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REVIEW ARTICLE

The impacts of COVID-19 restrictions on care-givers of people with cognitive impairment and their support needs: a mixed-methods systematic review

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Abstract

The COVID-19 pandemic and ensuing restrictions/lockdowns have caused significant physical and psychological consequences for people with cognitive impairment who are heavily dependent on their care-givers. However, little is known about the impact on care-givers, the factors that exacerbate their situation and what supports they need. The aims of this paper are threefold: (a) to examine the impact of COVID-19 physical restrictions on both formal and informal care-givers of people with cognitive impairment; (b) to identify attributing factors influencing this impact; and (c) to recognise their support needs. Further, this paper informs future research, policy and practice. Guided by the Joanna Briggs Institute framework, a systematic review was conducted using a mixed-methods convergent integrated approach. Eight databases were searched using keywords related to COVID-19 restriction, dementia care-givers, impacts and care settings, followed by a manual search. The study was limited to primary research published in English between January 2020 and December 2021. Of the 840 records identified, 30 met the inclusion criteria. Service withdrawal and social distancing has effectively led to the reprivatisation of care to the family, particularly women. Care-givers experienced negative impacts including reduced psychological wellbeing and physical health, increased care burden and financial difficulties. A number of clinical attributes and socio-demographic factors influenced the COVID-19 impact on care-givers. Consequently, counselling services, assistance with care and financial support were identified as support needs. Implementation of new support and the strengthening of existing services are recommended to enhance resilience, build capacity to support care-givers in any given situation and mitigate the effects of future outbreaks.

Keywords: COVID-19; care-givers; impacts; support needs; people with cognitive impairment

Introduction

People diagnosed with cognitive impairment are especially vulnerable to the COVID-19 pandemic and its negative impacts (Azevedo *et al.*, 2021). A number of studies highlight the serious impact of the COVID-19 pandemic restrictions on people with cognitive impairment, including decline in cognition (Devita *et al.*, 2021), worsening of behavioural and psychological symptoms (Baschi *et al.*, 2020), decline in daily living activities (Barguilla *et al.*, 2020) and lower quality of life (Suárez-González *et al.*, 2021). The vulnerability of people with cognitive impairment makes them extremely dependent on formal and informal care-givers (Hanna *et al.*, 2021). The widespread withdrawal of services and social distancing precipitated by the pandemic effectively led to the reprivatisation of care to the family (Daly, 2021), including care-givers of people with cognitive impairment. Often referred to as 'invisible second patients', these care-givers frequently report higher rates of care burden, social isolation and physical health issues than other care-givers (Brodaty and Donkin, 2009). Considering the essential role that care-givers play in supporting people with cognitive impairment, it is critical that effective support interventions and policies are developed and implemented to better meet the needs of family and care-givers of people with cognitive impairment, and to better prepare for future pandemic outbreaks.

COVID-19 restrictions and care-givers of people with cognitive impairment

Research pre-dating the current pandemic has demonstrated that effective interventions to support people living with cognitive impairment are very often those that are directed primarily, or in equal parts, towards their care-givers who provide essential support for their physical and psychosocial wellbeing and who facilitate their interactions with the wider world (Casafont *et al.*, 2020; Cheng *et al.*, 2020). During the pandemic, social isolation and reduced or altered access to formal care supports resulted in care-givers experiencing worsening physical health and mental health (Brown *et al.*, 2020; Altieri and Santangelo, 2021; Borelli *et al.*, 2021; Cohen *et al.*, 2021). Care-giver fatigue and burnout, a function of social isolation and limited access to services and support, were issues of primary concern (Bacsu *et al.*, 2021). COVID-19 restrictions have resulted in a notable increase in care-giver workload by reducing access to home care, respite care, day care programmes, health services, and support and volunteer programmes (Giebel *et al.*, 2021*a*; Roach *et al.*, 2021). The scoping review by Bacsu *et al.* (2021) of the experiences of people living with dementia indicated that COVID-19 restrictions created a significant burden for family and care-givers of people living with dementia. Findings from this paper highlight the need for further research that focuses on the impact of COVID-19 on care-givers of people with cognitive impairment, paying more attention to understanding their support needs. Although public health measures, including mandatory confinements and service restrictions, are now being relaxed worldwide, this research must interrogate how the pandemic has changed and challenged the way we care for care-givers to support better planning for future infectious disease outbreaks.

While care-givers of older people living with cognitive impairment were impacted significantly by the COVID-19 pandemic, synthesised literature on their burden and programmes supporting them remain limited. The rapid systematic review by Hughes *et al.* (2021) examined the impact of COVID-19 on the health and wellbeing of informal care-givers of people with dementia and found that COVID-19 had a negative impact on their psychological wellbeing, causing an increase in anxiety and depression. However, the review was limited in its focus on informal care-givers only and was restricted to health databases that potentially disregard studies that report on impacts beyond a strictly health focus. In the present study, we aim to synthesise evidence of the impacts of COVID-19 on both formal and informal care-givers of people with any cognitive impairments across the broader literature, including published and unpublished research and reports.

Methods

Study design

This systematic review was guided by the Joanna Briggs Institute's (JBI) *Manual for Evidence Synthesis* (Lizarondo *et al.*, 2019). The PICO (Population, Interest, Context and Outcomes) format was used to refine the inclusion and exclusion criteria and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) framework was used for reporting (Moher *et al.*, 2009). The review consisted of four steps: record identification, screening, eligibility and final inclusion (Figure 1). Each step of the review was independently carried out by two reviewers (TNMN and BJ). Conflicts were resolved by rigorous discussion and through a consensus process with referral to a third reviewer (LB) when required. All reviewers were involved in synthesising results. The population of interest was adult care-givers of people with cognitive impairment, including paid, unpaid and family care-givers. The phenomenon of interest was restrictions associated with public health measures triggered by the COVID-19 pandemic in any setting including residential aged care, long-term care, respite care, home care, and community and day care centres in a global context. Outcomes of interest were any consequence reported including social, psychological, physical or financial.

Search strategy

Our aim was to conduct a comprehensive search to identify relevant published and unpublished research articles. For research articles, six electronic databases were searched including: Cumulative Index of Nursing and Allied Health (CINAHL with full text), MEDLINE, PsycINFO, Embase, Scopus and PubMed. Another two databases, OpenGrey and MedNar, were searched for unpublished studies. Search engines Google Scholar and Google, as well as the reference list of all studies selected for critical appraisal, were manually searched for additional relevant studies. A preliminary search using basic search keywords including 'Covid-19', 'impact', 'support need*', 'carer*' and 'cognitive impairment*' was conducted in MEDLINE and CINAHL to identity relevant literature. Titles and abstracts of identified studies were screened to develop a full search strategy for the review. Initial search in MEDLINE used key search terms including: AB carers, AB caregivers, AB family members, AB relatives, AB volunteers, dementia, cognitive impair*,

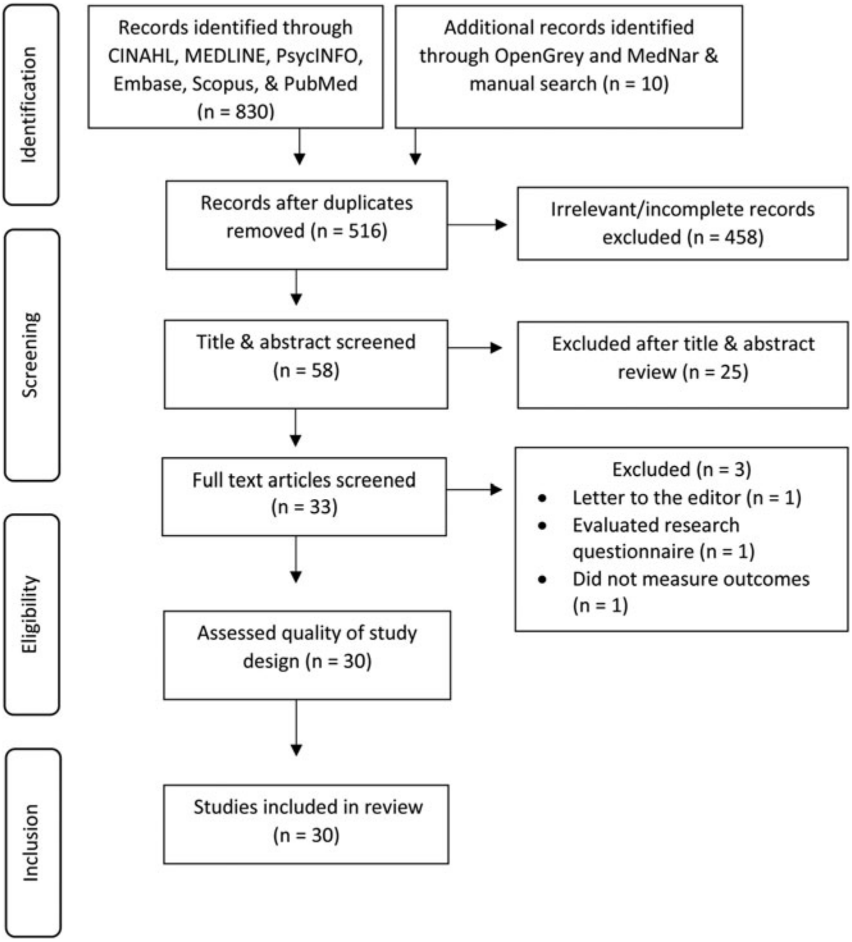

Figure 1. Article search and selection process using the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) framework (Moher *et al*., 2009).

Alzheimer*, AB impact, AB influence, AB effect*, AB perceived support, AB perceived need*, AB support need*, MH covid-19, MH coronavirus. Inclusion and exclusion criteria are provided in Table 1.

Study selection and quality appraisal

Identified studies were imported into and managed by EndNote x.X9 software (Clarivate, Philadelphia, PA, https://endnote.com/), and titles and abstracts were screened. Studies identified as potentially eligible for inclusion were then imported into the JBI System for the Unified Management Assessment and Review of Information package (JBI SUMARI) and full-text articles were reviewed. Articles that met the inclusion criteria were critically appraised for quality of study methodology and strength of analysis using the JBI Critical Appraisal Checklist appropriate

Table 1. Inclusion and exclusion criteria

Inclusion	Exclusion
• English language. • Published between January 2020 and December 2021. • Primary research using quantitative or qualitative research methods, including case study, experimental, quasi-experimental, cross-sectional and cohort studies. • Care-givers looking after people with cognitive impairment including dementia. • Any paid and unpaid care-givers. • Focused on COVID-19 impact.	• Languages other than English. • Published before 2020. • Not published in peer-reviewed journal. • Reviews, news/magazine articles, expert opinion, conference proceedings and any other grey literature. • Care-givers looking after people without cognitive impairment. • Care-givers aged below 18 years. • Studies focused on impacts other than those caused by COVID-19. • Studies that did not evaluate the impact on care-givers.

for quantitative and qualitative research studies by two independent researchers (TNMN and BJ) (Tables S1 and S2 in the online supplementary material). Regular meetings were held between them to discuss and resolve any disagreement. Thirty studies that met the inclusion criteria were appraised for quality and all were included.

Quality of the included studies

Although the 30 included studies met inclusion requirements, there were several limitations that are worth noting, mainly relating to research design and research process. In qualitative studies, information that reported the philosophical stances and influence of researchers on the research process remained vague and limited. Some quantitative studies included only a small number of participants, *e.g.* three quantitative studies included fewer than 50 care-giver participants (Borges-Machado *et al.*, 2020; Hwang *et al.*, 2021; Carbone *et al.*, 2021*b*). Furthermore, only five studies included some form of pre-pandemic measurement (Borges-Machado *et al.*, 2020; Giebel *et al.*, 2021*b*; Altieri and Santangelo, 2021; Hwang *et al.*, 2021; Carbone *et al.*, 2021*b*). This lack of baseline data makes it challenging to provide a rigorous or comprehensive understanding of the impact of the pandemic. This said, the sudden and unanticipated nature of the COVID-19 pandemic meant that most studies were unable to collect pre-pandemic measures.

Data extraction, analysis and synthesis

Data relating to details about the year and geographic place of study conducted, study design, the demographics of study population, context, data collection methods, outcomes measured, reported effects, a summary of the main findings, author conclusions and study limitations were extracted using the JBI data extraction tool. Extracted data were analysed following a convergent integrated approach that involved data transformation to allow us to combine quantitative and qualitative data for narrative synthesis (Hong *et al.*, 2017). In this approach, qualitative data were extracted verbatim and quantitative data were converted into textual descriptions or qualitative form described as 'qualitised'. The qualitative and qualitised data were then synthesised and analysed to identify key themes (Stern *et al.*, 2020).

Results

Study characteristics

The combined searches yielded 840 records. After removal of 324 duplicate records, and title and abstract screening, a total of 33 articles were retrieved for full-text review (Figure 1). Of these, three were excluded: one for not comprising primary research and two for not measuring outcomes for care-givers.

Characteristics of each study are described in Table 2. The majority of the studies (N = 20) involved quantitative research methods using cross-sectional survey questionnaires, nine utilised qualitative research methods and one was a mixed-methods study. The studies were undertaken across 16 countries including Italy (N = 5), the United Kingdom (UK) (N = 4), the United States of America (N = 3), Greece (N = 2), Brazil (N = 2), China (N = 2), India (N = 2), France (N = 2), Spain (N = 2), Poland (N = 2), Portugal (N = 1), Germany (N = 1), Finland (N = 1) and Canada (N = 1). Most studies were from the disciplines of medical and health sciences (N = 16), followed by neuroscience (N = 9), psychology (N = 3), psychiatry (N = 1) and medical sociology (N = 1).

There were a total 13,243 care-giver participants involved in the 30 included studies. Studies undertaken in India and China tended to have a larger sample size. In most studies (N = 27) participants cared for people at home. One study focused on family care-givers of people living in residential care facilities (Paananen *et al*., 2021), and two studies included both care-givers of people living at home and in residential care facilities (Giebel *et al*., 2021*a*; Macchi *et al*., 2021).

Demographic information about participants were variously reported across all studies with some not reporting this information at all. The care-givers in the included studies were overwhelmingly unpaid informal care-givers who were family members and mostly female, indicating a dearth of research on the impact of the pandemic on paid care-givers of people with cognitive impairment. The most common relationship between the care-givers and care recipients was either spouse or adult child. Only two studies (Yuan *et al*., 2021; Carbone *et al*., 2021*b*) included a small number of paid care-givers in addition to family care-givers, although these studies did not report separate findings of informal and formal care-givers' outcomes. Care-givers in studies conducted in low-income countries had lower educational and socio-economic backgrounds compared to those in studies conducted in high-income countries. The care recipients in the studies were mainly people with dementia. Outcome measurements varied in the 21 quantitative studies, including care burden, emotional distress, level of anxiety and depression, daily living activities such as sleep patterns and eating patterns, care-related quality of life and social isolation.

Findings of the review

The overarching finding of the review was that care-givers (the majority being unpaid family care-givers) described experiencing significant negative impact in caring for people with cognitive impairment during the COVID-19 pandemic. Our analysis indicates that care-givers experienced overlapping forms of increased negative impact on their (a) psychological wellbeing, (b) care burden, (c) physical health, and (d) financial difficulties (Table 3). Socio-demographic and clinical

Table 2. Study characteristics

Author (year)	Country	Study design	Aim	Care-giver study population	Care-giver outcomes
Alexopoulos *et al.* (2021)	Greece	Quantitative: cross-sectional using telephone interview	To examine relations between care-giver mental reaction and distress related to neuropsychiatric symptoms, memory impairment progression and functional impairment of people with neurocognitive disorder during COVID-19 confinement	67 informal care-givers of patients with mild or major neurocognitive disorder living at home	• Care-givers' distress severity was associated with the severity of cognitive impairment and the level of neuropsychiatric symptoms of the care recipients, as well as care-giver hyperarousal, avoidance symptoms and worries directly linked to the COVID-19 crisis.
Altieri and Santangelo (2021)	Italy	Quantitative: online survey	To measure the change of psychological symptoms during quarantine or self-isolation for COVID-19 and to investigate if the resilience is associated with psychological changes	84 care-givers of people with dementia	• Care-givers experienced significant psychological consequences while caring for people with dementia at home during the COVID-19 confinement, including increased depression and care-giver burden. • High resilience was associated with increased anxiety during the lockdown but lower levels of care-giver burden.
Azevedo *et al.* (2021)	Argentina, Brazil and Chile	Quantitative: cross-sectional using telephone questionnaires	To investigate the impacts of social isolation due to the COVID-19 pandemic on individuals with dementia and their family care-givers	321 family care-givers of people with dementia	• Care-givers experienced significant negative physical health impact due to social isolation during COVID-19 confinement including feeling more tired, more overwhelmed and experiencing problems with sleeping. • Care-givers experienced psychological and behavioural impacts due to social isolation including feeling sadder, more nervous and more irritable. • The level of these impacts, as well as the level of care burden, was associated with the level of dementia severity.

(*Continued*)

Table 2. (*Continued.*)

Author (year)	Country	Study design	Aim	Care-giver study population	Care-giver outcomes
Borelli *et al.* (2021)	Brazil	Quantitative: cross-sectional using telephone interview	To evaluate the neurological decline of patients with dementia and the care-givers' burden during the COVID-19 pandemic	58 care-givers of people with dementia living at home	• Care-givers experienced notable changes in their daily living routines including cancelled medical appointments, increased use of sleeping medication, changes to eating habits, weight changes and increased caring time. • Many care-givers experienced negative psychological symptoms during the COVID-19 confinement, including symptoms of anxiety and depression. Some care-givers reported increased care burden. • Increased care-giver distress was associated with worsening cognition in care recipients.
Borges-Machado *et al.* (2020)	Portugal	Quantitative: telephone interview	To analyse home confinement impact on individuals with neurocognitive disorders and examine how it has affected care-giving burden	36 care-givers of people with neurocognitive disorders living at home	• Care-givers increased the amount of time providing care during the COVID-19 confinement. • Care-givers reported increased care burden. • Care-givers experienced a decline in their general wellbeing.
Boutoleau-Bretonnière *et al.* (2020)	France	Quantitative: cross-sectional using survey	To assess neuropsychiatric functioning in the patients and the burden of their care-givers	74 informal care-givers of people with Alzheimer's disease or frontotemporal dementia living at home	• Care-givers experienced an increase in care burden. • Increase in care burden was associated with changes in behavioural symptoms of care recipients.

Budnick *et al.* (2021)	Germany	Quantitative: cross-sectional using online survey	To investigate the relation of COVID-19-related burden and support factors during the coronavirus pandemic with the care involvement of informal care-givers	315 informal care-givers of people with dementia living at home	• Many care-givers reported an increase in level of burden during COVID-19, and level of care burden was associated with the loss of professional care assistance service. • Care-givers experienced negative feelings, excessive demands and loss of support during COVID-19. • Care-givers of people with dementia reported challenges in implementation of COVID-19 health measures and the provision, comprehension and practicability of COVID-19.
Carbone *et al.* (2021*b*)	Italy	Quantitative: retrospective cohort study	To explore changes in and the association between the symptoms of dementia and care-giver's distress before and during COVID-19 confinement; associations in loneliness and resilience were also investigated	34 informal care-givers, and one paid living-in care-giver of people with dementia living at home	• Most care-givers experienced no changes in the level of distress before and during the COVID-19 confinement. • Female care-givers reported a lower level of distress and emotional loneliness and a higher level of resilience than male care-givers.
Carcavilla *et al.* (2021)	Spain	Quantitative: cross-sectional using online questionnaire	To explore the experience of care-givers of people with dementia during mandatory confinement due to the COVID-19 pandemic	106 family care-givers of people with dementia living at home	• Care-givers experienced a variety of psychological problems during the COVID-19 confinement including anxiety, mood disorder, sleeping difficulty and eating disorder. • Care-givers developed their own adaptive strategies to deal with care distress during COVID-19 lockdowns such as going to a balcony, cooking therapy, home cleaning, listening to music, playing games and meditation. • Care-givers need support in caring for people with dementia including support with assisting to care for daily activities and medication administration.

(*Continued*)

Table 2. (*Continued.*)

Author (year)	Country	Study design	Aim	Care-giver study population	Care-giver outcomes
Carpinelli Mazzi *et al.* (2020)	Italy	Quantitative: cross-sectional using telephone or online questionnaire	To evaluate the effects of the COVID-19 emergency lockdown on the psychological outcome in care-givers of patients with dementia and on the loss of welfare services	239 family care-givers of people with dementia	• Many care-givers reported loss of support and assistance from both professional and informal support resources. • Many care-givers experienced negative psychological impacts from the COVID-19 confinement including increased anxiety, depression and stress. • Many care-givers reported an increased in care burden. • The level of anxiety and depression was associated with level of education, gender (women reported higher levels of anxiety and depression) and number of days spent in isolation.
Giebel *et al.* (2021*b*)	UK	Quantitative: cross-sectional using telephone or online survey	To explore the impact of COVID-19 public health measures on access to social support services and the effects of closures of services on the mental wellbeing of older people and those affected by dementia	219 unpaid care-givers of people with dementia living in the community	• Many care-givers reported symptoms of anxiety and depression. • The level of negative psychological experience among care-givers was associated with the level of dementia severity. • The loss of previously utilised support and activities was associated with poor care-giver wellbeing.
Giebel *et al.* (2021*a*)	UK	Qualitative: thematic analysis of semi-structured interviews	To explore the effects of COVID-19-related social care and support service changes and closures on the lives of people living with dementia and unpaid care-givers	42 informal care-givers of people with dementia living at home in the community (N = 37) and in residential care homes (N = 5)	• Care-givers reported a significant loss in support services during COVID-19. • Care-givers experienced significant uncertainty and loss of control due to the pandemic.

Hanna *et al.* (2021)	UK	Qualitative: thematic analysis using semi-structured interviews	To explore the change in impact of COVID-19 public health measures on the mental wellbeing of people living with dementia and unpaid care-givers	16 unpaid care-givers of people with dementia	• Care-givers experienced negative mental health during lockdown including loneliness, anxiety, depression and increased use of related medications. • Care-givers reported experiencing stigma and shame when in public with care recipients. • Care-givers reported increased care burden and feared that this would continue even after the pandemic.
Hwang *et al.* (2021)	USA	Quantitative: cross-sectional using telephone questionnaire	To examine the influence of COVID-19 on concerns of current family care-givers of people living with dementia	34 family care-givers of people with dementia	• Care-givers experienced significant negative psychological impact from COVID-19 confinement including worry about passing COVID-19 to their care recipient and making their care recipient follow public health directions. • Many care-givers reported experiencing financial hardship during this time, and this contributed to anxiety and worry. • Care-givers reported spending more time care-giving during COVID-19. • COVID-19 negatively impacted the physical exercise routines of care-givers.
Li *et al.* (2021)	China	Quantitative: cross-sectional using online survey	To estimate the prevalence of anxiety, depression and sleep problems among care-givers of persons living with neurocognitive disorders during the COVID-19 pandemic	160 family care-givers of people living with neurocognitive disorders living at home	• Most care-givers experienced significant psychological symptoms during COVID-19 including anxiety, depression and sleeping problems. • The level of anxiety and depression among care-givers was associated with gender (women reported more anxiety and depression) and pre-existing mental disorders.

(*Continued*)

Table 2. (*Continued.*)

Author (year)	Country	Study design	Aim	Care-giver study population	Care-giver outcomes
Losada *et al.* (2022)	Spain	Quantitative: cross-sectional using telephone interview	To analyse care-givers' perceived impact of the COVID-19 pandemic on their mental health and the wellbeing of the care recipients	88 family care-givers of people with dementia	• The majority of care-givers reported negative psychological experiences including increased sadness, anxiety, fear, despair, and worry about family wellbeing, finances and loss of resources such as paid home carers. • The level of negative emotions felt by care-givers was associated with testing positive for COVID-19.
Macchi *et al.* (2021)	USA	Qualitative: rapid analysis via matrix design	To generate a person-centred description of the impact of COVID-19 from the perspectives of patients living with neurodegenerative disease and care-givers	90 care-givers of people with Alzheimer's disease, Parkinson's or related conditions living either at home or in assisted living facilities	• Care-givers reported that COVID-19 disrupted access to health care and support services. • Care-givers experienced increased strain and burnout, anxiety, depression and social isolation.
Mackowiak *et al.* (2021)	Poland	Qualitative: thematic analysis of semi-structured interviews	To investigate the experiences of people with dementia and informal care-givers during the closure of available social and medical services in Poland during the COVID-19 pandemic	21 informal care-givers of people with dementia living at home	• Care-givers provided intensified care during COVID-19 and experienced significant burden. • Care-givers experienced psychological responses including anxiety and social isolation. • New needs emerged for care-givers during COVID-19 including institutional support, social support and remote services.

Paananen *et al.* (2021)	Finland	Qualitative: inductive content analysis of thematic interviews	To examine the consequences of COVID-19-related isolation and social restrictions on the wellbeing of nursing home residents and their family members	41 care-givers of people with memory disorders living in nursing homes	• Care-givers experienced negative emotions and psychological symptoms during COVID-19 restrictions including anxiety, severe stress, frustration and grief. • Care-givers experienced anxiety related to the deteriorating condition of care recipients and being unable to visit them.
Pongan *et al.* (2021)	France	Quantitative: cross-sectional using online survey	To examine changes in behaviour among people with dementia and to look for associations between the evolution of behavioural and psychological symptoms of dementia and care-givers' mental health in the context of COVID-19	389 informal care-givers of people with dementia living at home	• Many care-givers reported experiencing negative psychological impacts of COVID-19 including anxiety and depression. • Many care-givers reported increase in care burden. • The level of anxiety, depression and burden among care-givers was associated with more severe behavioural and psychological symptoms of dementia.
Rainero *et al.* (2021)	Italy	Quantitative: cross-sectional using telephone interview	To investigate the clinical changes in patients with Alzheimer's disease and other dementias and evaluated care-givers' distress during COVID-19 quarantine	4,913 family care-givers of people with dementia living at home	• Many care-givers reported an increase in care burden and accordingly reported spending less time on their own activities. • Many care-givers experienced negative psychological impact during COVID-19 including increased anxiety, depression, irritability, distress and intra-family psychological conflicts.
Rajagopalan *et al.* (2021)	India	Mixed methods using telephone interview	To provide insights into the experiences of persons with dementia and their families during the early phases of the COVID-19 pandemic	104 family care-givers of people with dementia living at home	• Care-givers experienced symptoms of depression, anxiety and stress, as well as negative emotions including irritation, distress and 'feeling lost'. • The level of negative psychological impact among care-givers was associated with the severity of dementia. • Many care-givers felt that care-giving was already increasingly difficult and stressful, and COVID-19 did not change this.

(*Continued*)

Table 2. (*Continued.*)

Author (year)	Country	Study design	Aim	Care-giver study population	Care-giver outcomes
Rising *et al.* (2022)	USA	Qualitative: content analysis of semi-structured telephone interviews	To explore the impact of COVID-19 on people with dementia and care-givers	8 care-givers of people with dementia	• Care-givers reported increased burden and heightened feelings of fear and responsibility for their care recipient.
Roach *et al.* (2021)	Canada	Qualitative: reflexive thematic analysis using telephone interview	To understand the impact of the COVID-19 pandemic on wellbeing and virtual care for people living with dementia and care partners living in the community	19 care-givers of people with dementia living at home	• Care-givers reported losing informal support from family and community and well as the formal support of paid services, and consequently experienced care burnout. • Care-givers had difficulty getting care recipients to follow social distancing restrictions. • Cognitive decline in care recipients caused anxiety and concern for care-givers.
Rusowicz *et al.* (2021)	Poland	Quantitative: observational study using online questionnaire	To identify the needs, created because of the COVID-19 pandemic, of care-givers of people with Alzheimer's disease	85 family care-givers of people with Alzheimer's disease living at home	• Most care-givers reported high levels of stress. • Level of stress severity was associated with deterioration in care recipient's condition during COVID-19, changes in their daily functioning, and concerns about health of both care-giver and care recipient. • Care-givers identified various needs during COVID-19.
Sriram *et al.* (2021)	UK	Qualitative: thematic analysis of semi-structured interviews	To explore the impact of COVID-19 restrictions on care-givers of people with dementia living at home	23 family care-givers of people with dementia living at home	• COVID-19 restrictions negatively impacted care-giver wellbeing and physical health. • Care-givers experienced reduced social support, and lack of access to respite, health and care services.

Tsapanou *et al.* (2020)	Greece	Quantitative: cross-sectional using questionnaire	To analyse the impact of the COVID-19 pandemic on older adults with mild cognitive impairment or dementia and their care-givers	204 care-givers of people with mild cognitive impairment/ dementia	• Care-givers reported significant increase in physical and psychological burden. • Most care-givers did not have significant support during this period.
Vaitheswaran *et al.* (2020)	India	Qualitative: semi-structured interview	To describe the experiences and needs of care-givers of persons with dementia during the COVID-19 pandemic and lockdown	31 care-givers living with people with dementia at home	• Care-givers experienced increased and new challenges during COVID-19 including protecting care recipients from being infected and dealing with changes to daily routines. • Many care-givers reported financial impacts such as loss of work or income, or needing to work from home. • These issues generated various long- and short-term needs for care-givers.
Yuan *et al.* (2021)	China	Quantitative: cross-sectional study using telephone semi-structured interviews	To investigate the psychological impact of COVID-19 confinement on people with memory disorders and their care-givers	712 informal care-givers and 25 paid care-givers of people with dementia and other cognitive impairment	• Half of the care-givers reported distress and different level of care burden. • Many care-givers reported experiencing care burden, and some manifested depressive and anxiety symptoms. • Many reported that they needed a break or could no longer cope with the current situation. • The level of psychological burden was associated with the severity of neuropsychiatric symptoms of the patient.
Zucca *et al.* (2021)	Italy	Quantitative: cross-sectional telephone interview	To investigate if the COVID-19 pandemic increased the risk of psychological disturbances in family care-givers of patients with dementia	4,710 care-givers of people with dementia living at home in the community	• Most care-givers reported symptoms of stress. • Level of stress in care-givers was associated with female sex and anxiety was associated with younger age of care-giver. • Care-givers also reported symptoms of anxiety and depression, and feelings of helplessness and being overwhelmed.

Notes: UK: United Kingdom. USA: United States of America.

Table 3. Themes and sub-themes of the findings

Objectives	Themes	Sub-themes
Impact on care-givers	Psychological wellbeing	• Emotional distress and anxiety • Depression • Fear, shame and embarrassment • Social isolation
	Increased care burden	• Loss of formal and informal care services • Disruptions in daily activities • Neglecting self-care
	Physical health	• Lack of medical check-up • Lack of physical exercise • Decline in health • Sleep deprivation • Weight gain
	Financial difficulties	• Loss of income • Interruption with paid work
Attributing factors	Medical/clinical factors	• Level of severity of impairment • Fluctuation of behavioural symptoms of care recipients
	Socio-demographic factors	• Age • Gender • Resilience • Education
Service needs	• Counselling • Education and training • Assistance with care • Financial assistance	• Psychological counselling • Online support groups and other remote services • Assistance with care of the person with cognitive impairment under lockdown conditions • Flexibility to use more support services for care recipients • Receiving long-term trained home care support workers • Financial support

attributes compounded the impact on care-givers, and various supports were sought to mitigate the consequence of the COVID-19 pandemic and to enhance their ability to provide care.

Impact on psychological wellbeing

The literature makes clear that mandatory confinement during the COVID-19 pandemic period had a significant negative impact on care-givers' psychological wellbeing in the form of emotional distress, level of anxiety, depression, fear, shame, embarrassment and social isolation. The psychological impact most frequently reported by care-givers was anxiety and stress (Carpinelli Mazzi *et al*., 2020; Tsapanou *et al*., 2020; Vaitheswaran *et al*., 2020; Azevedo *et al*., 2021; Borelli *et al*., 2021; Budnick *et al*., 2021; Carcavilla *et al*., 2021; Hanna *et al*., 2021; Hwang *et al*., 2021; Li *et al*., 2021; Losada *et al*., 2022; Mackowiak *et al*., 2021; Paananen *et al*., 2021; Pongan *et al*., 2021; Rainero *et al*., 2021; Roach *et al*., 2021; Rusowicz *et al.*, 2021; Zucca *et al.*, 2021; Carbone *et al.*, 2021*b*). Care-givers attributed several different factors to their anxiety and stress, including feelings of uncertainty and loss of control, as well as the deterioration of neuropsychiatric symptoms of the person they were caring for, and difficulty following public health regulations.

One informal care-giver looking after a parent with dementia in the UK expressed her uncertainty as follows:

> We have no control over it [COVID-19 lockdowns], that's one thing and there seems to be no end to it, when we thought there was an end like I say when we had that little bit of hope that lockdown was easing then [area name] was put back into lockdown … we don't know when that's going to end and then will it actually end or will they continue it. (Hanna *et al.*, 2021: 6)

Many care-givers felt a heightened sense of responsibility due to the risks related to COVID-19. They were aware of the vulnerability of their care recipients in relation to COVID-19 and afraid of passing the virus on to their care recipient. As one study participant noted:

> I'm having to get close to her whilst showering her and I'm very conscious of that all the time… not passing anything on and there's been a couple of occasions where when I've gone to help mum, she's then just grabbed hold of me and hugged me. (Giebel *et al.*, 2021*a*: 1285)

Care-givers were also worried and anxious about becoming sick themselves and were deeply concerned about who would look after their loved one if they became too unwell to continue their care-giving responsibilities (Hanna *et al.*, 2021; Rising *et al.*, 2022; Rusowicz *et al.*, 2021). One care-giver described:

> My biggest fear would be if something happens to me, only because if it happens to me it's a big mess. (Rising *et al.*, 2022: 5)

Care-givers expressed concerns about the loss of important social care programmes, support services and routine medical appointments for their care recipient that were cancelled due to COVID-19 restrictions. They frequently expressed their concern that in the absence of those programmes and medical appointments, their care recipients' cognitive ability, health and general wellbeing were deteriorating, which further increased the care-givers' anxiety (Giebel *et al.*, 2021*a*; Mackowiak *et al.*, 2021; Paananen *et al.*, 2021; Rusowicz *et al.*, 2021):

> Literally, very soon after the day care facility was closed, my mother started to deteriorate in her health, especially the mental one. Her behaviours started to change, a lot of problems grew and for me it was a very big problem… (Mackowiak *et al.*, 2021: 6)

Family members caring for people with cognitive impairment living in residential facilities were similarly anxious about the health and wellbeing of their loved ones, as many perceived that their health condition declined rapidly over periods of extended lockdown and social isolation (Giebel *et al.*, 2021*a*; Paananen *et al.*, 2021). These care-givers experienced unique stressors and negative emotions in navigating how to communicate with facilities and maintain connection to their loved ones during visitor restrictions (Giebel *et al.*, 2021*a*; Paananen *et al.*, 2021):

> I don't know how to cope with this. Or how my mother copes with this. That is what we fear the most, that we cannot be close to her in her last days. If I may say, I have a constant fear that my mother will die. And I always keep my cell phone close by, mhm. (Paananen *et al.*, 2021: 8)

Care-givers further described their anxiety when leaving their house with care recipients who could not understand or follow public health regulations and health warnings. For example, one care-giver in Canada shared her concern about completing essential errands outside the home:

> Yeah, it's so difficult … That taught me a lesson. So we went out. I couldn't leave it, so I have to go pick it up today. And that's frustrating because it gives you more anxiety of just leaving the house. I don't have trouble leaving the house but if [person with dementia] comes with me he has to wait in the car. And then, it was just really stupid of me. I said my brain's going under too, a huge thing. Nothing's in sync. (Roach *et al.*, 2021: 2016)

Care-givers described how these experiences led to feelings of fear, embarrassment and shame when going out in public with their care recipients during lockdowns. One care-giver reported:

> She [person with dementia] said she wanted to go to this supermarket that she likes … she kept wanting to push closer to the lady in the front … I said no mum you can't do that you have to stay 2 meters behind the person in front of you … I said and you need to follow the arrows around the supermarket. (Hanna *et al.*, 2021: 5)

Care-givers also reported high levels of depression during the COVID-19 pandemic (Altieri and Santangelo, 2021; Borelli *et al.*, 2021; Hanna *et al.*, 2021; Li *et al.*, 2021; Macchi *et al.*, 2021; Pongan *et al.*, 2021; Rainero *et al.*, 2021; Zucca *et al.*, 2021). They reported increased use of medications including antidepressants, to tackle their mental health issues. One care-giver reported:

> The psychiatrist, they gave me some antidepressants … I did not want to take it but I felt as though I was going downhill a little bit, it's that I felt so isolated is the better way of putting it, I wasn't seeing another human face at all, no direct contact with anybody, not even a window cleaner. Crazy I know, everything stopped instantly it was like turning the light off it was that quick wasn't it when you think about it. (Hanna *et al.*, 2021: 4)

Many care-givers described feeling lonely and isolated from friends and family who previously provided both socialisation and support (Azevedo *et al.*, 2021; Carcavilla *et al.*, 2021; Hanna *et al.*, 2021; Mackowiak *et al.*, 2021; Rajagopalan *et al.*, 2021). One care-giver explained:

> I feel a sense of isolation and lack of support and honestly, I think I am out of words to even explain my situation. (Rajagopalan *et al.*, 2021: 13)

Increased care burden

Increased care burden was identified in 19 studies as a profound impact of COVID-19 on care-givers of people with cognitive impairment (Borges-Machado *et al.*, 2020; Boutoleau-Bretonnière *et al.*, 2020; Tsapanou *et al.*, 2020; Alexopoulos *et al.*, 2021; Azevedo *et al.*, 2021; Borelli *et al.*, 2021; Budnick *et al.*, 2021; Carcavilla *et al.*, 2021; Hanna *et al.*, 2021; Hwang *et al.*, 2021; Macchi *et al.*, 2021; Mackowiak *et al.*, 2021; Pongan *et al.*, 2021; Rainero *et al.*, 2021; Rising *et al.*, 2022; Rusowicz *et al.*, 2021; Sriram *et al.*, 2021; Yuan *et al.*, 2021). During lockdowns care-givers were unable to access formal care services such as dementia day care centres that were previously relied upon (Giebel *et al.*, 2021*b*; Vaitheswaran *et al.*, 2020; Budnick *et al.*, 2021; Macchi *et al.*, 2021; Mackowiak *et al.*, 2021):

> What I felt when they closed the day care facility? It was stress. And it still is. We had to organize something that worked well again. I didn't know when it would end, how we should work with mum. (Mackowiak *et al.*, 2021: 5)

Additionally, many care-givers reported that they lost the informal support provided by other family members or friends due to lockdowns (Carpinelli Mazzi *et al.*, 2020; Hanna *et al.*, 2021). One care-giver shared:

> She [sister] would have her over for the afternoon about the same times, and we had a cousin who we used to go Sunday dinner to once a month, but unfortunately that's all gone by the by. (Sriram *et al.*, 2021: 7)

This loss of support from both professional providers and other family members contributed to increased care-giver burden and resulted in a significant increase in the amount of time care-givers spent providing care and assisting with the care recipient's activities of daily living. One care-giver described that 'all of his other people are gone so the whole burden is on me' (Rising *et al.*, 2022: 34), and another shared their frustration:

> I lost all my support. All of it, except for few hours. So I was just left to just manage this on my own. Yeah … you know, I, going from, you know, 24 hours of day program and 35 hours of home care to nothing. They stripped all my support away. (Roach *et al.*, 2021: 2017)

The burden of care-giving and coping with heavy care duties contributed to care-givers feeling despair and hopelessness:

> There's no method to cope. I can't ask people, family to come and help me. I can't, there has been nothing I can do. No, I have not found anything for me personally

> that has been good about it. I have not been able to work. I have no socialization. I'm just left to cope on my own. (Roach *et al.*, 2021: 2013)

Many care-givers reported that increased care burden resulted in notable disruptions in their daily routine and activities (Borelli *et al.*, 2021; Mackowiak *et al.*, 2021), including neglecting self-care (Rainero *et al.*, 2021) and reduced healthy-eating habits (Borelli *et al.*, 2021; Hwang *et al.*, 2021).

Impact on physical health

Care-givers experienced impacts on their general health and physical wellbeing during COVID-19 lockdowns, including developing their own health problems (Azevedo *et al.*, 2021; Borelli *et al.*, 2021; Hwang *et al.*, 2021; Mackowiak *et al.*, 2021; Rusowicz *et al.*, 2021). Many care-givers reported difficulties in accessing medical services for both their existing and new health problems as many of their medical appointments were cancelled due to social restrictions and lockdowns (Carpinelli Mazzi *et al.*, 2020; Vaitheswaran *et al.*, 2020; Azevedo *et al.*, 2021; Borelli *et al.*, 2021; Mackowiak *et al.*, 2021). As one care-giver said:

> [I was] unable to access my eye doctor as I have retinal tears that need regular reviews; also unable to access my dentist. (Vaitheswaran *et al.*, 2020: 1189)

Lockdowns and increased care-giving responsibilities further restricted care-givers' physical exercise (Vaitheswaran *et al.*, 2020; Hwang *et al.*, 2021; Sriram *et al.*, 2021). As one care-giver explained:

> I get what I need [exercise], but I have not been able to get as much since March, obviously. (Sriram *et al.*, 2021: 5)

Many care-givers also reported other health impacts, including a general decline in physical health (Azevedo *et al.*, 2021; Hwang *et al.*, 2021; Rusowicz *et al.*, 2021), weight gain (Borelli *et al.*, 2021), difficulty sleeping (Azevedo *et al.*, 2021; Carcavilla *et al.*, 2021; Li *et al.*, 2021) and increased use of sleep medication (Borelli *et al.*, 2021; Mackowiak *et al.*, 2021).

Financial difficulties

Financial concerns including decreased income or loss of employment was another factor that caused anxiety among care-givers (Vaitheswaran *et al.*, 2020; Hwang *et al.*, 2021; Losada *et al.*, 2022; Rusowicz *et al.*, 2021). One participant in a study exploring the need for support among care-givers of people with dementia in India shared:

> I am not able to go to work. So there has been a loss in income. (Vaitheswaran *et al.*, 2020: 1189)

Additionally, those who worked from home due to the pandemic reported difficulties in balancing care-giving responsibilities while working from home, especially when the care recipient's behaviours were disruptive (Borges-Machado *et al.*, 2020; Vaitheswaran *et al.*, 2020; Rajagopalan *et al.*, 2021). One care-giver described:

> He comes and bangs on the door when I am in a call as I am working from home now. He doesn't like the doors being closed. (Vaitheswaran *et al.*, 2020: 1189)

Others worried about how they would return to work if formal care services continued to be unavailable:

> Yeah, like I am scheduled to start going back to work again and no one, no one can tell me what I'm supposed to do with my spouse, because the day programs are no longer active. So, for 24 hours a week now I don't know what I'm supposed to do. (Roach *et al.*, 2021: 2017)

Socio-demographic and clinical attributes and their impact

The included studies in this review identified socio-demographic and clinical attributes that influenced the impact of COVID-19 on care-givers at various levels. The level of negative psychological symptoms and care burden experienced by care-givers varied consistently with the level of cognitive impairment of care recipients (Boutoleau-Bretonnière *et al.*, 2020; Giebel *et al.*, 2021*b*; Alexopoulos *et al.*, 2021; Altieri and Santangelo, 2021; Azevedo *et al.*, 2021; Borelli *et al.*, 2021; Pongan *et al.*, 2021; Rajagopalan *et al.*, 2021; Yuan *et al.*, 2021; Zucca *et al.*, 2021). Care-givers providing care for people with moderate and severe cognitive impairment reported higher levels of psychological and physical impacts. Level of care burden was also associated with the level of, and changes to, behavioural symptoms in care recipients with dementia (Borges-Machado *et al.*, 2020; Boutoleau-Bretonnière *et al.*, 2020; Pongan *et al.*, 2021; Rajagopalan *et al.*, 2021). In one study, the length of time spent in isolation was also associated with higher levels of anxiety and depression (Carpinelli Mazzi *et al.*, 2020).

Gender was another factor that was found to be associated with the level of COVID-19-related psychological impact (Carpinelli Mazzi *et al.*, 2020; Zucca *et al.*, 2021; Carbone *et al.*, 2021*b*). However, the association between these two factors varied among studies. While female care-givers in a study measuring the impact of COVID-19 on care-giver distress among 35 care-givers in Italy reported lower levels of distress compared to their male counterparts (Carbone *et al.*, 2021*b*), female care-givers in other studies also conducted in Italy (Carpinelli Mazzi *et al.*, 2020; Zucca *et al.*, 2021) reported higher levels of anxiety, stress and depression. Care-givers' age and level of education were also associated with the level of impact of COVID-19 restrictions. Higher levels of education were associated with lower levels of anxiety and depression (Carpinelli Mazzi *et al.*, 2020; Zucca *et al.*, 2021). One study reported that care-givers who were under 70 reported higher levels of psychological impact (Zucca *et al.*, 2021).

Although some studies reported that the level of resilience in care-givers was associated with the levels of psychological impact they experienced, the direction of this association varied between studies. One study reported that care-givers with higher resilience levels reported a more limited worsening of care-giver distress over lockdown (Carbone *et al.*, 2021*b*), however, another study found that high resilience levels was associated with a higher increase in anxiety (Altieri and Santangelo, 2021).

Care-giver support needs

Even though care-givers experienced significant negative impacts of COVID-19 while providing care for people with cognitive impairment, the literature on their support needs remains limited. Only four studies explicitly identified the support that care-givers required (Vaitheswaran *et al.*, 2020; Carcavilla *et al.*, 2021; Mackowiak *et al.*, 2021; Rusowicz *et al.*, 2021). The most frequently reported support need was educational information and professional guidance on how to provide care for people with cognitive impairment during lockdowns, including advice on managing dementia-related behavioural symptoms, activities to keep care recipients entertained and engaged at home, and strategies to assist care recipients in following public health restrictions (Vaitheswaran *et al.*, 2020; Mackowiak *et al.*, 2021; Rusowicz *et al.*, 2021). For example, one care-giver suggested 'some means of engaging my mother will be very useful' (Vaitheswaran *et al.*, 2020: 1190). This includes a need for medical consultations with dementia specalists and other providers who are available to provide support even during lockdowns: 'keeping in contact and being available for support and help' (Vaitheswaran *et al.*, 2020: 1190). Care-givers also expressed the need for counselling or psychological services to better support their own mental health and wellbeing (Rusowicz *et al.*, 2021). In one study, participants advocated for online support groups for care-givers: 'it [on-line support for carers via communicators such as Zoom, Skype] is important' (Mackowiak *et al.*, 2021: 7).

Care-givers expressed a need for support with providing care at home, particularly during work-day hours, or to allow them to complete essential tasks or respite and self-care activities (Vaitheswaran *et al.*, 2020; Carcavilla *et al.*, 2021; Mackowiak *et al.*, 2021). They expressed a need for back-up care-givers who could assist with or take over care-giving responsibilities if they became unwell or infected with COVID-19 (Rusowicz *et al.*, 2021).

Many care-givers reported problems due to lockdown restrictions, and some wished that authorities would have been more flexible in implementing policies or allowing exemptions for people with cognitive impairment (Vaitheswaran *et al.*, 2020; Carcavilla *et al.*, 2021). For example, one care-giver suggested, 'allow these patients to take walks outside home with their caregivers without time restriction' (Carcavilla *et al.*, 2021: 535). Additionally, a large proportion of care-givers reported reduced income and accordingly expressed their need for financial support (Rusowicz *et al.*, 2021) or for the cost of medications to be subsidised (Vaitheswaran *et al.*, 2020). Care-givers also reported long-term support needs, including more trained home care support workers and improved social awareness about dementia:

> The police did not permit us to travel to our village where my father would be more settled. They did not know what dementia was. This is not just a problem for now. Even after the pandemic, something should be done to make them aware of dementia. (Vaitheswaran *et al.*, 2020: 1191)

Following the presentation of COVID-19 impacts on care-givers, and the services they required, we now provide a summary of recommendations of policy and practices synthesised from the included studies.

Recommendations in the reviewed articles

Authors in the reviewed studies provided a variety of policy recommendations, with most actively calling for policy makers and health-care providers to better support care-givers with targeted responses. They advocated for improving the capacity to provide flexible and bespoke support solutions for informal care-givers, including further developing the provision of remote support and virtual medicine, support in utilising telehealth services, and flexible mental and social support for both care-givers and their care recipients with cognitive impairment (Giebel *et al.*, 2021*a*; Mackowiak *et al.*, 2021; Roach *et al.*, 2021; Sriram *et al.*, 2021). Dementia day care centres and other service providers should be encouraged and supported to develop contingency plans so that they may continue to provide services and support in some capacity during future outbreaks or other crises (Borges-Machado *et al.*, 2020). Another key recommendation was that existing support structures and services should be maintained and strengthened in a 'resilience-focused' approach to build capacity to support care-givers even during normal times, to help mitigate the effects of future outbreaks (Vaitheswaran *et al.*, 2020; Carcavilla *et al.*, 2021).

Discussion

To our knowledge, this is the first comprehensive systematic review that takes an in-depth look at the lived experience of care-givers of people with cognitive impairment during the COVID-19 pandemic. Other systematic reviews were conducted to examine the impact of COVID-19 on care-givers (Aledeh and Adam, 2020; Hughes *et al.*, 2021; Giebel *et al.*, 2022), however, these studies were either rapid review, and/or illness specific, *e.g.* dementia only, or focused solely on mental health and wellbeing. Our review includes care-givers of people with any cognitive impairment and examines the impact of COVID-19 restrictions and lockdowns on psychological and mental wellbeing, burden of care, physical health and financial difficulties. This review also considers the factors associated with these impacts, the service responses desired by the care-givers and provides a synthesis of policy recommendations in the reviewed articles.

Findings from this review demonstrate that there is limited research on the impact of COVID-19 lockdown experienced by care-givers of people with cognitive impairment, and that most of this research focuses on informal, unpaid family care-givers. Our review found that the impacts on care-givers are complex and often overlapping, and our findings resonate with the results of another study (Muldrew *et al.*, 2022) to reveal that the COVID-19 pandemic not only heightened the care-givers' pre-existing struggles, but also added extra challenges for this population. The COVID-19 pandemic, physical distancing restrictions and subsequent lockdowns resulted in severe psychological consequences, which were also reported in another systematic review that examined the mental health of care-givers of people with dementia during the COVID-19 lockdown (Carbone *et al.*, 2021*a*). Similar to our study, this review found that anxiety, depression, stress and lack of control were the most frequently reported mental health consequences. Psychological and mental health outcomes were compounded by other challenges which were unique to these care-givers, as people with cognitive impairment are particularly vulnerable to COVID-19 and are at a heightened risk of severe outcomes after contracting the virus, therefore requiring constant care-giver support (Iodice *et al.*, 2021). Furthermore, accessing social and health-care services are essential for these patients and for their family care-givers (Aamir *et al.*, 2021; Giebel *et al.*, 2022). Closure of social and health-care support services during COVID-19 lockdowns resulted in further deterioration of care-givers' psychological and mental health (Giebel *et al.*, 2021*a*, 2022; Carbone *et al.*, 2021*b*).

Reduced social and health-care resources and increased isolation during the COVID-19 pandemic further resulted in heavy care responsibilities for family care-givers, as found in this review. The included studies mostly focused on psychological health rather than physical health. However, analysis showed that the negative psychological consequence coupled with increased care responsibilities also had an impact on care-givers' physical health. The impact of care responsibilities has been termed 'care-giver burden' throughout the literature included in this review. Care-giver burden is a multi-dimensional concept consisting of emotional, physical, social and/or financial burdens that care-givers experience when caring for their loved ones with cognitive impairment (Maggio *et al.*, 2021). Indeed, the care-givers in these studies reported neglecting self-care, ignoring their own health, exercising less due to increased care responsibilities and, consequently, experiencing declines in their own health and wellbeing.

This increased care burden was also clearly associated with the cessation of (or reduction in) formal care support services (like day care centres and regular medical appointments) as well as the loss of informal support networks. This highlights the need for governments, policy makers and service providers to find creative ways to continue providing support to informal care-givers, even during periods of infectious disease outbreak and lockdown. Furthermore, many care-givers expressed specific and significant anxiety about the possibility of contracting COVID-19 themselves, and being unable to provide adequate care for their care recipient. With respite centres and other paid care-giving services unavailable during lockdowns, this situation poses a particularly critical issue that must be addressed in future lockdowns/public health outbreaks. The impacts of service closures have been devastating for many families and policies need to balance infection risks with the benefit of care and social support measures. Diminished contact with family and friends who would normally provide regular informal respite and emotional and moral support to care-givers has a critical impact on care-giver burden, but is under-examined in the extant literature.

Additionally, several studies mentioned the significant stress and difficulty experienced by care-givers in relation to following public health advice, especially when care recipients did not sufficiently understand COVID-19-related information or the need to change their regular routines (Budnick *et al.*, 2021). In some studies, care-givers reported that public health advice felt impractical for the people for whom they were caring (Vaitheswaran *et al.*, 2020; Carcavilla *et al.*, 2021). This is also reflected in the wider literature, which has acknowledged that cognitive impairment and intellectual disability can impact a person's ability to understand and implement public health measures such as handwashing, social distancing and isolation, therefore placing additional demands on care-givers to monitor their behaviour (Courtenay and Perera, 2020). Policy responses to future public health outbreaks should consider the needs of this important group and ways to minimise any increase in burden of care. Although not explicit, evident in the research is the critical role care-givers play as advocates for people with cognitive impairment, including highlighting how important it is for care-givers' needs to be recognised, as these impact on the quality of care provided to recipients.

Financial difficulties among care-givers of people with cognitive decline were also reported in the wider literature (*e.g.* Kostyál *et al.*, 2021; Masoud *et al.*, 2022), particularly in terms of income loss, job loss, switching to part-time work, working from home (while caring for a person with cognitive impairment) or taking unpaid care leave. It is essential that policy makers implement strategies to alleviate the financial burden placed upon care-givers who are forced to reduce or leave their employment in order to care for others, particularly in times of crisis when regular support services are unavailable. The severity of impact on any of the issues on care-givers between lower-income and higher-income countries could not be examined in this review due to the limited number of studies from lower- to middle-income countries, with just four studies reporting on India (Vaitheswaran *et al.*, 2020; Rajagopalan *et al.*, 2021) and Brazil (Azevedo *et al.*, 2021; Borelli *et al.*, 2021).

Two factors were found to be associated with care-giver impact during COVID-19 confinements, namely medical/clinical conditions of the care recipients and socio-demographic factors of the care-givers. Care-givers providing care for people with moderate to severe cognitive impairment experienced higher levels of psychological and physical difficulties. Similarly, care-givers also experienced increased care burden when coping with severe or increasing behavioural and psychological symptoms of the care recipient. While this finding is new in the COVID-19 context, it is unsurprising and aligns with research conducted prior to the pandemic, which found that care-giving stress increased with the level of cognitive impairment or other disabilities in general (Kim, 2017).

Consistent with findings from a previous review (Hughes *et al.*, 2021), care-givers with lower levels of educational attainment are at greater risk of high levels of care burden. The association between care-givers' level of resilience, their psychological state and their care burden during COVID-19 lockdowns is inconsistent with previous studies and remains unclear. Although high resilience is considered a protective factor against care-givers' depression, anxiety and care burden (Ruisoto *et al.*, 2020; McKenna *et al.*, 2022), in contrast, Altieri and Santangelo (2021) found care-givers with higher resilience experienced a significant increase in anxiety level, but a decrease in care burden. High resilience may not protect care-givers from adverse outcomes during exceptional situations like the COVID-19 pandemic. Specific interventions for care-givers of people with cognitive impairment are therefore required, regardless of their levels of resilience.

Research limitations and recommendations for future studies and policy implementation

The inclusion of papers sourced from a wide variety of databases, including those that do not focus primarily on health or medical research, ensures that this review is not limited to findings from a narrow range of disciplines, and instead actively incorporates research from non-health fields, including social science perspectives and related applied fields. This review is limited in its exclusion of care-givers aged under 18 years. Young care-givers likely have unique experiences, and their support needs may differ from those discussed in this review, and this is an important direction for future research. Excluding articles published in languages other than English also limited the generalisability of our findings.

Many of the studies included in this review, while providing some important insights on the experiences of care-givers, predominantly considered impacts on care recipients, with minimal investigation of the impacts on their care-givers. Similarly, sample size varied across the included studies, impacting the generalisability of findings. There are also limited studies investigating the mediating factors that may have contributed to the impact of COVID-19 restrictions on care-givers and their support needs. Studies were mostly (N = 20) undertaken in European countries, with a small number in North America (N = 4), South America (N = 2) and Asia (N = 4). Current research on the impact of COVID-19 restrictions and lockdowns on care-givers therefore does not adequately represent populations from diverse cultural and geographical background. Differences in the experiences of care-givers from different linguistic and cultural backgrounds, socio-economic status, age and gender should be considered in designing policies to meet their needs.

The majority (N = 26) of studies on this topic focused on family care-givers of people with cognitive impairment living at home in the community. Although two studies in this review also included participants who were paid care-givers (Yuan *et al.*, 2021; Carbone *et al.*, 2021*b*) and two studies included family care-givers of people living in residential facilities (Giebel *et al.*, 2021*a*; Macchi *et al.*, 2021) in addition to family care-givers of people living at home, these studies reported aggregated results and did not distinguish outcomes between different types of care-givers. This makes it difficult to understand and report the unique experiences of care-giving in different contexts. The effects on and support required by family care-givers providing care at home are likely different to that of both paid care-givers and family care-givers of people who live in residential facilities, and future research should prioritise reporting disaggregated results for different types of care-givers. The experiences of formal and informal care-givers may vary greatly (Modi *et al.*, 2021), yet there has been limited research that compares the impacts of COVID-19 on these different populations. Investigating and comparing the impact of COVID-19 on these two groups is necessary to better understand their respective needs during emergency public health responses to infectious disease outbreaks. Although policy attention has traditionally focused on supporting formal paid care-givers or health-care workers rather than supporting family care-givers, researchers have recommended that policy makers prioritise better responses to support family care-givers (Lorenz-Dant and Comas-Herrera, 2021; Dawson and Comas-Herrera, 2022). The impact of COVID-19 lockdowns on family care-givers of people with cognitive impairment living in residential care facilities continues to be a significant gap in current literature.

Implicit in the findings is the role played by informal care-givers as the safety net for people with cognitive impairment when other social care and social support services are unavailable. This critical role in turn results in adverse consequences for care-givers who experience stress and increased care burden. Recommendations identified in the reviewed studies that would benefit care-givers include: more services to support the physical health and psychological wellbeing of care-givers, particularly those caring for people with moderate to severe cognitive impairment (Giebel *et al.*, 2021*a*; Roach *et al.*, 2021; Sriram *et al.*, 2021), including counselling support that should be made more widely available (Rusowicz *et al.*, 2021); funding for social care (Borges-Machado *et al.*, 2020; Vaitheswaran *et al.*, 2020; Carcavilla *et al.*, 2021); as well as state financial benefits for care-givers (Vaitheswaran *et al.*, 2020; Rusowicz *et al.*, 2021). These recommendations in combination may help address the issues of anxiety, financial stress and access to formal care-givers to limit care burden and burnout, and ensure care-givers have more time for respite and self-care. These recommendations have application at all times, not only during public health measures that respond to pandemics or other outbreaks of infectious disease.

Conclusion

Despite the critical role that care-givers play in supporting loved ones living with dementia and other forms of cognitive impairment, they have most often appeared as secondary figures in research conducted since the onset of the pandemic. This systematic review aims to consolidate knowledge and increase understanding about the impact of COVID-19 restrictions and confinement on care-givers and their support needs. Daly (2021) notes that families and informal care-givers have absorbed the costs of the adjustments required by the pandemic, including for both childcare and eldercare, which were effectively 'reprivatized to the family' (Daly, 2021: 115; *see also* Giebel *et al.*, 2021*a*). She highlights the risks of 'depletion' (Rai *et al.*, 2014) in this context, where 'resource outflows exceed resource inflows over a threshold of sustainability, making for a harmful situation for those engaged in this work' (Daly, 2021: 116). Understanding the impacts on care-givers is crucial to the development and implementation of appropriate and effective support interventions and policies to better meet the needs of family and care-givers of people with cognitive impairment, and to prepare for future pandemic outbreaks. Given the increasing life expectancy across the globe, combined with increasing rates of dementia, the care burden of care-givers of people with cognitive impairment is certain to be an important health issue for the future, even in non-pandemic times. Therefore, the role of both formal and informal supports and services for care-givers of people with cognitive impairment requires serious attention from scholars, practitioners and policy makers.

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