can particularly be the case for older spousal carers living with their relative with dementia, which can add to potential feelings of burnout and lack of respite from their caring duties. Considering the wider restrictions impacting on everyone, across the globe, it is unclear to what extent heightened levels of caring duties and lack of respite from caring contributed to poorer mental well-being, and to what extent generally living through an unknown and novel pandemic contributed. Longitudinal survey data has evidenced reductions in mental health across the general UK population in the early stages of the pandemic compared to prior (Pierce et al., 2020). On top of these impacts, evidence from this review illustrates the significant impact that informal caring duty and formal care access changes have had on unpaid carers (Dassel et al., 2021; Rajagopalan et al., 2021). Whilst more research is needed on the long-lasting mental health needs of unpaid dementia carers, and unpaid carers in general, findings from this review clearly highlight a need for improved access to mental health support, something that should be in place anyways considering the gravity of experiencing the diagnosis of a loved one and living through the diagnosis providing care and support.

One way for carers to try and stay connected with people other than the person with dementia was via digital technology. Whilst care services were not adapted to provide digital support at the beginning of the pandemic, some services very slowly adapted to providing care remotely, particularly peer support groups (i.e., Giebel et al., 2021c). Connecting with peers remotely to bypass the growing sense of social isolation and loneliness was also a solution for carers as reported by Tam et al. (2021), although less than a fifth of carers felt that digital social connectivity was as beneficial as face-to-face contact and a number of barriers have been identified. Recent research has highlighted how carer age also matters when connecting digitally with dementia services during the pandemic, as younger carers (adult children) appeared to be better equipped, highlighting the digital divide (Arighi et al., 2021). Whilst more research is required into the digital dementia care experiences since the pandemic, emerging research illustrates how digital connectivity can provide some benefits when lacking face-to-face engagement. Even when connecting remotely with peers and services, the unpaid carer still has to be with the person with dementia though to access care, and cannot engage in their own activities. Therefore, care should be provided face-to-face again in safe formats as soon as possible, whilst some long-term benefits may be drawn from digitally adapted services for people living in more rural communities – a frequent previous barrier to engaging with support services (Innes et al., 2006).

The mix of lack of support and access to care, poor mental well-being, and increased carer burden are all likely to contribute to people with dementia entering a care home earlier, at least compared to non-pandemic circumstances. In pre-pandemic times, when unpaid carers were unable to care for their relative at home any longer, due to increased carer burden or too many care needs, people with dementia would normally enter a care home (Sutcliffe et al., 2017). In the best case scenario, this would have been planned in advance to provide care home entry at the right time. Since the pandemic, people with dementia also appear to have deteriorated faster and received less care support in the community, as Part I of this interlinked systematic review has shown (Giebel et al., submitted) has shown, confirming earlier reported results (Suarez-Gonzalez et al., 2021). Thus, it is likely that people with dementia have entered a care home faster since the pandemic, based on the negative impacts of COVID-19 on community-residing people with dementia and carers, as evidenced in this review. However, care homes have faced different levels of restrictions, which are ongoing, often not allowing unpaid carers to visit their relative (Backhaus et al., 2021) and making it difficult to plan in advance. This may lead to further increases in carer burden, as well as guilt, if carers are unable to care for their relative at home but delay care home entry due to those restrictions, whilst others may see no alternative but to have their relative admitted. Very early indications about faster care home entry, and the ensuing guilt experienced by unpaid carers, has been reported in one of the included studies here in summer 2020 in the UK for example (Giebel et al., 2021c). However, more long-term research is required after two years of pandemic restrictions to explore the impact on carer well-being and burden on care home entry during the pandemic.

## Limitations

This mixed-method systematic review benefitted from searching numerous data bases and producing a timely report of the impact of the pandemic on unpaid carers. However, due to the nature of the research and a continuously growing evidence base, it was not feasible to update the searches. This review already included a large number of studies after exclusion criteria were applied, and thus provides a timely and time-period specific synthesis of the evidence base to inform future research and policy making. In terms of the research included, some studies were limited in providing retrospective accounts of for example mental health prior to the pandemic and changes noticed, as opposed to pre and post assessments using validated measures. However, mental health or burden is in general assessed largely by asking the person affected. The recall bias needs to be taken into account. However, a state-of the art pre-pandemic assessment was not presented for obvious reasons. Therefore, these data provide suitable evidence. One wider limitation, but also advantage, of this review is that it considered studies from 18 countries. Restrictions differed between countries and even between regions making it difficult to relate a type or severity of measure to an outcome. However, even considering this heterogeneity the studies identified a comparable impact on careers. All reported negative impacts on the support system, well-being and mental health of unpaid carers (except one study which purposefully explored positive experiences from interviews and was therefore biased – Tulloch et al., 2021). However, there were limitations in findings from lower- and middle-income countries (LMICs), with only two studies reporting on India and Brazil (Azavedo et al., 2021; Rajagopalan et al., 2021). Impacts are likely to differ across high-impact countries and LMICs, indicating a need for more research into the impacts in LMICs.

## Conclusions

Unpaid carers, similar to people with dementia, have been harmfully affected during the pandemic from access to adequate care and support to increased levels of carer burden and poor mental health. Findings in this review from across the globe thus illustrate how unpaid carers urgently need to be supported better in not only their caring role, but also as an individual, taking into account their own personal needs. Whilst restrictions may ease in certain countries and many, albeit not all, societies benefit from protection offered from vaccinations, the early impacts of the pandemic are likely going to have long-lasting effects on the mental and physical health of unpaid carers. Future research ought to explore the long-lasting impacts of COVID-19 on this group, especially in light of care recipients entering care homes.

## Declarations

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### Conflicts of interest

None.

### Author contributions

CG led the systematic review, drafted the protocol and manuscript, and scored citations for Stage 1 and 2. ASG generated the search strategy. RT, KL, CT, KHL, EW scored citations for inclusion in the review. EW extracted all data from included studies and quality rated all studies. RT, CT, ASG, KHL, KL, EW, JC, HT discussed the findings jointly, placed them into context, and read through drafts of the manuscripts before approving the final draft.

## References

1. Alexopoulos, P., Soldatos, R., Kontogianni, E., et al. (2021). COVID-19 Crisis Effects on Caregiver Distress in Neurocognitive Disorder. *J Alzheimers Dis*, *79*(1), 459–466.
2. Altieri, M., & Santangelo, G. (2021). The Psychological Impact of COVID-19 Pandemic and Lockdown on Caregivers of People With Dementia. *Am J Geriatr Psychiatry*, *29*(1), 27–34.
3. Arighi A, Fumagalli GG, Carandini T, et al. Facing the digital divide into a dementia clinic during COVID-19 pandemic: caregiver age matters. *Neurological Sciences* 2021;42:1247–1251.
4. Azevedo, L., Calandri, I. L., Slachevsky, A., Graviotto, H. G., Vieira, M. C. S., Andrade, C. B.,... Caramelli, P. (2021). Impact of Social Isolation on People with Dementia and Their Family Caregivers. *J Alzheimers Dis*, *81*(2), 607–617.
5. Bacsu JDR, O'Connell ME, Webster C, et al. A scoping review of COVID-19 experiences of people living with dementia. *Canadian Journal of Public Health* 2021;112:400–411.
6. Bianchetti A, Rozzini R, Guerini F, et al. Clinical presentation of COVID-19 in dementia patients. *Journal of Nutrition, Health & Ageing* 2020; doi: 10.1007/s12603-020-1389-1
7. Borelli, W. V., Augustin, M. C., de Oliveira, P. B. F., Reggiani, L. C., Bandeira-de-Mello, R. G., Schumacher-Schuh, A. F.,... Castilhos, R. M. (2021). Neuropsychiatric Symptoms in Patients with Dementia Associated with Increased Psychological Distress in Caregivers During the COVID-19 Pandemic. *J Alzheimers Dis*, *80*(4), 1705–1712.
8. Borg, C., Rouch, I., Pongan, E., Getenet, J. C., Bachelet, R., Herrmann, M.,... Dorey, J. M. (2021). Mental Health of People with Dementia During COVID-19 Pandemic: What Have We Learned from the First Wave? *J Alzheimers Dis*, *82*(4), 1531–1541.
9. Borges-Machado, F., Barros, D., Ribeiro, O., & Carvalho, J. (2020). The Effects of COVID-19 Home Confinement in Dementia Care: Physical and Cognitive Decline, Severe Neuropsychiatric Symptoms and Increased Caregiving Burden. *Am J Alzheimers Dis Other Demen*, *35*, 1533317520976720.
10. Boutoleau-Bretonniere, C., Pouclet-Courtemanche, H., Gillet, A., Bernard, A., Deruet, A. L., Gouraud, I.,... El Haj, M. (2020). Impact of Confinement on the Burden of Caregivers of Patients with the Behavioral Variant of Frontotemporal Dementia and Alzheimer Disease during the COVID-19 Crisis in France. *Dement Geriatr Cogn Dis Extra*, *10*(3), 127–134.
11. Carcavilla, N., Pozo, A. S., Gonzalez, B., Moral-Cuesta, D., Roldan, J. J., Erice, V., & Remirez, A. G. (2021). Needs of Dementia Family Caregivers in Spain During the COVID-19 Pandemic. *J Alzheimers Dis*, *80*(2), 533–537.
12. Carpinelli Mazzi, M., Iavarone, A., Musella, C., De Luca, M., de Vita, D., Branciforte, S.,... Postiglione, A. (2020). Time of isolation, education and gender influence the psychological outcome during COVID-19 lockdown in caregivers of patients with dementia. *Eur Geriatr Med*, *11*(6), 1095–1098. doi:10.1007/s41999-020-00413-z
13. Clemmensen TH, Lauridsen HH, Andersen-Ranberg K, Kristensen HK. 'I know his needs better than my own' - carers' support needs when caring for a person with dementia. *Scandinavian Journal of Caring Sciences* 2021;35(2):586–599.
14. Cohen, G., Russo, M. J., Campos, J. A., & Allegri, R. F. (2020a). COVID-19 Epidemic in Argentina: Worsening of Behavioral Symptoms in Elderly Subjects With Dementia Living in the Community. *Front Psychiatry*, *11*, 866. doi:10.3389/fpsy.2020.00866
15. Cohen, G., Russo, M. J., Campos, J. A., & Allegri, R. F. (2020b). Living with dementia: increased level of caregiver stress in times of COVID-19. *Int Psychogeriatr*, *32*(11), 1377–1381. doi:10.1017/S1041610220001593
16. Dassel, K. B., Towsley, G. L., Utz, R. L., Ellington, L., Terrill, A., Scammon, D.,... Mickens, M. (2021). A Limited Opportunity: COVID-19 and Promotion of Advance Care Planning. *Palliat Med Rep*, *2*(1), 194–198.
17. Giebel C, Hanna K, Rajagopal M, et al. The potential dangers of not understanding COVID-19 public health restrictions in dementia: "It's a groundhog day – every single day she does not understand why she can't go for a walk". *BMC Public Health* 2021;21:762.
18. Giebel, C., Hanna, K., Cannon, J., Eley, R., Tetlow, H., Gaughan, A.,... Gabbay, M. (2020). Decision-making for receiving paid home care for dementia in the time of COVID-19: a qualitative study. *BMC Geriatr*, *20*(1), 333.
19. Giebel, C., Pulford, D., Cooper, C., Lord, K., Shenton, J., Cannon, J.,... Gabbay, M. (2021b). COVID-19-related social support service closures and mental well-being in older adults and those affected by dementia: a UK longitudinal survey. *BMJ Open*, *11*(1), e045889.
20. Giebel, C., Hanna, K., Callaghan, S., Cannon, J., Butchard, S., Shenton, J.,... Gabbay, M. (2021c). Navigating the new normal: accessing community and institutionalised care for dementia during COVID-19. *Aging Ment Health*, 1–6. doi:10.1080/13607863.2021.1914545
21. Giebel, C., Cannon, J., Hanna, K., Butchard, S., Eley, R., Gaughan, A.,... Gabbay, M. (2021d). Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study. *Aging Ment Health*, *25*(7), 1281–1288.
22. Giebel, C., Sutcliffe, C., Darlington-Pollock, F., Green, M. A., Akpan, A., Dickinson, J.,... Gabbay, M. (2021e). Health Inequities in the Care Pathways for People Living with Young- and Late-Onset Dementia: From Pre-COVID-19 to Early Pandemic. *Int J Environ Res Public Health*, *18*(2).
23. Giebel, C., Lord, K., Cooper, C., Shenton, J., Cannon, J., Pulford, D.,... Gabbay, M. (2021f). A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. *Int J Geriatr Psychiatry*, *36*(3), 393–402.
24. Hanna, K., Giebel, C., Butchard, S., Tetlow, H., Ward, K., Shenton, J.,... Gabbay, M. (2022). Resilience and supporting people living with dementia during the time of COVID-19; A qualitative study. *Dementia (London)*, *21*(1), 250–269.
25. Hanna, K., Giebel, C., Tetlow, H., Ward, K., Shenton, J., Cannon, J.,... Gabbay, M. (2021). Emotional and Mental Wellbeing Following COVID-19 Public Health Measures on People Living With Dementia and Carers. *J Geriatr Psychiatry Neurol*, doi:10.1177/0891988721996816
26. Hariyanto TI, Putri C, Arisa J, et al. Dementia and outcomes from coronavirus disease 2019 (COVID-19) pneumonia: A systematic review and meta-analysis. *Archives of Gerontology and Geriatrics* 2021;93:104299.

27. Helvacı Yılmaz, N., Polat, B., Ermis, A., & Hanoglu, L. (2021). Clinical deterioration of Alzheimer's disease patients during the Covid-19 pandemic and caregiver burden. *Journal of experimental and clinical medicine*, *38*(3), 255–259.
28. Hughes MC, Liu Y, Baumbach A. Impact of COVID-19 on the health and well-being of informal caregivers of people with dementia: a rapid systematic review. *Gerontology and Geriatric Medicine* 2021; doi: 10.1177/2F23337214211020164
29. Hwang, Y., Connell, L. M., Rajpara, A. R., & Hodgson, N. A. (2021). Impact of COVID-19 on Dementia Caregivers and Factors Associated With their Anxiety Symptoms. *Am J Alzheimers Dis Other Demen*, *36*, 15333175211008768.
30. Innes A, Cox S, Smith A, et al. Service provision for people with dementia in rural Scotland: Difficulties and innovations. *Dementia* 2006;5(2):249–270.
31. Kmet LM, Lee RC, Cook LS. Standard quality assessment criteria for evaluating primary research papers from a variety of fields. Edmonton: Alberta Heritage Foundation for Medical Research. AHFMR, 2004.
32. Kostyál, L. Á., Széman, Z., Almási, V. E., Fabbietti, P., Quattrini, S., Socci, M.,... . Gagliardi, C. (2021). Impact of the COVID-19 Pandemic on Family Carers of Older People Living with Dementia in Italy and Hungary. *Sustainability*, *13*(13).
33. Losada, A., Vara-García, C., Romero-Moreno, R., Barrera-Caballero, S., Pedrosa-Chaparro, M. D. S., Jimenez-Gonzalo, L.,... . Marquez-Gonzalez, M. (2021). Caring for Relatives with Dementia in Times of COVID-19: Impact on Caregivers and Care-recipients. *Clin Gerontol*, 1–15. doi:10.1080/07317115.2021.1928356
34. Ng, K. P., Chiew, H. J., Hameed, S., Ting, S. K. S., Ng, A., Soo, S. A.,... . Kandiah, N. (2020). Frontotemporal dementia and COVID-19: Hypothesis generation and roadmap for future research. *Alzheimers Dement (N Y)*, *6*(1), e12085.
35. Orellana K, Manthorpe J, Tinker A. Day centres for older people – attendance characteristics, access routes and outcomes of regular attendance: findings of exploratory mixed methods case study research. *BMC Geriatrics* 2020;20:158.
36. Parveen S, Peltier C, Oyebode JR. Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise. *Health and Social Care in the Community* 2017;25(2):734–742.
37. Pierce M, Hope H, Ford T, et al. Mental health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population. *The Lancet Psychiatry* 2020;10(7):883–892.
38. Panerai, S., Tasca, D., Musso, S., Catania, V., Ruggeri, F., Raggi, A.,... . Ferri, R. (2016). The impact of COVID-19 confinement on the neurobehavioral manifestations of people with Major Neurocognitive Disorder and on the level of burden of their caregivers. *Life Span and Disability*(2), 303-320. Retrieved from [http://www.lifespanjournal.it/client/abstract/ENG371\\_6\\_%20Panerai.pdf](http://www.lifespanjournal.it/client/abstract/ENG371_6_%20Panerai.pdf)
39. Pongan, E., Dorey, J. M., Borg, C., Getenet, J. C., Bachelet, R., Lourieux, C.,... . Rouch, I. (2021). COVID-19: Association Between Increase of Behavioral and Psychological Symptoms of Dementia During Lockdown and Caregivers' Poor Mental Health. *J Alzheimers Dis*, *80*(4), 1713–1721.
40. Rainero, I., Bruni, A. C., Marra, C., Cagnin, A., Bonanni, L., Cupidi, C.,... . Group, S. I. C.-S. (2020). The Impact of COVID-19 Quarantine on Patients With Dementia and Family Caregivers: A Nation-Wide Survey. *Front Aging Neurosci*, *12*, 625781.
41. Rajagopalan, J., Arshad, F., Hoskeri, R. M., Nair, V. S., Hurzuk, S., Annam, H.,... . Alladi, S. (2022). Experiences of people with dementia and their caregivers during the COVID-19 pandemic in India: A mixed-methods study. *Dementia (London)*, *21*(1), 214–235.
42. Rising, K. L., Salcedo, V. J., Amadio, G., Casten, R., Chang, A., Gentsch, A.,... . Gerolamo, A. M. (2022). Living Through the Pandemic: The Voices of Persons With Dementia and Their Caregivers. *J Appl Gerontol*, *47*(1), 30–35.
43. Rusowicz, J., Pezdek, K., & Szczepanska-Gieracha, J. (2021). Needs of Alzheimer's Charges' Caregivers in Poland in the Covid-19 Pandemic-An Observational Study. *Int J Environ Res Public Health*, *18*(9). doi:10.3390/ijerph18094493
44. Savla, J., Roberto, K. A., Blieszner, R., McCann, B. R., Hoyt, E., & Knight, A. L. (2021). Dementia Caregiving During the "Stay-at-Home" Phase of COVID-19 Pandemic. *J Gerontol B Psychol Sci Soc Sci*, *76*(4), e241-e245.
45. Sriram, V., Jenkinson, C., & Peters, M. (2021). Impact of COVID-19 restrictions on carers of persons with dementia in the UK: a qualitative study. *Age Ageing*, *50*(6), 1876–1885.
46. Suarez-Gonzalez A, Rajagopalan J, Livingston G, Alladi S. The effect of COVID-19 isolation measures on the cognition and mental health of people living with dementia: A rapid systematic review of one year of quantitative evidence. *Eclinical Medicine* 2021;39:101047.
47. Talbot, C. V., & Briggs, P. (2021). 'Getting back to normality seems as big of a step as going into lockdown': the impact of the COVID-19 pandemic on people with early to middle stage dementia. *Age Ageing*, *50*(3), 657–663.
48. Tam, M. T., Dosso, J. A., & Robillard, J. M. (2021). The Impact of a Global Pandemic on People Living with Dementia and Their Care Partners: Analysis of 417 Lived Experience Reports. *J Alzheimers Dis*, *80*(2), 865–875.
49. Tsapanou, A., Zoi, P., Kalligerou, F., Blekou, P., & Sakka, P. (2021). The Effect of Prolonged Lockdown Due to COVID-19 on Greek Demented Patients of Different Stages and on Their Caregivers. *J Alzheimers Dis*, *83*(2), 907–913. doi:10.3233/JAD-210702
50. Tretteteig S, Vatne S, Rokstad AMM. The influence of day care centres designed for people with dementia on family caregivers – a qualitative study. *BMC Geriatrics* 2017;17.
51. Tuijt, R., Frost, R., Wilcock, J., Robinson, L., Manthorpe, J., Rait, G., & Walters, K. (2021a). Life under lockdown and social restrictions - the experiences of people living with dementia and their carers during the COVID-19 pandemic in England. *BMC Geriatr*, *21*(1), 301.
52. Tuijt, R., Rait, G., Frost, R., Wilcock, J., Manthorpe, J., & Walters, K. (2021b). Remote primary care consultations for people living with dementia during the COVID-19 pandemic: experiences of people living with dementia and their carers. *Br J Gen Pract*, *71*(709), e574-e582.
53. Tulloch, K., McCaul, T., & Scott, T. L. (2021). Positive Aspects of Dementia Caregiving During the COVID-19 Pandemic. *Clin Gerontol*, 1–11. doi:10.1080/07317115.2021.1929630

54. Vaitheswaran, S., Lakshminarayanan, M., Ramanujam, V., Sargunan, S., & Venkatesan, S. (2020). Experiences and Needs of Caregivers of Persons With Dementia in India During the COVID-19 Pandemic-A Qualitative Study. *Am J Geriatr Psychiatry*, *28*(11), 1185–1194.
55. Werner, P., Tur-Sinai, A., & AboJabel, H. (2021). Examining Dementia Family Caregivers' Forgone Care for General Practitioners and Medical Specialists during a COVID-19 Lockdown. *Int J Environ Res Public Health*, *18*(7).
56. West, E., Nair, P, Barrado-Martin, Y., Walters, K. R., Kupeli, N., Sampson, E. L., & Davies, N. (2021). Exploration of the impact of the COVID-19 pandemic on people with dementia and carers from black and minority ethnic groups. *BMJ Open*, *17*(5), e050066.
57. World Health Organisation (WHO). *Dementia – Factsheet*. Geneva, 2021. Last accessed 27/01/2022: <https://www.who.int/news-room/factsheets/detail/dementia>
58. Zucca, M., Isella, V., Lorenzo, R. D., et al. (2021). Being the Family Caregiver of a Patient With Dementia During the Coronavirus Disease 2019 Lockdown. *Front Aging Neurosci*, *13*, 653533. doi:10.3389/fnagi.2021.653533
59. Zuin M, Guasti P, Roncon L, Cervellati C, Zuliani G. Dementia and the risk of death in elderly patients with COVID-19 infection: Systematic review and meta-analysis. *International Journal of Geriatric Psychiatry* 2020;36(5):697–703.

## Figures

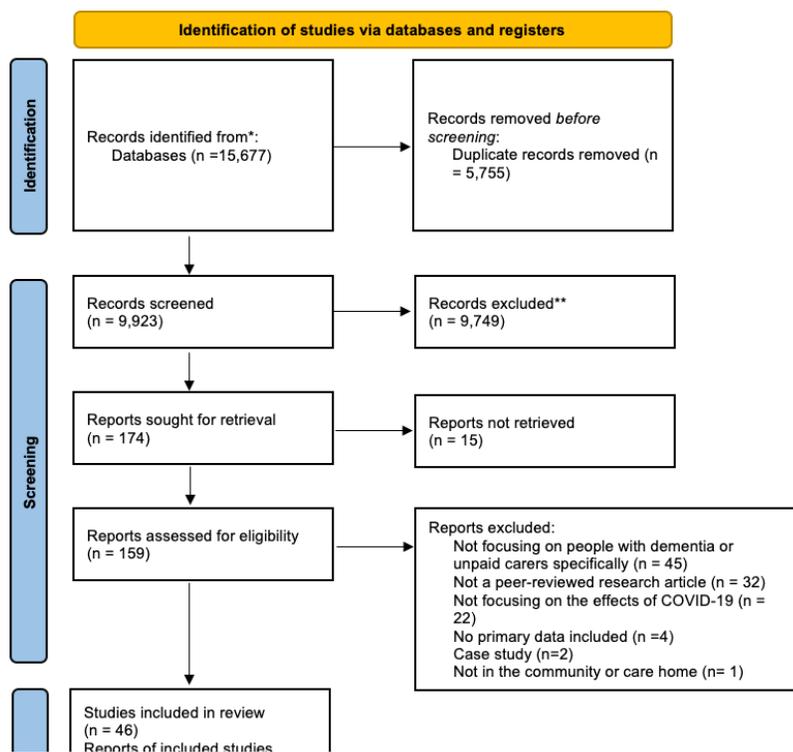


Figure 1

PRISMA Flowchart