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

**Clarissa Giebel1,2,\*, Katarzyna M Lion3, Klara Lorenz-Dant4, Aida Suárez-González5, Catherine Talbot6, Emily Wharton2,7, Jacqueline Cannon8, Hilary Tetlow2,9, Jochen René Thyrian10,11**

1 Department of Primary Care & Mental Health, University of Liverpool, Liverpool, UK

2 NIHR ARC NWC, Liverpool, UK

3 Menzies Health Institute Queensland, Griffith University, Brisbane, Australia

4 Care Policy and Evaluation Centre, Department of Health Policy, London School of Economics and Political Science, London, UK

5 Dementia Research Centre, UCL Queen Square Institute of Neurology, London, UK

6 Faculty of Science & Technology, Bournemouth University, UK

7 School of Sport and Exercise Sciences, Liverpool John Moore’s University, Liverpool, UK

8 Lewy Body Society, Wigan, UK

9 SURF Liverpool, Liverpool, UK

10 German Centre for Neurodegenerative Diseases (DZNE), Rostock/ Greifswald, Greifswald, Germany

11 Institute for Community Medicine, University of Greifswald, Greifswald, Germany

*Correspondence should be addressed to:* Clarissa Giebel, University of Liverpool. Email: Clarissa.giebel@liverpool.ac.uk

**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.

**Keywords:** dementia, COVID-19, social care, mental health, activities of daily living

**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 (Hariyato et al., 2021; Zuin et al., 2020).

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 disorder**s**"[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, 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-f; 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., 2021), 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., 2021).

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.

**[insert Figure 1 and Table 1]**

**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.

*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; Helvaci Yilmaz et al., 2021; Rainero et al., 2021) 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., 2021d).

*Communication*

Deteriorations in communication and language skills have been reported in two studies. Capozzo et al. (2021) reported significant deteriorations in language in people living with Fronto-temporal dementia as measured via the Clinical Dementia Rating scale before and since the pandemic in 47% of participants. Talbot & 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. (2021) 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. (2021), and Rainero et al. (2021) 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 the first national lockdown), and subsequently at follow-up three months later, including basic activities such as feeding (Giebel et al., 2021e,f).

**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, 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., 2021; Lara et al., 2020; Panerai et al., 2021; Pongan et al., 2021; Panerai 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., 2021; Carlos et al., 2021; Cohen et al., 2021; El Haj et al., 2021a, b; 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 and colleagues (2021b) 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 and colleagues (2021) 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. (2021) 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., 2021; 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., 2021d). 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,f) 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., 2021d). Discontinuation of care was equally reported in other studies from other countries (Carpinelli Mazzi et al., 2021; Capozzo et al., 2021; Cohen et al., 2021), including impacts on health care services such as home-based physiotherapy (Rajagopalan et al., 2021; 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.

**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., 2021; 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., 2021d). 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., 2021; 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., 2017), 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., 2021; 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 and 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., 2020), 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., 2021) 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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**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.

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| **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. | 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 eachCountry), 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. | Communtiy | 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. | Communtiy | May 2020 to July2020 |
| Borg et al. 2021 | 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) to10 (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. | 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 (Bvftd) and38 Alzheimer disease (AD) carers (about carers) | Cognition, Mental Health, care burdenBehaviour, 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 March - 9th May 2020 |
| Cagnin et al. | 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 multicentreNation-wide 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 |
| Capozzo et al. | 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. | Community | 10 April and 30 April2020. |
| Carlos et al. | Italy | 204 participants were interviewed: 166 (81.4%) Abbiategrasso 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. | Unable to adapt and suffered from depression and cognitive complaints. | Community | 9th April 2020 – 4th May 2020 |
| 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 assessmentScales (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 dementiaLiving 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 thatfamily 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 ofboth subjects with dementia and family membersand problems of management, rehabilitation, andcare that subjects experienced during the first 4 weeks of the coronavirus quarantine in our setting, anxiety, burnout and stressthat 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. | 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. | China | 205 people with dementia (about people with dementia) | Cognition | A descriptive and retrospective study based on medicalRecords | Demography, medical history, and neuropsychologicalevaluation that included the C-MMSE), MoCA, activities of daily living, the Neuropsychiatric Inventory, and theetiological data at baseline and follow-up were reviewed. TheClinical 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 |
| 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 peoplewith 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. 2021, 2022 (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 |
| Helvaci Yilmaz et al. | 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. | 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. | Worsening of neuropsychiatric symptoms – agitation, apathy and aberrant motor activity being the most affect symptoms. | Community | 2 months |
| Manini et al. 2021 | Italy | 94 carers (about people with dementia) | BehaviourMental 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. | Singapore | 50 people withMild 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 |
| Panerai et al. | Italy | 128Carers 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. | 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. | 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 April – 15th June 2020 |
| Rainero et al. | 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. | 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. | 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-November2020 |
| Talbot; Briggs | 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. | 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. | Greece | 339 carers (about carers and people with dementia) | Carer burdenMental healthHealth | 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 ownburden | 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 |
| Tuijt et al. (2 papers) | UK | 30 people living with dementia, 31Family carer (about people with dementia and carers) | Cognition, care burdenAccess to care | Qualitative | Interviews were semi structuredSemi-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 - August2020 |
| West et al. | UK | 15 participants (people with dementia andCarers) | Health, access to care, Mental health, care burden | Qualitative | Semi structured qualitativeInterviews. | 8 key themes, with subthemes: Fear and anxiety, food and eating (encompassing foodShopping 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 |

**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. | 0.94 |
| Borelli et al. | 1.00 |
| Borg et al. 2021 | 0.94 |
| Borges-machado et al. | 0.94 |
| Boutoleau-bretonnière et al. | 1.00 |
| Cagnin et al. | 1.00 |
| Capozzo et al. | 0.83 |
| Carcavilla et al. | 0.67 |
| Carlos et al. | 1.00 |
| Carpinelli mazzi et al. | 0.78 |
| Cohen et al. | 1.00 |
| Cohen et al. | 0.89 |
| El haj et al. | 0.83 |
| El haj et al. 2020 | 0.83 |
| Gan et al. | 1.00 |
| Giebel et al. 2021 (2 papers) | 1.00 |
| Helvaci yilmaz et al. | 0.94 |
| Lara et al. 2020 | 0.89 |
| Manini et al. 2021 | 1.00 |
| Ng et al. | 0.78 |
| Panerai et al. | 1.00 |
| Paolini et al. | 1.00 |
| Pongan et al. | 0.94 |
| Rainero et al. | 1.00 |
| Rajagopalan et al. | 0.94 |
| Tam et al. | 0.89 |
| Tsapanou et al. | 0.89 |
| Werner et al. | 0.94 |

**Table 4. Quality assessment for qualitative studies**

|  |  |
| --- | --- |
| Research Paper | Overall Score |
| Giebel et al. 2021 | 0.95 |
| Giebel et al. 2021/ Hanna et al. 2021, 2022 (5 papers) | 0.90 |
| Rajagopalan et al. | 0.85 |
| Rising et al. | 0.65 |
| Talbot & Briggs | 0.90 |
| Tuijt et al. (2 papers) | 0.90 |
| West et al. | 0.90 |

**Identification of studies via databases and registers**

Records removed *before screening*:

Duplicate records removed (n = 5,755)

Records identified from\*:

Databases (n =15,677)

**Identification**

Records screened

(n = 9,923)

Records excluded\*\*

(n = 9,749)

Reports sought for retrieval

(n = 174)

Reports not retrieved

(n = 15)

**Screening**

Reports excluded:

Not focusing on people with dementia or unpaid carers specifically (n = 45)

Not a peer-reviewed research article (n = 32)

Not focusing on the effects of COVID-19 (n = 22)

No primary data included (n =4)

Case study (n=2)

Not in the community or care home (n= 1)

Reports assessed for eligibility

(n = 159)

Studies included in review

(n = 46)

Reports of included studies

(n = 53)

**Included**

**Focus on unpaid carers:**

Studies included in review

(n = 36)

Reports of included studies

(n = 43)

**Focus on people with dementia:**

Studies included in review

(n = 33)

Reports of included studies

(n = 40)

*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

**Figure 1. PRISMA Flowchart**