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The early impacts of COVID-19 on people living with dementia: part I of a mixed-methods systematic review

Clarissa Giebel^{a,b} , Katarzyna M. Lion^c , Klara Lorenz-Dant^d, Aida Suárez-González^e, Catherine Talbot^f, Emily Wharton^{b,g}, Jacqueline Cannon^g, Hilary Tetlow^{b,h} and Jochen René Thyrian^{i,h,j,k}

^aDepartment of Primary Care & Mental Health, University of Liverpool, Liverpool, UK; ^bNIHR ARC NWC, Liverpool, UK; ^cMenzies Health Institute Queensland, Griffith University, Brisbane, Australia; ^dCare Policy and Evaluation Centre, Department of Health Policy, London School of Economics and Political Science, London, UK; ^eDementia Research Centre, UCL Queen Square Institute of Neurology, London, UK; ^fFaculty of Science & Technology, Bournemouth University, Poole, UK; ^gSchool of Sport and Exercise Sciences, Liverpool John Moore's University, Liverpool, UK; ^hLewy Body Society, Wigan, UK; ⁱSURF Liverpool, Liverpool, UK; ^jGerman Centre for Neurodegenerative Diseases (DZNE), Greifswald, Germany; ^kInstitute for Community Medicine, University of Greifswald, Greifswald, Germany

ABSTRACT

Objectives: The aim of this Part I systematic review was to understand the impact of the COVID-19 pandemic on the lives of people with dementia living in the community or in residential care. Part II focused on unpaid carers.

Methods: This review was registered on PROSPERO [CRD42021248050]. Five data bases (PubMed, CINAHL, Embase, Scopus, Web of Science) were searched in July 2021. Studies were included if they reported on the impacts of the pandemic on people living with dementia, either in the community or residential settings, and published in English, German, Polish, or Spanish. Risk of bias was assessed using the Standard Quality Assessment QualSyst.

Results: Forty papers from 33 studies reported on the effects of COVID-19 on people with dementia. Included studies were conducted across 15 countries, focusing on single-country evaluations except in one study. Three studies focused on care homes, whilst the remainder reported on the community. Studies were categorised into five impacts: Cognition; Independence and physical functioning; Behavioural symptoms; Well-being; and Access to care. All studies evidenced the negative pandemic impacts, including faster cognitive, physical, and behavioural deterioration, limited access to care, and poorer mental and social health.

Conclusions: Future restrictions need to consider the need for people with dementia to stay cognitively, physically, and socially stimulated to live well, and this review provides a call for a future pandemic strategy for dementia. Longitudinal research is required on the long-term impacts of the pandemic on the lives of people with dementia, including time to care home entry.

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Introduction

Over 55 million people are living with dementia world-wide (WHO Factsheet, 2021), yet many more are affected by dementia by providing unpaid care. With the majority of people living with dementia being aged 65+, this population has been particularly susceptible to the COVID-19 virus. Evidence suggests higher risk of COVID-19 infection and if infected, greater likelihood to experience severe outcomes and death compared to people of the same age without dementia (Bianchetti et al., 2020). Those residing in care homes have faced particular challenges, with care homes having seen large waves of COVID-19 deaths (Comas-Herrera et al., 2021).

Already prior to the pandemic, facing dementia has not been easy. People living with the condition require adequate support. Community-based services such as paid home care, day care centres, and peer support groups can help people to live well and independently at home for longer (i.e. Orellana et al., 2020). However, these services are not accessible equitably for everyone (Giebel et al., 2021a) and some cultures and countries experience language, knowledge, or stigma barriers to seeking help outside the family (Parveen et al., 2017). Indeed, unpaid carers (family, friends) providing care also need to be supported to maintain a good level of well-being and to continue being able to care for their relative or friend with dementia.

The pandemic appears to have increased difficulties for people living with dementia to access and utilise vital care and generally live well with the condition (Capuzzo et al., 2021; Lara et al., 2020). Emerging research has indicated how social support services have been closed down or operated on a minimum level during the early stages of the pandemic (Giebel et al., 2021b). Care homes have equally been affected in a variety of ways, for example: care homes were shut down in some countries for over a year to outside visits, apart from occasional window or pod visits between family members and residents, or digital remote visits (Backhaus et al., 2021). Reports about countries implementing clear guidance on safe care home visitation early in the pandemic, like the Netherlands in May 2020, are rare (Verbeek et al., 2020). Whilst research is emerging at a faster rate these days, there has been no overarching systematic review of the existing evidence to date, and it remains unclear how people with dementia have been affected by the pandemic globally.

To date, limited evidence syntheses have been published on this topic, and have only focused on particular areas, such as population type or outcome. A recent rapid review by Suarez-Gonzalez et al. (2021) has shown how the pandemic has negatively affected the cognition and mental health of people living with dementia for example. In addition, a scoping review by

Bacsu et al. (2021) has solely explored the experiences of those living with dementia, and included non-primary research articles such as letters and commentaries reporting carer burnout, decreasing cognitive and neuropsychiatric functioning, and lack of access to support services. Other systematic reviews and meta-analyses have only focused on clinical outcomes in relation to COVID-19 (Hariyanto et al., 2021; Zuin et al., 2021).

Therefore, the aim of this mixed-methods systematic review was to understand the impact of the COVID-19 pandemic on the lives of people living with dementia living either in the community or in a care home. Specifically, we focused on people's health and well-being and the impact on face-to-face and remote health and social care access.

Methods

The protocol of this dual systematic review was registered on PROSPERO [ID: CRD42021248050]. Final included studies were divided into two parts, with this first part focusing on people living with dementia, and Part II focusing on unpaid carers (see Giebel et al., submitted). The development of the review protocol was guided by two unpaid carers (JC, HT), who were also involved in the discussion of the findings and reviewing the manuscript.

Inclusion and exclusion criteria

Both quantitative (observational, survey and neuropsychological assessment studies, as well as RCTs) and qualitative studies (interview and focus group studies) were included in this review. Studies were included if they focused on: people living with dementia aged 18+ either living in the community or living in a care home; unpaid carers of people living with dementia aged 18 and older. We excluded studies of people without a diagnosis of dementia; people with a formal and paid caring role for someone living with dementia; people aged 17 and younger. Only empirical studies were included in this review (i.e. literature reviews were not included). No limits were placed on the type or stage of dementia.

Search strategy

We searched the following databases from 2020 (when literature first started to be published on the COVID-19 pandemic) to July 2021: PubMed, CINAHL, Embase, Scopus, Web of Science. Restrictions were applied to specify studies written in English, German, Polish, or Spanish language. The search terms included Covid-19 and a combination of MeSH Terms and search terms relating to dementia (e.g. dementia, Alzheimer, cognitive impairment). The syntax was customized for individual databases according to each database specific conventions. The search terms were developed in consultation with an experienced librarian and piloted before being used: 'Covid-19 AND ("dementia"[MeSH Terms] OR "dement*" [All Fields] OR "alzheimer*" [All Fields] OR "neurocognitive disorders" [MeSH Terms] OR "cognitive impairment" [All Fields] OR "lewy bod*" [All Fields] OR "Creutzfeldt-Jakob" [All Fields] OR "Frontotemporal Lobar Degeneration" [All Fields] OR "Huntington*" [All Fields]).

Data extraction

Citations were merged in Endnote and transferred into Excel after all duplicates were removed. All titles and abstracts of all

papers were screened, with the task split across three reviewers due to the large number of search results, involving one reviewer screening 60% of results (EW), and two reviewers each screening 20% of results respectively (CG, KL). Ten percent of the sample were screened by an independent additional reviewer (KHL), and any discrepancies about included papers were discussed between the reviewers until consensus was achieved. Following Stage 1 screening, each full paper was read by two reviewers overall, with the task split among four reviewers (CG, CT, RT, EW) screening 50% of the full papers. Again, this was based on the large number of Stage 1 inclusions (also see Figure 1 for PRISMA flowchart of citations and included studies). Similar to Stage 1, any discrepancies were discussed until consensus was reached. All papers which belonged to one study were included, if they were showing up in our searches, as each paper reported on different angles of the findings from a study. Thus, none were excluded and we did not duplicate information in the synthesis.

One researcher (EW) extracted the following data, which was checked by another researcher (CG): Country, population, focus (which of the 5 impacts), design, measures, qualitative themes OR quantitative outcomes, setting, and time period of data collection.

Quality assessment

Study quality was assessed using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (QualSyst) (Kmet et al., 2004) by two researchers independently. QualSyst has 14 criteria to assess the criteria of quantitative studies, and 10 criteria for qualitative studies. Each criterion can be scored from '0' (not addressed) to '2' (fully addressed), with an additional option of 'not applicable'. The criteria are outlined in Table 1. A total percentage score was provided, with 100% indicating good quality, and a score of 75% the threshold for a paper to meet good quality. Any discrepancies between ratings were discussed jointly, with a third researcher being consulted in cases which were unclear. Quality ratings did not influence study selection, but were used to inform discussions of findings.

Data synthesis

Data were synthesised by two researchers (CG, EW), with extracted data focusing on country, population, type of study, outcome measures (for quantitative studies only), and focus. In discussion with all team members, studies were then categorised into different outcomes based on discussion amongst the entire research team.

Results

Overview of included studies and data selection

159 full texts were read through for inclusion, with 53 papers covering 46 studies included for the overall systematic review (Part I and II). Specifically, 40 papers reporting on 33 studies focusing on the impacts of the pandemic on people living with dementia were included in this Part 1 of the systematic review (see Figure 1 for PRISMA flowchart).

Table 2 describes the study characteristics. Research emerged from 15 countries, including Israel, the UK, Italy,

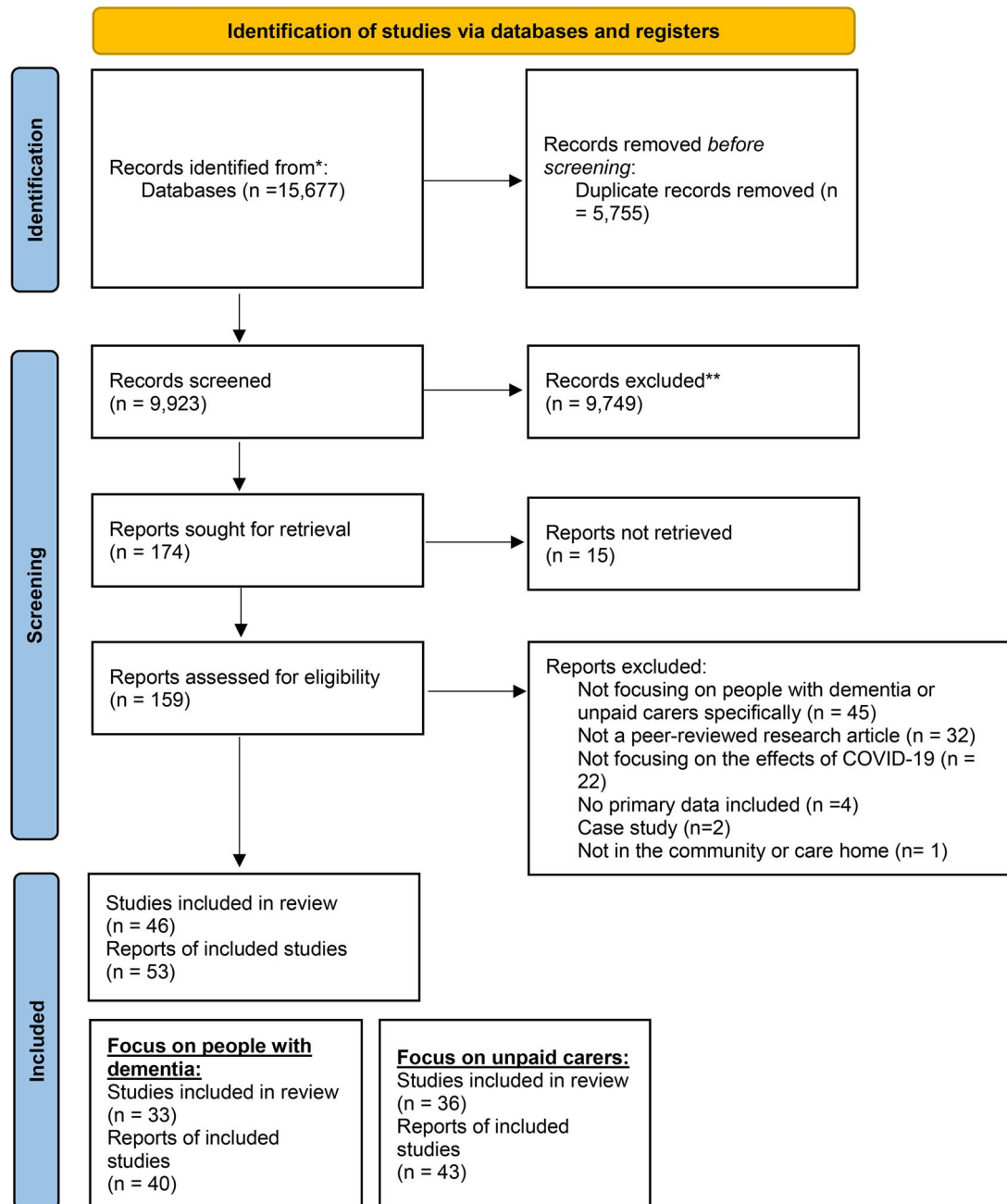


Figure 1. PRISMA Flowchart. From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi:10.1136/bmj.n71.

Singapore, and Canada, with one study reporting on cross-country comparisons between Argentina, Brazil, and Chile (Azevedo et al., 2021). Some studies collected data from unpaid carers about themselves and/or their relative with dementia (i.e. Manini et al., 2021; Pongan et al., 2021), some collected data from both people with dementia and unpaid carers (Giebel et al., 2021a, 2021b, 2021c, 2022, 2021e, 2021f; Tuijt et al., 2021a, 2021b), and others only collected data from people with dementia (i.e. Lara et al., 2020; Talbot & Briggs, 2021). The vast majority of studies focused on community-residing people living with dementia (i.e. Caratozzolo et al., 2021; Tam et al., 2021), with only three studies focusing on people with dementia living in residential care (Borg et al., 2021; El Haj et al., 2020, 2021). Types of data collected included qualitative interviews (i.e. West et al., 2021), specifically designed surveys some of which involved validated tools on depression and anxiety (i.e. Cohen et al., 2020a), quantitative assessment of cognition, mental health, or neuropsychiatric symptoms

(i.e. Lara et al., 2020; Pongan et al., 2021), as well as longitudinal cohorts which commenced prior to the pandemic and thus have baseline data to compare against (i.e. Borelli et al., 2021; Cagnin et al., 2020).

The findings from the 33 included studies were categorised into five different pandemic impacts under the umbrella of health, mental health, and care access: Cognition; Independence and physical functioning; Behavioural symptoms; Well-being; and Access to care, with some studies reporting on multiple impacts.

Impact on cognitive abilities

Ten studies focused on changes in different areas of cognition in dementia during COVID-19. These include quantitative assessments, as well as cohort comparisons with data from before the pandemic outbreak and qualitative experiences.

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 of data collection
Azevedo et al., 2021	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 were reported feeling more tired and overwhelmed.	Community	May to July 2020
Borelli et al., 2021	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 2020 to July 2020
Borg et al., 2021	France	398 carers accompanying a person with dementia living at home (HC) and 159 accompanying a person 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 care homes	17th March–11th May 2020
Borges-Machado et al., 2020	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	November 2019–June 2020
Boutoleau-Bretonnière et al. (2 papers)	France	38 carers (about people with Alzheimer's disease and carers) 38 behavioural variant frontotemporal dementia (bvft) 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. Bvft carers—increased burden regardless of behavioural changes. AD carers—increased burden related to changes in people with AD neuropsychiatric symptoms.	Community	26th March–9th May 2020
Cagnin et al., 2020	Italy	87 Memory centres, 4,913 family carers (about people with dementia on regular clinical follow-up)	Mental Health, Carer burden, Cognition, Behaviour	Quantitative, observational sub-study nested in a larger multicentre survey	Nation-wide survey—regarding people with dementia and carers' modifications of dementia-related symptoms after beginning of quarantine and clinical data on previous physical independence and awareness of current pandemic.	Quarantine induces a rapid increase Behavioural and psychological symptom (60%) and stress-related symptoms of carers (two-thirds).	Community	14th–24th April 2020

(Continued)

Table 1. (Continued)

Authors	Country	Population (people with dementia/carers/sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period of data collection
Capozzo et al., 2020	Italy	32 people with dementia and Carers (about people with dementia)	Mental health, behaviour	Quantitative population-based study	Structured questionnaire: Clinical Dementia Rating Scale–frontotemporal dementia (CDR–FTD), the Behaviour and Language items.	Significant worsening of clinical picture and quality of life since the start of social distancing, significant worsening of behaviour and language functions. Unable to adapt and suffered from depression and cognitive complaints.	Community	10 April and 30 April 2020.
Carlos et al., 2021	Italy	204 participants were interviewed: 166 (81.4%) Abbiategrosso Brain Bank (ABB) donors and 38 (18.6%) Memory Clinic patient (about people with dementia)	Behaviour, Cognition, Mental health	Quantitative, cross-sectional telephone-based survey	Medical records, DSM-5 criteria, CDR scale, self-devised a Structure Questionnaire, GDS-5 scale.		Community	9th April 2020–4th May 2020
Carpinelli Mazzi et al., 2020	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., 2020a	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., 2020b	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 2020
El Haj et al. 2021	France	72 participants (about people with AD)	Mental health	Quantitative	Invited the carers to rate the severity of depression of people with dementia using a four-point scale.	Increased depression in the people with dementia during the lockdown.	Retirement homes	12th May–27th November 2020
El Haj et al., 2020	France	58 Participants (about people with Alzheimer's disease)	Mental health	Quantitative	On-site carers instructed participants to assess their depression and anxiety with the Hospital Anxiety and Depression Scale.	Participants reported higher depression and anxiety during than before the Covid-19 crisis.	Retirement homes	N/A
Gan et al., 2021	China	205 people with dementia (about people with dementia)	Cognition	A descriptive and retrospective study based on medical Records	Demography, medical history, and neuropsychological evaluation that included the C-MMSE, MoCA, activities of daily living, the Neuropsychiatric Inventory, and the etiological data at baseline and follow-up were reviewed. The Clinical Dementia Rating Scale (CDR) was used to assess the severity of CI as 0.5, 1.0 (mild), 2.0 (moderate), or 3.0 (severe).	Confinement might ease the cognitive and neuropsychiatric deterioration of people with AD compared to those not in crisis and help prevent RCD in people with AD.	Community	1 April and 30 November 2020

(Continued)

Table 1. (Continued)

Authors	Country	Population (people with dementia/carers/sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period of data collection
Giebel et al. 2021	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	January–March 2020
Giebel et al. 2021 (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–August 2020
Giebel et al. 2021/ Hanna et al. 2022a, 2022b (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 2020
Helvacı Yılmaz et al., 2021	Turkey	54 individuals diagnosed with AD and carers (about people with dementia and carers)	Caregiver burden, cognition, mental health	Quantitative	Survey	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. Worsening of neuropsychiatric symptoms—agitation, apathy and aberrant motor activity being the most affect symptoms.	Community	April 1st–May 30rd 2020
Lara et al., 2020	Spain	40 with Mild cognitive impairment and Alzheimer's disease (about people with dementia)	Mental health	Quantitative	The Neuropsychiatric Inventory and euroqol-5D questionnaire.		Community	2 months
Manini et al., 2021	Italy	94 carers (about people with dementia)	Behaviour Mental health	Quantitative	A telephone-based questionnaire developed by authors—patient's clinical data, living arrangements, and access to day care services, living arrangements and lifestyle habits due to lockdown measures; access to outdoor spaces, access to emergency care.	Apathy, irritability, agitation, aggression and depression were the most common symptoms by people with dementia.	Community	30th April–8th June 2020 and follow up 9th March–15th May 2020
Ng et al., 2020	Singapore	50 people with Mild FTD and 50 people with mild AD dementia (both)	Access to care, behaviour	Quantitative	Phone based survey—to identify major themes of particular concern to patient—Caregiver 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

(Continued)

Table 1. (Continued)

Authors	Country	Population (people with dementia/carers/sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period of data collection
Panerai et al., 2016	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 14th and May 16th 2020
Paolini et al., 2021	Italy	38 older adults with mild/moderate dementia (about people with dementia)	Mental health, cognition	Quantitative	Two questionnaires, the Perceived Stress Scale (PSS) and the FLEI Mental Ability Questionnaire (FLEI)	Cognitive functioning worsened during lockdown and experienced stress (S) during the first wave of lockdown.	Community	March to May
Pongan et al., 2021	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-Dscale(CenterforEpidemiologicStudies-Depression)	Impact on behavioural disorders in people with dementia and these disorders are associated with poorer mental health of carers.	Community	15th April–15th June 2020
Rainero et al., 2020	Italy	97 dementia centres, 4913 people with dementia (about people with dementia and carers)	Care burden, 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 2020
Rajagopalan et al., 2022	India	104 dementia and their carers (about people with dementia and carers)	Care burden, behaviour, mental health	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 25 June 2020.
Rising et al., 2022	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	August–November 2020
Talbot & Briggs, 2021	UK	19 people with dementia (about people with dementia)	Cognition, Mental health	Qualitative	Semi-structured interviews	Generated five themes: the forgotten person with dementia, confusion over government guidance, deterioration of cognitive function, loss of meaning and social isolation, safety of the lockdown bubble.	Community	June–July 2020
Tam et al., 2021	Canada	498 participants carers and people with dementia (about people with dementia and carers)	Care 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 8, 2020, and August 19, 2020.
Tsapanou et al., 2021	Greece	339 carers (about carers and people with dementia)	Carer burden Mental health	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	November 2020–April 2021

(Continued)

Table 1. (Continued)

Authors	Country	Population (people with dementia/carers/sample size)	Focus	Design	Measures	Qual: themes generated Quant: outcomes	Setting	Time period of data collection
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
West et al., 2021	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

Cognitive functioning

Using different methods, quantitative and qualitative research reported on deteriorations in different cognitive symptoms since the pandemic, including memory, attention, and orientation. Whilst research emerged from different countries, including Turkey, France, and the UK, quantitative research from Italy into cognitive changes was the most frequent. Paolini et al. (2021) asked people with dementia in the mild to moderate stages to complete a mental ability questionnaire every two weeks during the first lockdown in Italy, with cognitive functioning showed to have significantly worsened throughout lockdown. Asking unpaid carers about their relatives cognitive functioning changes since the pandemic, four studies (Azevedo et al., 2021; Borelli et al., 2021; Helvacı Yilmaz et al., 2021; Rainero et al., 2020) reported worsening cognitive symptoms including memory in over 50% of people with dementia, which was particularly pronounced in Alzheimer's disease dementia and Lewy Body dementia in the latter study. Comparing cognitive status prior to the pandemic using the Clinical Dementia Rating Scale, Carlos et al. (2021) reported dementia to be significantly associated with higher risk of worsened memory functioning since the pandemic. This was supported by general faster deteriorations in cognitive and other functions in dementia since the pandemic in the UK, as reported via qualitative interviews with unpaid carers (Giebel et al., 2022).

Communication

Deteriorations in communication and language skills have been reported in two studies. Capozzo et al. (2020) reported significant deteriorations in language in people living with Frontotemporal dementia as measured via the Clinical Dementia Rating scale before and since the pandemic in 47% of participants. Talbot and Briggs (2021) interviewed people living with dementia about their experiences of the pandemic on their lives. People with the condition themselves had noticed changes in speech since the beginning of the pandemic, linked to stopping engaging in more active and challenging activities pre-pandemic.

Impact on independence and physical functioning

Six studies reported on the worsening of functional independence, including basic and instrumental activities of daily living, and physical functioning, such as mobility and gait, since lockdowns and restrictions to stay at home. Borges-Machado et al. (2020) compared measures on everyday and physical functioning as completed by unpaid carers about their relative with dementia before and after the introduction of COVID-19 measures. They reported a significant decline in everyday functioning. Two third of carers also reported physical deteriorations due to home confinement, with one fifth of people with dementia having fallen at least once. Findings by Borelli et al. (2021) support deteriorations in everyday functioning since the pandemic commenced, with one third of people with dementia reported by their carers to have deteriorated in activities such as personal care and continence. Azevedo et al. (2021), Cohen et al. (2020a), and Rainero et al. (2020) provide further quantitative evidence, with Cohen and Rainero et al. reporting worsening gait disturbance and motor functioning.

Longitudinal qualitative data collected from unpaid carers and people with dementia highlights faster deteriorations in symptoms already at baseline in April 2020 (one month after

Table 2. QualSyst checklist criteria.

Criteria for assessing quantitative studies	Criteria for assessing qualitative studies
Question/objective sufficiently described?	Question/objective sufficiently described?
Study design evident and appropriate?	Study design evident and appropriate?
Method of subject/comparison group selection or source of information/input variables described and appropriate?	Context for the study clear?
Subject (and comparison group, if applicable) characteristics sufficiently described?	Connection to a theoretical framework/wider body of knowledge?
If interventional and random allocation was possible, was it described?	Sampling strategy described, relevant and justified?
If interventional and blinding of investigators was possible, was it reported?	Data collection methods clearly described and systematic?
If interventional and blinding of subjects was possible, was it reported?	Data analysis clearly described and systematic?
Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?	Use of verification procedure(s) to establish credibility?
Sample size appropriate?	Conclusions supported by the results?
Analytic methods described/justified and appropriate?	Reflexivity of the account?
Some estimate of variance is reported for the main results?	
Controlled for confounding?	
Results reported in sufficient detail?	
Conclusions supported by the results?	

Table 3. Quality assessment for quantitative studies.

Research paper	Overall score
Azevedo et al., 2021	0.94
Borelli et al., 2021	1.00
Borg et al., 2021	0.94
Borges-machado et al., 2020	0.94
Boutoleau-bretonnière et al., 2020	1.00
Cagnin et al., 2020	1.00
Capozzo et al., 2020	0.83
Carcavilla et al., 2021	0.67
Carlos et al., 2021	1.00
Carpinelli mazzi et al., 2020	0.78
Cohen et al., 2020a	1.00
Cohen et al., 2020b	0.89
El haj et al., 2021	0.83
El Haj et al., 2020	0.83
Gan et al., 2021	1.00
Giebel et al. 2021 (2 papers)	1.00
Helvacı yilmaz et al., 2021	0.94
Lara et al., 2020	0.89
Manini et al., 2021	1.00
Ng et al., 2020	0.78
Panerai et al., 2016	1.00
Paolini et al., 2021	1.00
Pongan et al., 2021	0.94
Rainero et al. 2020	1.00
Rajagopalan et al. 2022	0.94
Tam et al., 2021	0.89
Tsapanou et al., 2021	0.89
Werner et al., 2021	0.94

the first national lockdown), and subsequently at follow-up three months later, including basic activities such as feeding (Giebel et al., 2021e, 2021f).

Impact on behavioural symptoms

14 studies have assessed behavioural symptoms or conducted qualitative interviews about behavioural impacts of the pandemic in people living with dementia. Many studies had quantitative baseline pre-pandemic data to compare against,

Table 4. Quality assessment for qualitative studies.

Research paper	Overall score
Giebel et al. 2021	0.95
Giebel et al. 2021/Hanna et al., 2022a, 2022b (5 papers)	0.90
Rajagopalan et al., 2022	0.85
Rising et al., 2022	0.65
Talbot & Briggs, 2021	0.90
Tuijt et al. (2 papers)	0.90
West et al., 2021	0.90

enabling clear reports of increased neuropsychiatric behavioural problems, including agitation and apathy, in a large proportion of people with dementia (i.e. Azevedo et al., 2021; Borges-Machado et al., 2020; Lara et al., 2020; Panerai et al., 2016; Pongan et al., 2021). The most common tool used to assess neuropsychiatric symptoms was the Neuropsychiatric Inventory Questionnaire, adapted to different languages, including French, Spanish, and Portuguese. In a pre-post comparison in France, Pongan et al. (2021) reported 43.3% of people living with dementia to have experienced increases in behavioural and neuropsychiatric symptoms. Findings were closely aligned with ratings of deteriorations in behavioural symptoms in 48.3% of people with dementia in a remote survey with carers in Brazil (Borelli et al., 2021). Comparing pre-pandemic data with behaviours experienced 5 months since lockdown in Spain, Lara et al. (2020) noted that apathy, agitation, and aberrant motor behaviour were particularly affected in people with Alzheimer's disease dementia. For dementia in general, Azevedo et al. (2021) found particular increases in symptoms of agitation in advanced dementia, whilst many people with dementia of any cognitive stage reported appetite changes.

Impact on well-being

Twenty-four studies have either quantitatively or qualitatively assessed the impact of the pandemic on the well-being of people with dementia, with studies including a focus on mental health and social health.

Mental health

A great deal of studies reported on high or increased levels of anxiety and depressive symptoms in people living with dementia since the pandemic (Azevedo et al., 2021; Borg et al., 2021; Cagnin et al., 2020; Carlos et al., 2021; Cohen et al., 2020a; El Haj et al., 2021; Giebel et al., 2021e; West et al., 2021). Some studies had baseline data from before the pandemic, and could compare levels of anxiety and depression using validated tools such as the General Anxiety Disorder 7 (GAD-7) or the Hospital Anxiety and Depression Scale (HADS). El Haj et al. (2021) asked care home staff to rate anxiety and depression levels of care home residents living with mild Alzheimer's Disease both before the pandemic and since, and found significant increases in both during the pandemic. Using a similar approach, Azevedo et al. (2021) remotely interviewed unpaid carers of people with dementia living in the community, asking unpaid carers to rate their relative's mental health pre and since social isolation as a result of quarantine and lockdown, reported increased levels of anxiety and depression in their relatives with dementia, which also supports findings by Cagnin et al. (2020) and Carlos and colleagues (2021). Linking to specific levels of social support service usage changes since the pandemic, Giebel et al. (2021e) further reported reductions in service usage were associated

with higher levels of anxiety in people living with dementia, who completed the remote survey themselves either via phone or online.

Findings from qualitative interviews with people with dementia and unpaid carers from minority ethnic backgrounds in the UK provided detail about the types of fears experienced by people with dementia (West et al., 2021). Feelings encompassed existential fear about the pandemic, as well as a fear of catching the virus when travelling on public transport for example, with some awareness about higher susceptibility to the virus in people from minority ethnic groups. In the UK, people with dementia from White ethnic backgrounds expand on these findings, with Hanna et al. (2022) evidencing increased levels of depression and anti-depressant usage as a result of the pandemic, as well as ongoing levels of uncertainty affecting people's mental health.

Social health

The impact of the pandemic on social health was reported across a number of studies, whilst social isolation in general featured as an underpinning factor linked to impacts on cognition, behaviour, and physical functioning. Tam et al. (2021), as well as various other qualitative studies (Cohen et al., 2020a; Talbot & Briggs, 2021; West et al., 2021), reported increased levels of social isolation and loneliness in people living with dementia. Considering the increased length of lockdown periods in the UK for example, people with dementia grew increasingly socially isolated as time went by, experiencing a lack of meaning due to cancelled previously enjoyed activities, with many feeling more reluctant and anxious in re-engaging with society once restrictions were eased (Talbot & Briggs, 2021). Socialising and staying in contact with family and friends was often difficult, also considering digital barriers and dementia-related barriers struggling to comprehend remote engagement platforms such as Zoom or facetime (Giebel et al., 2022). This is where having an unpaid carer was found to be very beneficial to people living with dementia, not only in supporting them with unmet care needs and enabling digital connectivity, but also in providing some level of otherwise lacking social engagement. Tuijt et al. (2021a) reported particular benefits of well-established family relationships to the well-being of the person with dementia, whilst generally lockdown could also strain some caring relationships.

Impact on access to care

Nine studies explored the impact of the pandemic on accessing and using health or social care, with all reporting on reductions or discontinuations of accessing care. Using a three-time-point longitudinal online and telephone survey, Giebel et al. (2021e, 2021f) reported on the sudden and significant reduction in accessing social support services for dementia in April, with large proportions of people with dementia suddenly not accessing any care anymore compared to prior to the pandemic. Over a period of up to five months, accessing social support services, including day care, respite care, and peer support groups, only minimally increased for peer support groups and paid home care. Any other services remained at a low, with paid home care having been the least affected. The qualitative complementary study provided insights into potential reasons for these variations between variations on the impact of different types of

services. The authors reported that unpaid carers faced difficult decisions about whether to continue or discontinue paid home care, with some unpaid carers cancelling the paid care for fear of virus transmission, yet others continuing paid care for inability to manage otherwise (Giebel et al., 2021c). However, cancelling care, as well as the continued lack of general social support services, was found to lead to some people with dementia entering a care home faster at study follow-up (Giebel et al., 2022). Discontinuation of care was equally reported in other studies from other countries (Carpinelli Mazzi et al., 2020; Capozzo et al., 2020; Cohen et al., 2020b), including impacts on health care services such as home-based physiotherapy (Rajagopalan et al., 2022; Tuijt et al., 2021b). People living with dementia and unpaid carers reported issues with primary care consultations in the UK, including technological barriers. People with dementia and unpaid carers mostly avoided primary carer consultations for fear of COVID-19 and wanting to minimise NHS burden. In addition, dementia-related barriers such as lack of prompts to remember problems caused difficulties with remote consultations, leaving people less cared for than before the pandemic (Tuijt et al., 2021b). This is supported by a study from Israel reporting half of unpaid carers had forgone approaching health care services for their relative's care needs (Werner et al., 2021).

Quality ratings

All included papers were of good quality, with total percentage scores ranging from 0.78 to 1.00 (see Tables 3 and 4).

Discussion

This is the first comprehensive systematic review reporting on the impacts of the pandemic on people living with dementia both in the community and in residential care in the early stages of COVID-19. A continuously growing evidence base has highlighted the many different pandemic effects on people's lives, including reported faster cognitive, behavioural, and functional deterioration, as well as poorer mental health and well-being and reduced access to vital care.

Overall, faster dementia deterioration has been repeatedly reported by unpaid carers as early as April 2020, only a few weeks after the WHO declared COVID-19 a pandemic. Evidence from across the globe has highlighted significant, faster deteriorations in cognition, everyday and physical functioning, and behavioural symptoms—via quantitative pre- and post-assessments or surveys or qualitatively via interviews (Borges-Machado et al., 2020; Paolini et al., 2021). The sudden, and continued, lack of previously established routine, social activities, and overall cognitive, social, and physical stimulation by being locked into the home, appears to be linked to those faster deteriorations. There are no control groups of people with dementia who have continued to live a 'normal', non-restrictive life due to the nature of a pandemic. However, pre- and since quantitative assessments as well as qualitative reports from people with the condition and those caring for someone with dementia clearly indicate that restrictions and the pandemic at large have had, and continue to have, an enormous impact on dementia symptomatology. Considering the lack of control groups, it is important to point out that some of these deteriorations are likely to be the case of the neurodegenerative nature of the dementia itself, whilst the findings from across multiple studies and countries and methodologies provide scientific

evidence that the pandemic has further exacerbated any naturally experienced deteriorations. As the UK is seeing no further restrictive measures, future research ought to assess whether these faster declines are potentially reversible, through adequate care, support, and rehabilitation, to enable people with dementia to regain some of their functioning and abilities.

However, there have been some early warnings of faster care home entry as a result (Giebel et al., 2022). In light of difficult and changing restrictions in care homes, leaving family members often unable to visit their relatives (Backhaus et al., 2021), as well as care homes having been the epicentres of COVID-19 outbreaks (Burton et al., 2021), there are additional reasons as to why care home residency has been avoided. Future research needs to use big data on care home residency to establish a quantitative relationship between COVID-19 and point of care home entry.

Amongst the different impacts, one type of functioning was picked up on in only a few studies—language (Capozzo et al., 2020; Talbot & Briggs, 2021). Besides the general reported impact on wider cognition, including memory, executive functioning, and attention, language also appeared to deteriorate faster since the pandemic in some studies. Different subtypes of dementia are characterised by more pronounced language difficulties, such as primary progressive aphasia and semantic dementia (Volkmer et al., 2020). However, language and communication in general was found to deteriorate regardless of specific subtype since the pandemic, indicating the wide-ranging and long-lasting implications of confinement and lack of stimulation. Losing the ability to communicate effectively is going to cause increased difficulties for people with dementia in engaging with peers remotely during the ongoing pandemic and face-to-face, whenever care resumes to be delivered in this fashion. This added barrier may further result in poorer mental health and well-being, so that research is required to track the language functioning of people with dementia throughout the pandemic and different waves and restrictive measures.

Whilst faster deteriorations, as reported in every single study, were linked to a general lack in cognitive, physical, and social stimulation (i.e. Borelli et al., 2021), this lack of engagement was increased due to the significant reductions of social care and support services, as well as difficulties in accessing physical health care. Accessing social support services after a diagnosis enables independence and well-being in the community for as long as possible (Strandenaes et al., 2018), which has been known prior to the pandemic. The pandemic has starkly highlighted the very extent of the benefits of services needed though, such as paid home care, peer support groups, and day care centres. Therefore, any future restrictions need to take into account the need to facilitate face-to-face care provision, as lack thereof has also been linked to increased levels of unpaid carer burden (Hanna et al., 2022; see Part II).

One of the only aspects which may be more easily reversed with adequate support is poor mental health. Numerous studies have reported higher levels of depressive symptoms and anxiety since the pandemic among people with dementia as well as poorer levels of social health (Cagnin et al., 2020; Carlos et al., 2021). Social health encompasses loneliness, social isolation, and social engagement, which is unsurprisingly lower since the pandemic due to face-to-face restrictions. However, we know from longitudinal surveys how high levels of loneliness can be linked to worse cognitive functioning (Yin et al., 2019) and even to increased rates of care home entry (Hanratty et al., 2018).

Again, this highlights the need for longitudinal exploration of the welfare and place of residence of people with dementia during the pandemic. To provide action now, however, findings strongly indicate the need for adequate mental health provision for people with dementia to support them with their emotional and social needs—some of which can be met by re-introducing safe face-to-face social support services such as day care centres and peer support groups.

Strengths and limitations

Concerning the included studies, an array of different methodologies and data collection approaches were used to generate an understanding about the impact of the pandemic on people with dementia—ranging from surveys and established neuropsychiatric assessments and validated questionnaires either in the early stages of the pandemic or before and since, to qualitative accounts of the experiences of the impact. Many studies involved interviews with unpaid carers about their relatives with dementia. Given the high levels of emotions and stress which the pandemic has brought with it, interview data from unpaid carers is subjective based on their own experiences, so that having quantitative assessments provides an additional layer of validity for the findings. Whilst these studies provide a unique insight into the early impacts across the globe, big data and longitudinal analyses focusing on the long-term are missing, as are investigations into the impacts on care home residents. The majority of research has been conducted with community-dwelling people with dementia, which was foreseeable given the complete closures of care homes during the early, and later, stages of the pandemic. Moreover, only one study (West et al., 2021) specifically explored the experiences of people with dementia from minority ethnic backgrounds. In light of the increased susceptibility of people from minority ethnic backgrounds to the virus (Ayoubkhani et al., 2021), more research into these population groups is required. This also applies to a greater need for research from lower- and middle-income countries (LMICs), as only two studies provided insights from one or more LIMCs—India (Rajagopalan et al., 2022) and Argentina and Brazil (Azevedo et al., 2021).

Concerning this systematic review, its strengths lie in the thorough and systematic searches of five evidence bases, double screening of each citation (Stage 1) and full text (Stage 2), quality rating each included study, and a general mixed-methods approach of included literature. We only included published studies up until July 2021, focusing on the early impacts of the pandemic. With a continuously growing evidence base, it would have been unmanageable to include any updated searches and additional studies, particularly as the present review already comprises a large amount of included research. Any further studies would have diluted the focus of the review, so that future evidence syntheses should explore the long-term implications of the pandemic. An additional strength of this review is that we solely focused on people living with dementia, as we excluded many studies where dementia was mixed with other cognitive impairments or older adults without cognitive deficits.

Conclusions

Early on, the pandemic has had detrimental impacts on the lives and functioning of people with dementia across the globe and the mid- to long-term impact cannot be foreseen yet. These

faster deteriorations in symptomatology are unlikely to be reversed. As we are continuing to live through the pandemic with varied restrictions and different levels of immunity in different countries, findings from this comprehensive systematic review call attention to a need to stay cognitively, physically, and socially stimulated throughout. One way of achieving this is for care services to provide face-to-face support in a safe manner, which needs to be taken into account when imposing any future restrictions, and also need to be enabled for unpaid carers (see Giebel et al., submitted—Part II). We therefore call for a pandemic strategy for people living and caring for those with dementia, to be fully prepared. To provide further strength to this argument, longitudinal research ought to explore the long-term impacts of COVID-19 on dementia, including focusing on the time to care home entry before and since the pandemic—a likely negative consequence of the faster deteriorations reported in all studies in this review and something that will have been captured to a greater extent in literature published since the early impacts.

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Authors' 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.

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ORCID

Clarissa Giebel  <http://orcid.org/0000-0002-0746-0566>
Katarzyna M. Lion  <http://orcid.org/0000-0002-3699-6896>

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