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Exploring the impact of Covid-19 on the care and quality of life of people with dementia and their carers: A scoping review

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Abstract

This article reports on findings of a scoping review aimed to map the published literature concerning the impact of Covid-19 on the care and quality of life of people living with dementia and their carers. Twenty-nine articles were included in the review. Three overarching themes were identified: (1) Impact on people with dementia – unmet and increased care needs; (2) Impact on carers – increased stress and burden and (3) Impact according to demographics. Overall, findings show that Covid-19 has led to a reduction in support from health and social services and to a move towards technology-based support. Furthermore, Covid-19 has had a negative impact on the care and quality of life of

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Ethical approval

Ethics approval is not required for this scoping review study because the methodology of the study only consists of data from articles in public domains.

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people living with dementia and their carers, and that this impact was influenced by the severity of dementia.

Keywords
Dementia, carer, Covid-19, lockdown, quality of life, review

Introduction

Dementia has become one of the greatest healthcare challenges of the 21st century, linked to high demand for medical, social and institutional care (Ibarria et al., 2016; World Health Organization 2017; Lindeza et al., 2020). Family carers play a major role in supporting people with dementia, not only in their daily activities and personal care, but also in preserving the individual's sense of self and mental wellbeing (Dening et al., 2012; Farina et al., 2017; Lindeza et al., 2020). The challenges of caring are significant, and a large body of scholarly evidence demonstrates the detrimental impact on the physical and mental health of dementia carers (Connell et al., 2001; Schoenmakers et al., 2010; Gilhooly et al., 2016; Lindeza et al., 2020). Supporting the estimated 50 million people affected by dementia worldwide has therefore become a key national and international health policy priority (World Health Organization, 2012; Alzheimer's Disease International (ADI), 2016). Due to the unprecedented situation and concerns regarding the impact of Covid-19 on people with dementia and their carers, there has been a high volume of rapidly published research. In this review, we explore evidence concerning the impact of Covid-19 on the care and quality of life (QoL) of people with dementia and their carers. QoL is highly debated but widely recognised as a multi-dimensional construct comprising both subjective and objective aspects (Bowling, 1995). In relation to dementia and for the purposes of this review, we draw on the conceptual model developed by Lawton (1997). This model considers QoL across four domains: 1. Behavioural competence (ability to function in adaptive and socially appropriate ways, e.g. social relationships with family and friends, and social engagement); 2. Objective environment (aspects external to the individual, e.g. physical safety, presence of amenities, housing/place of residence and healthcare); 3. Psychological wellbeing (e.g. happiness, agitation, depression, affect state, emotional expression and spirituality) and self-esteem (self-esteem, life satisfaction and morale) and 4. Subjective satisfaction with the overall QoL.

The need to focus on people living with dementia and their carers has been heightened as a result of the Covid-19 pandemic. During most of 2020 (and a significant proportion of 2021), quarantine rules, designed to protect those most at risk, have led to restricted freedoms, limited contact with others and potentially increased isolation of people living with dementia and their carers. Furthermore, government responses to Covid-19 have prioritized income support and the withdrawal of health and social services, support groups, social activities and respite care initiatives, limiting the level of formal and informal support available (Daly, 2020; Giebel et al., 2020a). Relatedly, international evidence is beginning to emerge that demonstrates that people with dementia are disproportionately impacted by Covid-19 with the condition exacerbating the risk of mortality (Alzheimer's Disease International (ADI), 2020; Numbers & Brodaty, 2021). For example, evidence from the National Health Service (NHS) in the UK shows that people with dementia were at a higher risk of Covid-19 hospital deaths (Williamson et al., 2020). Similarly, estimates show that people with dementia accounted for nearly one third of all Covid-19 related deaths in Scotland and a quarter of such deaths in England and Wales (Suárez-González, et al., 2020) The particular vulnerabilities to Covid-19 that people with dementia face, coupled with a specific type of policy response, raise important questions concerning the impact of the disease on the QoL of people with dementia. It is particularly important to understand whether the impact of Covid-19 can be traced along lines such as gender, type of dementia and severity, and living arrangements all of which have been shown to have an impact on QoL outcomes of people with dementia and their carers (Schumann et al., 2019).

The aim of this scoping review was to map research on the impact of Covid-19 on people with dementia and their carers. Specifically, we consider:

- How Covid-19 and linked changes in provision of services have influenced the care and QoL of people with dementia and their family carers?
- How the impact of Covid-19 differs according to diagnosis and illness severity, type of care facility (i.e. primary care, acute care, residential care, the community, etc.), gender and other relevant demographic characteristics?

Methods

A scoping review methodology was chosen, as this is an emerging and rapidly evolving area of research. Scoping reviews aim to provide a 'map' of the available evidence on a topic area (Aromataris & Munn, 2020). They do not focus on assessment of included studies but, instead, they are concerned with systematically charting a broad area of research with the aim of summarizing overarching findings and identifying gaps in the existing research literature (Arksey & O'Malley, 2005). The methodology for this review draws on the scoping review guidelines developed by the Joanna Briggs Institute (Peters et al., 2015). The objectives, inclusion criteria and methods for this scoping review were specified in advance and documented in a protocol developed by the team.

Eligibility criteria

Articles were included if: (1) the primary focus was people with dementia and their family carers; (2) the settings for the research reflected the community or care settings (hospitals, nursing/residential care homes and assisted living facilities); (3) they reported on primary research data on outcomes related to care provision and/or QoL; (4) they were reviews of primary research with a replicable methodology and (5) they were published in English. All types of study designs were considered.

Articles were excluded if: (1) they did not have a clear focus on people with dementia or their carers. For example, studies where dementia was one of many variables and where it was not possible to disaggregate the reported results (e.g. research looking at all residents in a care home setting); (2) they did not report primary research data (e.g. commentary or opinion piece) and (3) they were not published in English.

Search strategy

To identify potentially relevant documents, the following databases were searched from February to October 2020: MEDLINE, CINAHL, PsycINFO as well as Google Scholar. Sources of grey literature were searched, for example, clinical trial databases or special registers. (For a complete list of grey literature sources see Supplementary file 1). Reference lists of publications were hand searched for additional articles.

Search terms were constructed following a review of published systematic reviews (including Cochrane reviews) on the topic of dementia and Covid-19, in order to identify specific terms relevant to this review. Details of the search process were documented throughout for transparency and replication (see Supplementary file 2 for all search strategies). An initial search strategy was developed and piloted by the lead author and further refined through team discussion. Searches were carried out combining two different search arms: ‘dementia’ and ‘Covid-19 and quarantine’. Although the search terms were broad, the number of results was manageable within the timescale for this review and did not require further refinement. The example search strategy for MEDLINE is shown in Table 1.

The lead author (PMA) and MCA carried out the searches and the review process, which involved two levels of screening: a title and abstract review followed by a full-text review. The research team then met to discuss and review full-text papers that were unclear. See Figure 1 for the PRISMA flow diagram (Centre for Reviews and Dissemination, 2009) that describes the review process.

Data charting process

A bespoke template for data extraction was prepared in consultation with all team members. As recommended by the Centre for Reviews and Dissemination (2009), data extraction forms were piloted on a sample that included 10 studies in order to guarantee that the relevant information was captured, and resources were not wasted in extracting irrelevant data. Two reviewers (PMA and MCA) independently extracted the data, discussed the results and iteratively updated the data extraction form. Information was extracted on author, title, country, publication type, aims/purpose of the study, setting/context, sample characteristics (e.g. age, gender, ethnic group, socio-economic status and health), methodology, characteristics of interventions/initiative/support service (if applicable) and key findings. A further check on data extraction from a random 10% sample of the included studies was undertaken by the remaining three team members (GW, MH and NK). No disagreements were identified.

Synthesis of results

We used Arksey and O’Malley’s (2005) scoping review framework to map key concepts across different studies and to summarize in the form of themes, the main overarching findings, identifying gaps and priorities in the existing literature. Extracted data were categorized according to the review questions and outcomes of interest identified prior to the research but also according to other issues that emerged through the research. Similar categories were combined and organized to highlight key themes. The research team organized regular meetings to review extracted data. An iterative process was followed in order to collectively evaluate, refine and collate all data into categories to develop the final themes. Conflicts regarding the themes, although minimal, were resolved by comparing and discussing different interpretations during regular team meetings. The final themes and sub-themes were mapped onto Lawton’s (1997) four QoL domains: behavioural competence, psychological wellbeing, environmental quality and perceived QoL.

Table 1. Search strategy for MEDLINE.

Database: MEDLINE (EBSCOhost) limiters: Date (Feb–Oct 2020), English language

Search arm	Query
Dementia	(TX dementia OR dement* OR Alzheimer* OR dementia care OR dementia carers OR dement* adj care* OR TX ‘dementia carer’ OR exp dement* OR exp dementia/OR exp Alzheimer/) **AND**
Covid-19 and quarantine	(exp coronavirus/OR covid-19 OR 2019-ncov OR ‘corona virus’ OR exp pandemic/OR exp epidemic/OR respiratory* adj2 acute OR respiratory* adj2 disease OR respiratory* adj2 illness OR respiratory* adj2 condition OR exp quarantine/)

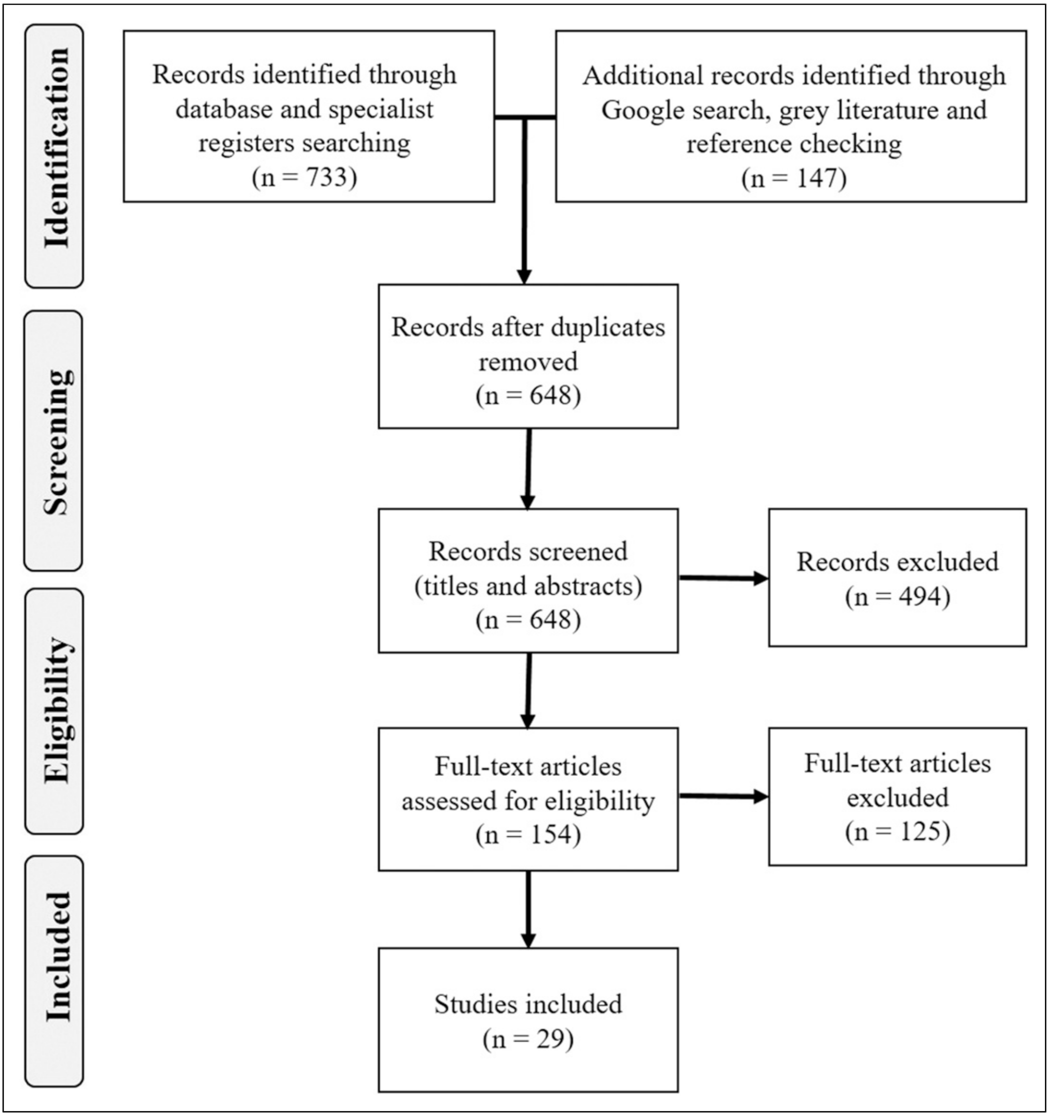

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for the scoping review process.

Results

Selection of sources of evidence

A total of 880 studies were identified during the search process. Following the removal of duplicates, this number was reduced to 648. After screening titles and abstracts against the eligibility criteria, 494 were excluded, with 154 full text articles retrieved and assessed for eligibility. Twenty-three studies were excluded because they did not have a clear focus on dementia. One hundred studies were excluded for not reporting on primary research data (e.g. commentaries and opinion pieces). Finally, two studies were excluded because they were not in English. Following this, 29 studies were included (Figure 1).

Characteristics of sources of evidence

Table 2 presents the characteristics of all included studies and relevant data extracted. Thirteen studies aimed at exploring the consequences of the epidemic (related lockdown and social distancing measures) on neuropsychiatric, cognitive and psychological health symptoms. Two were focussed on exploring the impact of loss of services in particular, and four others aimed to evaluate/assess technological adaptations of services (via telephone, TV or online). A significant number of included studies were reviews (n=9) looking at remote and technology-based approaches, the impact of Covid-19 on wellbeing indicators and experiences on the implementation of guidelines and policies.

The studies were conducted in several countries with a majority based in Europe (n=16). Most empirical studies were set within the community (n=18) with participants being people with dementia and/or carers living at home. One study presented data in a hospital setting and another in a care home setting. The remaining studies (n=9) were literature and systematic reviews. Most studies collected demographic data relevant to this review on age (n=17), gender (n=17) and living arrangements of participants (n=12). A small number recorded data on ‘educational attainment’ (n=8), and very few on ethnicity (n=4) or hours of care (n=4). The majority of included studies carried out telephone interviews (n=10) or online surveys (n=7).

Synthesis of results

Analysis of extracted data identified three main themes with subthemes (Table 3).

Theme 1: Impact on people with dementia - unmet and increased care needs

Impact of service withdrawal and isolation. A substantial number of the included studies (n = 11) focussed on the detrimental impact arising from the absence of regular services and isolation for people with dementia. The Covid-19 outbreak and the enforced prolonged conditions of social isolation affect behavioural and psychological symptoms and QoL of people with dementia. Studies reported on negative impacts on cognitive symptoms such as memory (Canevelli et al., 2020; Carpinelli & Lavarone 2020), orientation abilities (Canevelli et al., 2020) and difficulty concentrating (Alzheimer’s Society, 2020) as well as functional decline in terms of reduced level of independence in personal care and housekeeping (Suárez-González, 2020). Nine studies reported a negative impact on apathy, anxiety, agitation/aggression, as well as on depression of people with dementia (Alzheimer’s Society, 2020; Carpinelli & Lavarone, 2020; Canevelli et al., 2020; Cohen et al., 2020a; El Haj et al., 2020; Lara et al., 2020; Manca et al., 2020; Simonetti et al., 2020; Suárez-González, 2020). Two studies also described how the stress from the Covid-19 pandemic and lockdown triggered fear and contagion phobia and other PTSD-like symptoms (Cagnin & Di Lorenzo, 2020; Savla et al., 2020) for which patients with dementia are inherently more vulnerable due to the neuropathology of dementia.

The pandemic has led to a reduction in staff numbers and specialist support for people with dementia (e.g. specialist dementia wards) (including therapists) due to redeployment, sickness and shielding (Royal College of Psychiatry, 2020). This, as hospital leads that took part in the study carried out by the Royal College of Psychiatry (2020) report, has negatively impacted the quality of care for people with dementia, including the discharge process which was often considered to have

Table 2. Characteristics of all included studies and relevant data extracted (PWD: People with dementia; VD: Vascular dementia; BPSD: Behavioural and psychological symptoms of dementia; AD: Alzheimer's disease; YOD: Young onset dementia; MDT: Multidisciplinary team).

Authors (country)	Intervention, design and method	Sample	Key findings
Giebel et al. (UK)	No intervention Online survey: Pre-(T1) and post-(T2) Covid-19 Demographic data as well as the following scales: The short Warwick–Edinburgh mental well-being scale The generalised anxiety disorder 7 The personal health questionnaire 9	Total sample (*n* = 569) - PWD (*n* = 61, 70±10 yrs.), current carers (*n* = 219, 61±13 yrs.), former carers (*n* = 66), older adults (*n* = 223) 68% of participants female; 97% from white ethnic background; 74% living with other(s); 71% retired Of PWD: AD (41%), followed by mixed (23%) and VD (14%)	Findings demonstrated a link between COVID-related service loss and detrimental impacts on PWD and family carers The group with the highest proportion scoring above the cut off for both anxiety (33%) and depression (48%) were those living with dementia. They did not find a demonstrable relationship with depression

(continued)

Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Cagnin et al. (Italy)	No intervention This is a sub-study of a multicentre nation-wide survey. Structured telephone interview was delivered to PWD and their carers	Interviews with 4913 PWD and their carers after a mean quarantine period of 47.2 ± 6.4 days Patients had a diagnosis of AD in 69% of cases, VD in 16%, FTD in 8%, and DLB in 7% PWD - age (mean 78.3 +_8.2) 59.7% female CARERS: Age (mean 59.3 +-13), 53.9 female	Increased BPSD was reported in 59.6% of patients as worsening of pre-existing symptoms (51.9%) or as new onset (26%), and requested drug modifications in 27.6% of these cases Irritability, apathy, agitation, and anxiety were the most frequently reported worsening symptoms and sleep disorder and irritability the most frequent new symptoms Profile of BPSD varied according to dementia type, disease severity, and patients' gender. Anxiety and depression were associated with a diagnosis of AD, mild to moderate disease severity and female gender During quarantine a large range of stress-related feelings were reported by 65.9% (*n*=3240) of carers. Almost 46% had symptoms of anxiety, followed by helplessness (34.2%) and anguish Stress-related symptoms were experienced by two-thirds of carers and were associated with increased patients' neuropsychiatric burden Symptoms of depression and anxiety more prevalent in women, particularly in the mild stages of the disease, while apathy and irritability were more prevalent in males

Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Cohen et al. (Argentina)	No intervention Survey. Demographic data as well as questions regarding the challenges of care and management that subjects and relatives experienced during the first 8 weeks of the quarantine	Carers (*n* = 119) of persons with AD or related dementia living at home The mean age of the carers: was 58.61 ± 13.60 years Most carers were female. PWD: Mean age: 81.16±7.03 Diagnoses 67% AD and 26% mixed dementia. Stages were 34.5% mild cases, 32% intermediate stage, and 33% severe cases as per clinical dementia rating score	PWD: Increased anxiety (43% of the sample), insomnia (28% of the subjects), and depression (29%), worsening gait disturbance (41%), and increase use of psychotropics to control behavioural symptoms 12% of the family members felt that the burden of care was severe before the epidemic, and this number increased to 42% during the epidemic. There was a high rate of discontinuation of rehabilitation during the epidemic: 76% discontinued physical therapy, 91% occupational therapy, and 77% cognitive rehabilitation
Giebel et al. (UK)	No intervention Telephone semi-structured interviews Questions on experiences of accessing social support services, including paid home-care services, before and since the COVID-19 outbreak	Unpaid carers with experiences of accessing paid home care (*n* = 15). Mostly female (93.3%) and spouses (53.3%). Age 59.6±7.2 yrs.). 93% from white ethnic background 73.3% of carers lived with the PWD. Dementia subtypes: AD (46.3%), VD (13.3%), and YOD (6.7%)	Thematic analysis identified three overarching themes: Risk (virus transmission and lack of PPE - feeling unprepared and providing additional care) Making difficult choices and risk management (cancelling care vs keeping care, avoiding hospitals and health providers) Many unpaid carers decided to discontinue paid carers – this lead to increase hours of care

(continued)

Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Savla et al. (USA)	No intervention 30-min telephone interview comprising survey items and open-ended questions. Interviews were conducted between Apr 14 and May 1	123 family carers of PWD (64.23±11.06 yrs.). 85% white ethnic background. 67.9% living with the person with dementia	Most carers (62%) expressed concern about the pandemic and meticulously followed guidelines. Yet, 26% thought the stay-at-home order did not affect their lives in any major way. 59% rated the services they were receiving now as sufficient. 41% expressed weariness because paid carers had reduced days or hours or stopped coming 68% of carers received help with grocery shopping or social interactions in person or via phone and video calls, 32% were not receiving enough support from family. 57% of carers used active coping strategies (e.g. taking some 'me-time', going outside alone or gardening). 43% used passive approaches (e.g. twiddling on their phones) 47% of carers reported high role overload during lockdown Sufficient informal support significantly decreased the odds of reporting higher overload
Vaitheswaran et al. (India)	No intervention Semi-structured telephone interview carried out by consultant psychiatrists. Clinical dementia ratings (CDR) scores were taken from notes	PWD n=31 (17 female and 14 male) 41.9% AD, 19.4% VD. Mean age of PWD 70.68+9.26. Mean age of carers 54.06 years (51.6% female)	They propose a model to understand the needs of carers of PWD during the pandemic. The model presents two sets of issues: - Directly related to their caregiving role - Not related directly to their caregiving role

(continued)

Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Canevelli et al. (Canada)	No intervention Telephone survey conducted by medical staff from Apr 9th to 15 April 2020 as part of standard clinical routine. Questions referred to the first month of lockdown	PWD (*n*=96): Age [76–85] (mean 80.5) 55.2% female MCI (*n*=43), female 72.1% and age [65.5±77.5] (mean 73) Carers of PWD and MCI also completed a survey	Worsening of cognitive symptoms of PWD in 31.7% of the sample. A functional decline was noticed in 19 patients described as reduced levels of independence in activities of daily living 54.7% of patients experienced the worsening or the onset of behavioural disturbances such as agitation/aggression, apathy, and depression 49.5% of carers reported higher levels of stress and exhaustion compared with the previous month
El Haj et al. (France)	No intervention Data collected by care home workers: Hospital anxiety and depression scale They compared means on scales before versus during the Covid-19 crisis	PWD (*n*=58) with a clinical diagnosis of probable AD (37 women and 21 men; M age = 71.79±5.54; years of formal education = 9.26±2.33)	Participants reported higher depression and higher anxiety levels during than before the Covid-19 crisis
Giebel et al. (UK)	No intervention Telephone interviews Topic guide focussing on experiences before and after the COVID-19 pandemic in respect of care services, coping, symptoms, challenges, benefits, strategies and impacts	Unpaid carers (*n*=42–60± 8.8 yrs.) and PWD (*n*=8–63.6 ±6.5 yrs.). Most female (76% - carers 83.3% and PWD 37.5%) and most carers were spouses (55%) Types of dementia: AD (43%), VD (16%) and 12% YOD.	Many carers and PWD experienced a loss of control over the situation, with drastic changes having taken place when lockdown commenced Worry about the uncertainty of the re-opening of social support service provision in the future and how this would be achieved. Uncertainty about public health restrictions Very few people continued to be offered their social support. Some services adapted in providing remote support groups via Zoom and regular phone calls. However, this support was limited and participants did not feel it could make up for the face-to-face socialising and care pre Covid-19

(continued)

Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Cohen et al. (Argentina)	No intervention Retrospective pre-test post-test design (4 weeks into lockdown) Online questionnaire: Demographic data and questions testing the presence of anxiety, burnout and stress	Carers (*n*=80, 69.23% women). 28.8% had a relative in the initial stage of dementia, 41.3% in an intermediate stage, and 30.0% had a relative who had severe dementia. Average age 56.21 ± 14.07 and 18.46 ± 6.84 years of education PWD (80.51 ± 7.65 yrs.). Average years of education was 13.95 ± 4.94.62.5% were women. The family was the primary provider of care in 65% of cases	More than 90% of the patients discontinued therapies during the pandemic – this percentage did not differ significantly for persons in the three stages of dementia 28.6% of family carers chose to suspend services from paid carers - the rate of non-suspension being higher in the more advanced stages There was no difference in the level of burden before coronavirus pandemic for family carers of persons in the three stages of dementia. However, the level of burden of the family carer after 4 weeks in quarantine was higher, especially for advanced stages of dementia Overall, lockdown increased stress carer independently of the dementia stage, but those caring for severe cases had more stress compared to milder forms of the disease. Half of the PWD experienced increased anxiety. Most family carers discontinued all sorts of cognitive and physical therapies
Lara et al. (Spain)	No intervention Pre-post-test design Telephone data collection at baseline (1 month prior to lockdown) and after 5 weeks of lockdown. Outcome measure: Neuropsychiatric inventory and EuroQol-5D questionnaire	40 patients with a diagnosis of amnesic mild cognitive impairment or mild AD. 77.4±5.25 yrs., 60% female. Most (*n* = 24) were living with a partner/spouse (60%), while nine (22.5%) were living alone with an occasional carer	Significant worsening in neuropsychiatric symptoms EQ-5D: The patient's health condition had worsened after 5 weeks of confinement, 30% (12) of the patients and 40% (16) of the carers reported worse scores The most affected symptoms were apathy and anxiety for patients with MCI. Apathy, along with agitation and aberrant motor behaviour were the most commonly affected symptoms in patients with AD.

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Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Di Lorito et al. (UK)	Process evaluation of the promoting activity, independence and stability in early dementia (PrAISED) RCT. Mixed-methods approach Control group: Receiving brief falls assessment and advice. Intervention arm: individually tailored programme of up to 50 visits at home over a period of 52 weeks from a MDT.	Study protocol – recruitment of people with early dementia	Trial expected to end around spring 2021
Geddes et al. (Global)	Literature review	No information provided regarding number of studies included in the review	Video conference shown promise for cognitive assessments and offers advantages over telephone assessments. Still a lack of validation and norms There is no difference in the efficacy comparing in-person diagnosis with diagnosis made via video conference Potential pitfalls: Threat to patient privacy and confidentiality, limitations in clinical data acquisition, risks to quality and continuity of care, and the potentially negative impact on patient-clinician relationships
Goodman-Casanova et al. (Spain)	Study nested in the **TV-AssistDem RCT.** Intervention group: Television-based assistive integrated service between users, carers, and healthcare professionals Control group: Treatment as usual Telephone-based survey on health perception-health management (2 weeks into confinement)	Total n=93 PWD (MCI or mild dementia). 65% female, 42% living with spouse, 26% living alone. Mean age 73.34±6.07 years	The physical and mental health and well-being of participants was overall optimal. Living alone was found to be a risk factor for greater psychological negative impact and sleeping problems The fact that respondents with TV-AssistDem performed significantly more memory exercises than control respondents suggests the potential of television-based activity for cognitive stimulation

(continued)

Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Boutoleau-Bretonnière et al. (France)	No intervention Telephone interviews with carers. Outcome measure: Neuropsychiatric inventory-questionnaire Carers were also invited to rate the distress they experience due to each symptom	38 participants (23 women; 71.89±8.24 yrs.) with a clinical diagnosis of probable AD. Carers (68.43±12.16 yrs.). Most of the carers were the patients' spouses (*n* = 32), five were their daughters and one was a sister. All participants were living with their carers	The confinement exacerbated neuropsychiatric symptoms in patients with low cognitive function, whereas no such symptoms were induced in patients with more preserved cognition Among the 38 patients, only 10 presented neuropsychiatric changes during the confinement. The duration of confinement significantly correlated with both the severity of their neuropsychiatric symptoms, as well as with the distress experienced by their carers
Lai et al. (Hong Kong)	Control group: Weekly care service via telephone covering topics on well-being of community living Intervention group: Enhanced care services through online methods (e.g. Zoom) Interviews and questionnaires (pre and post lockdown). Outcome measures: Montreal cognitive assessment, the revised memory and Behaviour problem checklist and the quality of life in Alzheimer's disease assessment Data from carers: The short form 36 version 2, the Zarit burden interview scale and the revised caregiving self-efficacy scale	Total *n*=60: Control group (*n*=30): PWD (72.73±0.84 years and 12:18 female male ratio). Carers (71.83±0.80 years and 18:12 female: male ratio) Intervention group (*n*=30): PWD (72.87±0.84 years and 13:17). Carers (72.43±0.80 years and 17:13)	Reduction in cognitive functioning in the NCD subjects in the control group, and the additional delivery of health content via video conference was associated with a resilience against this reduction The impact of telehealth via video conference on the care-recipients' cognitive functioning appeared best described as resilience, notable improvement in QoL over time was demonstrated in the intervention group. It contrasted sharply with the deteriorating trend in the control group over the same period
Alzheimer's society (UK)	Literature search and review	—	In England and Wales, dementia was the most common pre-existing health condition of all Covid-19 deaths. The largest increase in excess non-Covid19 deaths was in PWD. A series of recommendations for government and policy are put forward

(continued)

Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Alzheimer's society (UK)	No intervention Policy analysis of legislation and guidance. Nine focus groups and a survey of healthcare professionals	75 people affected by dementia and Covid-19	Since Feb 2020,- steady decline in dementia diagnosis rates, which now fall below the national target. There is evidence of an increase in the proportion of PWD being prescribed anti-psychotic drugs
Alzheimer disease international (Global)	Scoping review. Includes data from the WHO global dementia Observatory between Dec 2017 and May 2020	—	The pandemic has greatly impacted on post diagnostic support services globally and there is real concern that it will impact on diagnostic pathways and disrupt research and clinical trials
Royal college of Psychiatrists (UK)	No intervention Three separate short surveys for PWD, their carers/families and for hospital leads for dementia. The surveys were open between 17 Jun and 17 Jul 2020	57 responses from hospital leads (53 in England; 4 in Wales) 32 responses from carers for PWD, from 21 English hospitals 13 responses from PWD, from a single hospital	Negative impact of the pandemic on the quality of inpatient care for PWD Examples of emerging good practice (e.g. the use of technology) Other findings: Issues around communication and complications around use of PPE, family visits, low staffing levels and impact of avoiding hospital admissions of PWD.
TIDE (UK)	No intervention Qualitative study - no details provided on design and data collection methods	No details provided	PWD and their family carers found themselves more isolated Increased the level of stress on carers and exacerbation of the existing issues in health and social care services Distress due to restrictions on visits in care homes – negative impact on the physical and mental health of many residents

(continued)

Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Suárez-González et al. LTCP network (Global)	Literature review	—	Worsening of functional independence and cognitive symptoms during the first month of lockdown (31% of people surveyed) Exacerbated agitation, apathy and depression (54%). Deterioration of health status (40%). Increased used of antipsychotics/related drugs (7%) The ban on visits in care homes: Believed to be causing a significant deterioration in the health and wellbeing of residents with dementia
Alzheimer's society (UK)	No intervention A short online survey to understand the impact that Covid-19 has had on PWD and their family carers	A total of 2721 responses: 2% PWD living alone 3% PWD living with someone 34% family carers living with the person with dementia 29% family carers but not living with the person with dementia 33% none of the above	Impact on PWD: Increased in difficulty concentrating (48%), memory loss (47%), and agitation (45%) PWD living alone were more likely to report an increase in their symptoms compared to PWD living with others 46% of PWD considered that the pandemic has had a negative impact on their mental health. 56% of PWD living alone stated that they feel lonelier, compared to 23% of PWD living with others 44% of carers reported that the pandemic had left them struggling with caring for themselves. 41% of those who receive a care and support package reported this having been reduced/stopped since lockdown began
Simonetti et al. (Global)	Systematic review methodology (Mar – Jun 2020)	20 papers were included	Apathy, anxiety and agitation are the most frequently reported symptoms. Apathy appears to be consistently impacted by persistent isolation in PWD during the Covid-19 pandemic

(continued)

Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Manca et al. (Global)	Systematic review methodology. (Papers published up to the 7 Jul 2020	15 articles were included	All studies found that different neuropsychiatric symptoms emerged and/or worsened in older adults with and without dementia. These changes were observed as the consequence of both Covid-19 infection and of the enforced prolonged conditions of social isolation. Delirium, agitation and apathy were the symptoms most commonly detected in PWD.
Alonso-Lana et al. (Global)	Literature review	12 studies were included	Few studies reporting cognitive symptoms related to Covid-19. Increased morbidity and mortality also due to the indirect effects of the pandemic on the healthcare system that PWD dementia rely upon
Altieri and Santangelo (Italy)	No intervention The online survey including a sociodemographic questionnaire, the hospital anxiety and depression scale to evaluate levels of anxiety and depressive symptomatology, the resilience scale for adults and the carer burden inventory	Eighty-four participants (71 women, 13 men) Carers: Mean age 48.7 years and 84.5% female. Mean years of education 13.8.54.8% were employed immediately before the lockdown, 45.2% unemployed. 75% cohabiting with PWD. PWD: 72.6% females, mean age 78.5±10.1 yrs. 56% AD, 31%VC.	During lockdown, carers with high resilience reported a significant increase of levels of anxiety In carers with low resilience, there was no significant increase of anxiety levels Lower levels of resilience and a higher functional dependence of the person with dementia predicted higher levels of carer burden during the lockdown

(continued)

Table 2. (continued)

Authors (country)	Intervention, design and method	Sample	Key findings
Carpinelli Mazzi et al. (Italy)	No intervention A telephone interview/online questionnaire (once lockdown started and during all this period)	239 participants (men = 124; women = 115) with a mean age of 54.4 years The mean age of carers: 54.4±12.1 yrs. Mean number of years of education was 14.31±2.86 years The mean age of PWD was 76.3±10.9 years and their mean number of years of education was 9.49±4.56 years Types of dementia: AD (66%), VD (13%), mixed dementia (17%). 48% of the participants were living in the same home with his/her patient with dementia while the other 52% were living nearby	Support and assistance were discontinued in 43% of cases. Among these, 42% lost the assistance of professional nurses and domestic aids For carers, as isolation time increased, higher levels of depression and anxiety were recorded. Educational level appears to be a protective factor. Women seem to suffer the consequences of the lockdown on anxiety, depression and stress more than the men
Ryoo et al. (Korea)	Narrative review (Dec 2019 up to Jul 2020)	92 studies were included	Impact of stringent social restrictions and COVID-19 pandemic-mediated policies on dementia patients and care providers

Table 3. Identified themes, subthemes and QoL domains.

Themes	Sub-themes	QoL domain (Lawton 1997)
Theme 1: Impact on people with dementia – unmet and increased care needs	Impact of service withdrawal and isolation	Behavioural competence Objective environment Psychological wellbeing
	Increased use of technology	Objective environment
Theme 2: Impact on carers – increased stress and burden	Increased burden on carers	Psychological wellbeing Perceived QoL
	Impact of services uncertainty on carers	Behavioural competence
	Ways of coping with Covid-19	
Theme 3: Impact according to demographics	Greater impact on people with dementia living alone	Behavioural competence
	Residency of people with dementia – lost social relations	Objective environment
	The role of illness severity on the impact of Covid-19 on people with dementia	Psychological wellbeing
	The impact of illness severity on carers	

been rushed, poorly planned or unsafe, hence causing an increase in length of stay of people with dementia.

Increased use of technology. Five studies provide findings on the use and acceptance of novel technologies (e.g. video conferencing, telehealth and TV) as a means to address the needs of people with dementia during periods of confinement (Di Lorito et al., 2020; Suárez-González, 2020; Goodman-Casanova et al., 2020; Lai et al., 2020; Royal College of Psychiatry, 2020). For example, Goodman-Casanova et al. (2020) aimed to explore the effects of a television-based assistive integrated technology (TV-AssistDem) on cognitive stimulation and health status of people with dementia. Although they found no significant differences in QoL outcomes, respondents using TV-AssistDem performed more exercises than those in the control group.

There is limited evidence in relation to the application of novel technologies within clinical settings (e.g. clinical assessment, referrals or reviews) undertaken via phone/video call. Geddes et al. (2020) carried out a review of telemedicine studies in Alzheimer's disease and cognitive impairment. The authors report that there was no difference in the efficacy comparing in-person diagnosis with diagnosis made via video conference and that this online approach had been shown to be acceptable for carers and people with dementia. They conclude that, in the context of the pandemic and similar future crisis, telemedicine has the potential benefits of enabling access to specialists among patients with reduced mobility and/or geographical constraints and improved patient convenience and comfort.

This review shows that evidence on the use of remote technological adaptations to professional care are still scarce and that these adaptations are underpinned by the need for rapid service transition and, consequently, require further development and evaluation. Remote support and digital technologies need to be 'fit for purpose' and supplemented (not replaced) by face-to-face social activities and support services that meet the needs of people with dementia and their carers (Giebel et al., 2020b; TIDE 2020; Vaitheswaran et al., 2020). Importantly, three studies report that not everybody has access or knows how to use 'technology' and that age-related perceptual, language and cognitive barriers of people living with dementia must be considered (Geddes et al., 2020; Giebel et al., 2020b; Savla et al., 2020). Patient privacy and confidentiality, risks to quality and continuity of care, and the potentially negative impact of remote care on patient–clinician relationships should all be considered ahead of implementing technology mediated services (Geddes et al., 2020).

Theme 2: Impact on carers – increased stress and burden

Evidence suggests that. during the Covid-19 pandemic carers have experienced higher levels of stress and exhaustion. They have found themselves more isolated and being exposed to critical levels of stress because of having to manage, with little external support, complex circumstances (Alzheimer's Society, 2020; Cagnin et al., 2020; Canevelli et al. 2020; Cohen et al., 2020a; Savla et al., 2020; TIDE, 2020; Vaitheswaran et al., 2020). Seven studies reported that family members felt that the burden of care and depression-related symptoms had severely increased because of the pandemic (Altieri & Santangelo, 2021; Canevelli et al., 2020; Cohen et al. 2020a; Cohen et al. 2020b; Giebel et al. 2020b; Savla et al., 2020; TIDE, 2020). For example, Cohen et al. (2020a) found that 12% of family members felt 'the burden' was severe before the pandemic, noting an increase to 42% during the pandemic. Studies such as the one carried out by the Alzheimer's Society (2020) report that the pandemic has had a strong negative emotional impact on mental health outcomes for carers (44%) and that emotional outcomes strained their relationship to their relative (42%). Altogether, carers reported struggling to care for themselves and for their relative (22%).

Increased burden on carers. A number of reasons are presented as factors driving the impact on QoL. Firstly, carers have expressed concern about deterioration in the symptoms of the person they care for due to lack of social interaction and cognitive stimulation. This deterioration has, in turn, led to increased complexity of care required by the care receiver and therefore, an increase in care burden (TIDE, 2020). Secondly, carers have found themselves dealing with the difficulties of balancing risk (e.g. whether to go out for a walk; how to get food and medication if you have been told by your GP not to leave your home) (Cagnin et al., 2020; Goodman-Casanova et al., 2020). Thirdly, the lack of services and support for the people with dementia and for themselves has been one of the main sources of concern to carers. Restrictions such as lockdowns have had negative consequences on the possibility of carers being psychologically and emotionally supported by others, leading to social isolation and disconnection from support networks (Altieri & Santangelo 2021). TIDE (2020) report how carers 'had never felt less visible' and felt there had been a loss of identity as the media started referring to all health and social care workers as 'carers'.

Impact of services uncertainty on carers. The uncertainty on what services will look like after the pandemic and on the timing for their re-opening has also been a source of increased worry and distress as has the lack of clarity on the extent and duration of public health restrictions (Giebel et al., 2020b; Giebel et al., 2020c; TIDE, 2020). Many carers found themselves repeatedly trying to explain the distancing and confinement rules to people with dementia, who often struggled to understand (Savla et al., 2020).

Ways of coping with Covid-19. Despite their many challenges, some carers found ways to cope with isolation and other restrictions (Goodman-Casanova et al., 2020; Savla et al., 2020). Carers reported 'passive' strategies such as computer games or phone conversations with others and 'active' strategies such as going for walks on their own or gardening. All were used to create space for themselves.

Altieri & Santangelo (2021) found that resilience played a role in determining how carers reacted to this crisis. In this study, they compared the impact on levels of depression and anxiety before and after lockdown according to carer's resilience and found a large effect size. Carers with high resilience reported lower levels of depression and anxiety before the lockdown when compared with carers with low resilience. This study also found that lower levels of resilience and a higher functional dependence of people with dementia predicted higher levels of carer burden during the lockdown. The impact of the pandemic is reported to have been ameliorated by communities demonstrating resourcefulness in striving to continue to support the needs of carers and people with dementia (e.g. delivery of meals and prescriptions, phone calls) (Savla et al., 2020). This support contributed favourably to carers' ability to continue providing care.

Theme 3: Impact according to demographics

Greater impact on people with dementia living alone. Several studies identified living alone as a significant contributing factor that increases the risk of negative QoL outcomes related to the Covid-19 restrictions (Alzheimer's Society, 2020; Goodman-Casanova et al., 2020). For example, Goodman-Casanova et al. (2020) report that participants living alone reported being sad and bored, and experienced greater anxiety and more sleeping problems than those sharing a household. A study carried out by the Alzheimer's Society (2020) found that during the first period of lockdown people with dementia living alone were more likely to report an increase in symptoms such as memory loss and difficulty in reading or writing during lockdown compared to people with dementia living with others. According to their study, people with dementia living alone were least confident going outside during the easing of lockdown rules and were more likely to describe their experience of the pandemic negatively. In fact, 56% of people with dementia living alone stated feeling lonely, compared to 23% for people with dementia living with others.

Residency of people with dementia – lost social relations. There is limited evidence from care home settings, with Suárez-González (2020) suggesting that the ban on care home visits from spouses and partners is causing a significant deterioration in the health of residents with dementia. A study by the Royal College of Psychiatry (2020) reports on the impact of visiting restrictions on QoL outcomes such as increased feelings of isolation and loneliness as well as reduction in the levels of stimulation.

The role of illness severity on the impact of Covid-19 on people with dementia. The severity of the dementia influences the impact of the pandemic on people with dementia. Vaitheswaran et al. (2020) report on how the confinement has exacerbated neuropsychiatric symptoms on patients with low cognitive function, whereas no such symptoms were induced in patients with more preserved cognition. They further report that AD patients with low cognitive function may be more prone to experience confusion and disorientation, exacerbated by reduced social contact and/or reduced physical activity.

Cohen et al. (2020a) report that when comparing the frequency of behavioural symptoms within each dementia group category, anxiety, depression and insomnia were more prevalent in subjects with mild dementia compared to subjects with severe dementia. Cohen et al. (2020a) further explain that one possible explanation for these findings is that comparatively, mild dementia subjects might have suffered a more radical modification in their lifestyle habits during quarantine (e.g. significant reduction in social interactions and physical activity).

The impact of illness severity on carers. Five studies found that psychological outcomes were dependent on the severity of the dementia (Carpinelli-Mazzi et al., 2020; Cohen et al., 2020a; Cohen et al., 2020b; Giebel et al., 2020a; Giebel et al., 2020b). For example, Carpinelli-Mazzi et al. (2020) conclude that higher increase in stress levels in relatives of people with severe dementia are linked to the fear of losing the support from paid carers. This was the case for 42% of participants, who lost the assistance of professional nurses and domestic aids. On the other hand, the stress levels of relatives of people with mild dementia were found to be mainly linked to concern for the risk of Covid-19 transmission and of passing on the disease (Cohen et al., 2020a; Giebel et al., 2020b). Similarly, other studies reported on how carers were put in the position of having to make difficult choices such as discontinuing external caring/support services (and also avoid hospitals or health clinics) because of fear of infection, even in cases of severe dementia, when services are most needed (Cagnin et al., 2020; Giebel et al., 2020a). During the 2020 initial lockdown, these difficult choices were shown to have a direct negative impact on stress-related symptoms in carers of people with severe dementia. A study carried out in Argentina by Cohen et al. (2020b) found that 60% of carers stopped visiting relatives in care homes irrespective of the severity of their illness because of fear of infection. In contrast, only 28.6% of their sample suspended home paid care. They concluded that, overall, the level of burden on the family carer after 4 weeks of quarantine was higher for those with relatives with advanced dementia.

Discussion

This scoping review has explored the impact of Covid-19 on the care and QoL of people with dementia and their family carers. Most of the studies investigated the impact of the enforced isolation and withdrawal of health and social care services during the pandemic and cut across the four domains of Lawton's (1997) conceptual model of QoL.

People with dementia lost invaluable support offered by health services and community organizations, and family carers lost vital respite support resulting in feelings of abandonment and despair (Dening & Lloyd-Williams, 2020; Giebel et al., 2020a; Wang et al., 2020). Hence psychological wellbeing and ability to function was compromised for people with dementia, with worsening symptoms, behavioural disturbances and adverse psychological consequences. Similarly, for carers, Covid-19 restrictions and accompanying lack of support led to even higher levels of stress and exhaustion, both at a critical point before the pandemic.

Our review echoes what others have reported, that the full impact of Covid-19 is only now emerging. By the time the pandemic is under control, millions of patients living with health problems, including dementia, will have been affected. Millions will have missed vital opportunities to receive initial assessments and diagnosis and necessary treatment (British Medical Association, 2020). In fact, since February 2020, there has been a steady decline in dementia diagnosis rates in England, dropping from 67.6% in February 2020 to 63.2% in July (National Health Service (NHS), 2020). Misdiagnosis of dementia has always been a matter of concern; however, the risk at hand is not having any diagnosis at all. Similarly, the impact of Covid-19 among those who rely on social care, and those working to care for them, is becoming clear. Ironically, by putting a spotlight on the social care sector, Covid-19 has played a vital role in exposing the urgent need for its reform. Although a world pandemic was always likely to cause major disruption, the drastic shut down of routine care is a consequence of over a decade of underinvestment and cuts to services (including public health and social care) and long-lasting structural issues (The Health Foundation, 2020). Without changes to the funding of long-term care and enhanced support for carers, care quality will continue to deteriorate (British Medical Association, 2020; The Health Foundation, 2020;

Manthorpe & Iliffe, 2021). Recovery should include the reform of support systems for carers, informed by lessons learnt during the pandemic to mitigate against future crisis situations (Altieri & Santangelo 2021); Boutoleau-Bretonnière et al., 2020; Canevelli et al., 2020; Cohen et al., 2020a; Cohen et al., 2020b; El Haj et al., 2020; Giebel et al., 2020a; Giebel et al., 2020b; Giebel et al., 2020c; Simonetti et al., 2020; Suárez-González, 2020)

Adapting services – a move towards remote service delivery

There is a clear evidence gap on how health and social care services were adapted during the pandemic to meet the needs of people with dementia and their carers. Our findings indicate that further exploration of the effectiveness of internet and technology-based supportive interventions is warranted. Their low cost and potential to reach larger numbers of people compared to face-to-face services make them an attractive alternative. A recent review of RCTs (Leng et al., 2020) found that internet-based supportive interventions are generally effective at ameliorating depressive symptoms, perceived stress, anxiety and self-efficacy in family carers of people with dementia and have potential benefits on care recipients. Technology-mediated services may then be a useful complement to existing services. Similar to studies in the field of cancer (Heynsbergh et al., 2018), our review supports the need for future research to explore the feasibility, usability and acceptability of adapting traditional services to a technology mediated service. This need is particularly severe in the case of studies focussing on people with dementia since most evidence to date has focussed on exploring the feasibility and impact of technology-based interventions on family carers (Killin et al., 2018). Hence, future research should incorporate an understanding of the barriers to access and the personal experiences of people with dementia and their family carers with technology use, considering cognitive decline, age (Hunsaker & Hargittai, 2018) and levels of income and education (Silver, 2014; Gell et al., 2015; Dorsey et al., 2017;). Research should also ensure that online services match the clinical, social, psychological and practical requirements of people with dementia and their carers. Finally, the development of implementation guides that address the level of skill and training required of those delivering these online services would be beneficial.

Review limitations

The search for this review focused on research databases and grey literature sources judged to be the most appropriate for the aim of this review. Some, however, relevant articles and reports may have been missed. There has been a rapid turnaround of research publications as a result of the pandemic, but at the time of this review the amount of published evidence was still relatively limited. It is likely the restrictions placed on society in terms of contact with others, and the pressure of rapid changes to online modes of teaching and undertaking research may have led to delays in the development and publication of Covid-19 related studies. Similarly, the impact of the restrictions may have led to people with dementia and their carers being initially unwilling to take part in studies. As society has begun to adapt to the situation and researchers have adapted to different ways of working, further research not captured in this review is likely to become available. Also, only studies written or translated into English were included in this review because of limited financial resources to translate; relevant studies written in other languages may have been left out.

There was also an overall lack of representation of studies carried out in lower income countries and of diversity in the study populations. Participants were more likely to be white and female, there was no explicit LGBTQ representation, and scarce attention was paid to those with lower socio-economic backgrounds. People living in rural and remote areas where service provision is often limited were not clearly represented. In most of the studies, the data were collected online or via telephone from people already receiving services. Consequently, the impacts reported in this article are likely to be under-estimated.

Conclusion

Evidence from the review suggests overwhelmingly that people with dementia and their carers experience poorer QoL as a result of the Covid-19 pandemic and its associated policy responses. This review has specifically focused on outcomes relating to service withdrawal and its impact on quality of care. The need for clearly articulated policy that seeks to acknowledge and address the vulnerability of people with dementia and their carers to the virus must be extended beyond protectionism and removal of risk and move towards acknowledging and supporting outcomes relating to QoL as well as protection from harm. Our review found that the policies of restricted movement had detrimental impact upon the QoL of people with dementia and their family carers and could be understood as unintended consequences which require further investigation. Crucially, the voices of people with dementia and their carers will be critical in rebuilding and learning from the pandemic, if there is to be a shared effort to develop systems of support for recovery.

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Supplemental Material

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Author Biographies

Patricia Masterson-Algar, Dr, is a health researcher interested in improving the lives of those affected by a neurological condition. Her research explores the impact that these conditions can have not only on the lives of those affected by them but also on the family as a whole. In 2017 Patricia and her colleagues completed a research project where they designed and evaluated a lay peer support intervention for stroke rehabilitation. Leading from that work Patricia was successful in attracting Welsh Government RCBC Wales post-doctoral fellowship funding. In her fellowship Patricia applied innovative approaches to map the experiences and identify the sources of support of young adults living in families affected by a neurological condition. Patricia has recently joined the Centre for Ageing and Dementia Research (CADR) where she continues to develop research focussed on designing and evaluating interventions tailored to support young carers of people living with dementia.

Maria Cheshire Allen, Maria's main research interests are in developing research that supports policy and practice, that promotes age equality and is informed by the views and experiences of older people, particularly those older people who are seldom heard in research and policy making processes. She completed her undergraduate degree at Swansea University in Philosophy and Sociology and subsequently worked for the Welsh Local Government Association, and various national NGOs in Wales including Oxfam Cymru, Action for Hearing Loss Cymru, and The Welsh Refugee Council. Maria worked as the Equality and Inclusion Manager at Age Cymru for 5 years, and during this time completed her Master's degree in Equality and Diversity at Cardiff University.

Martin Hyde, Dr, is an Associate Professor in Gerontology at Swansea University. His main research interests are ageing and later life and he has published on a wide range of topics from quality of life, work and retirement, health inequalities and globalization. He has published widely in peer reviewed journals, numerous reports and book chapters as well as 3 books. He has been involved in a number of large scale studies including the English Longitudinal Study of Ageing (ELSA), the Survey for Health, Retirement and Ageing in Europe (SHARE) and the Swedish Longitudinal Occupational Study of Health (SLOSH).

Norah Keating, Professor, is a social gerontologist whose theoretical and empirical research has created evidence, challenged discourses and influenced policy in global, social and physical contexts of ageing. She has placed this work on the international stage through the Global Social Issues on Ageing which fosters collaboration and critical thinking about ageing at the interfaces of regional issues and global trends. Professor Keating has created evidence of the extent and consequences of family care; and has contributed to conceptual innovation in lifecourses of family care. This body of work has made family care and its consequences visible and has challenged discourses of family care as normative, ideal and cost free. Her extensive interactions and consultations with governments have brought to policy makers attention the fragility of the family care sector and have contributed to legislation and programmes to support family carers.

Gill Windle, Professor, Gill Windle is a Chartered Psychologist and Gerontologist who specialises in interdisciplinary research. Gill's research aims to improve the health, wellbeing and resilience of older people, people with dementia and their supporters, and improve care and service provision. Gill leads and contributes to mixed-methods studies and intervention trials, and has led and contributed to externally win research funding totalling £19,858,090.00, representing £10,464, 912.00 from UK Research Councils (ERSC; MRC; AHRC), £7,142,988.00 from Welsh Government research infrastructure awards and £ 2,102,190.00 from other sources including the Wellcome Trust. Her most recent research achievement is the award of £1,480,000.00 from the National Institute of Health Research to lead a randomised controlled trial of an e-health intervention 'iSupport' to help dementia carers develop skills and take care of themselves.