


# Caregiving for People With Dementia or Cognitive Impairment During the COVID-19 Pandemic: A Review

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## Abstract

The COVID-19 pandemic has been a major source of stress for informal caregivers for people with dementia. Studies show the unique challenges caregivers face, such as social isolation, extended work hours, and adherence to public health guidelines. We conducted a narrative review of factors impacting well-being of informal caregivers of older adults with dementia during the COVID-19 pandemic. Sixty-four papers were identified as published between June 2020 and December 2021. All studies were conducted in the U.S. or other Western countries and were cross-sectional and conducted prior to COVID-19 vaccines. Articles highlighted increasing burdens such as financial and physical stress, as well as worsened psychological well-being from anxiety and depression. Protective factors such as social support and telehealth interventions also emerged. Limitations include lack of longitudinal information to identify broader themes on caregiving during the pandemic. Studies not only identified new, pandemic-related risk factors, but also a heightened effect of pre-existing risk factors (e.g., income, living situation) on caregiver burden.

## Keywords

COVID-19, caregiving, psychological well-being, dementia, cognitive impairment

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## Introduction

Since the start of the pandemic, caregivers of older adults have faced greater demands on time and services than ever before (Liu et al., 2020). Caregivers are defined as people who “provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis” (CDC, 2022). Caregivers may work at formal institutions such as nursing homes and hospices, or as informal caregivers in patient homes, often as family or friends of the recipient (Liu et al., 2020). Specifically, informal caregivers are typically those “who [provide] some type of unpaid, ongoing assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a chronic illness or disability” (Roth et al., 2015). Because caregivers tend to multiple facets of recipients’ lives including personal care, household chores, medical needs, and social support, they commonly report higher psychological distress than non-caregivers, especially caregivers for those with cognitive impairment or dementia (Liu et al., 2020).

The well-being of caregivers for older adults with dementia is especially important to examine during the COVID-19 pandemic. While studies have focused on the impact of COVID-19 on the well-being of healthcare workers, adolescents, and older adults, relatively few have examined the unique impact of the pandemic on caregivers, especially informal ones (Dubey et al., 2020). Due to pandemic-related factors, caregivers often experienced greater isolation, extended work hours, job insecurity, and reduced autonomy during the first year of COVID-19 (Daley et al., 2022; Dang et al., 2020). Caregivers of adults with dementia faced added challenges of witnessing the decline of recipients’ functional status and the fear of transmitting COVID to family members, who tend to be older adults at higher risk of

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infection (Dubey et al., 2020). Additionally, the likelihood of COVID-19 infection has been associated with older adults' cognitive impairment and frailty status (Salini et al., 2022). These factors point toward a need to better understand caregiver perspectives during the pandemic, in an effort to provide them with more robust support systems on the personal and community levels.

Two prominent themes in the growing literature on caregiving during the pandemic are caregiver burden and psychological well-being. Caregiver burden is defined as "the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time" (Liu et al., 2020). Risk factors include female sex, higher caregiving hours, residence with the recipient, social isolation, financial stress, low education, familial relation to the recipient, and lack of choice in caregiving (Beach et al., 2021; Brandt et al., 2021; Budnick et al., 2021; Connors et al., 2020; Liu et al., 2020).

Related to caregiver burden, the psychological well-being of caregivers is typically reflected in their subjective experience of anxiety, depression, or distress (Altieri & Santangelo, 2021; Carpinelli Mazzi et al., 2020; Park, 2021). Loneliness is another key contributor to mental health, as perceived isolation from family, friends, and co-workers are common features of the caregiver experience during the pandemic (Altieri & Santangelo, 2021). In this narrative review, we identify key factors impacting the well-being of informal caregivers of older adults with dementia during the pandemic, while expounding on the rapidly expanding literature at this time. We focus on informal caregivers due to the qualitative distinctions in their caregiving experience and the rise in informal caregiving during the pandemic.

## Methods

### Search Strategy

A narrative review of the literature was conducted using the PubMed database, as this approach provided the broadest representation of published materials on the subject (Grant & Booth, 2009). We initially conducted two searches: "(COVID-19) AND (older adults) AND (dementia) AND ((caregiving) OR (caregiver))" and "(COVID-19) AND (older adults) AND ((caregiving) OR (caregiver))." The first search term included "dementia," but this limited the number of relevant articles and did not capture caregivers of older adults with milder cognitive impairments along the continuum of symptomatology. Thus, we chose the latter search to include articles discussing recipients with neuropsychiatric symptoms and cognitive decline not limited to dementia. Most studies were cross-sectional surveys of caregivers or caregiver/recipient dyads between  $N=100$  and 500, as well as qualitative interviews and interventions for caregiver support. The selected articles were published from June 2020 to December 2021, as this

appears to be the time in which the greatest number of studies on the first year of the pandemic were published. However, we did not explicitly exclude studies based on publication year when conducting our search.

### Inclusion/Exclusion Criteria

The search yielded 550 articles, from which ( $N=64$ ) articles were selected (Figure 1) using the PRISMA flow diagram for reviews (Rethlefsen et al., 2021). Studies were restricted to those (a) written in English, (b) published in a peer-reviewed journal, and (c) available online. All designs including systematic reviews, meta-analyses, letters to the editor, commentaries, and expert opinions were included. Articles from countries outside the U.S. were included to offer a breadth of cultural contexts. Articles that did not discuss (a) the COVID-19 context, (b) caregiving, (c) older adults, (d) dementia or cognitive impairment, or (e) formal caregivers (i.e., paid) were excluded. From the search, four main themes emerged: (1) caregiver burden ( $N=28$ ), (2) caregiver mental health ( $N=23$ ), (3) protective factors on caregiver well-being ( $N=7$ ), and (4) caregiver support ( $N=6$ ), from which categorized each study (Figure A1 in Appendix). Type of cognitive impairment, study design, location, and demographic variables (sample size, age, and sex) were also coded during the full-text review.

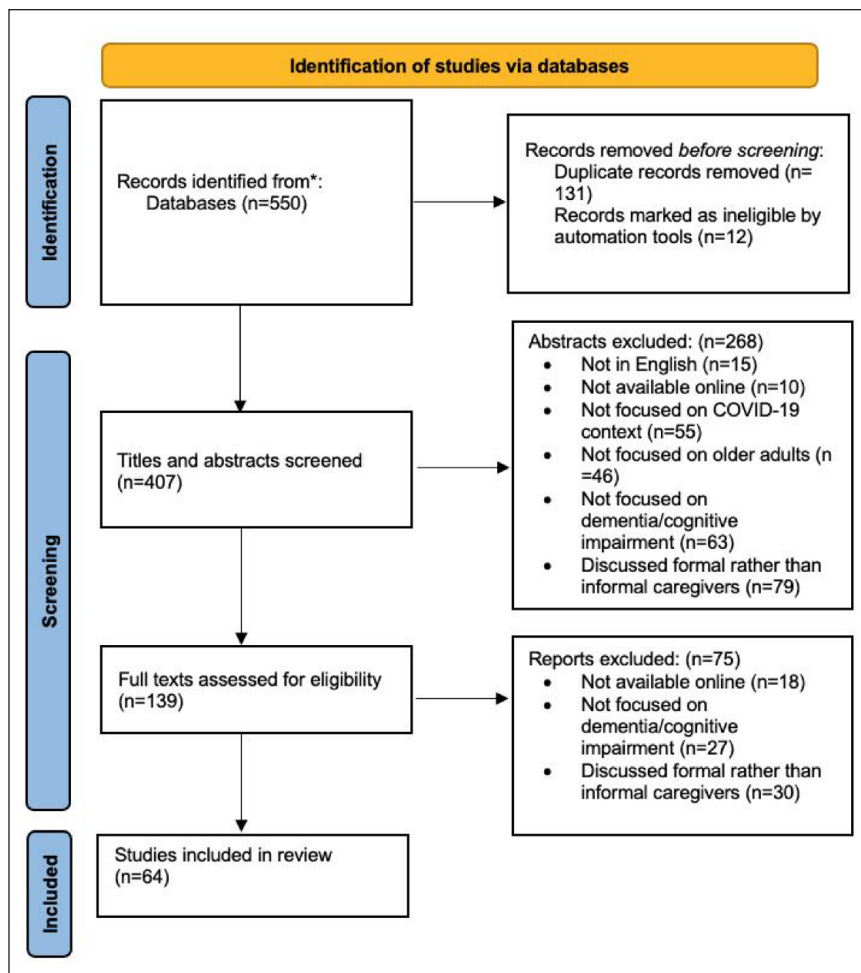
## Narrative Review

### Caregiver Burden

In accordance with research prior to the pandemic, previously identified risk factors for caregiver burden are largely intensified during the pandemic (Borelli et al., 2021; Borges-Machado et al., 2020; Greenberg et al., 2020; Penteadó et al., 2020; Rajovic et al., 2021). Risk factors for burden include female gender, younger age, ethnicity, residence with care recipients, duration of care including days in isolation, confusion on public health guidelines, personal financial burden, care complexity, care intensity, and health of the caregiver (Beach et al., 2021; Carpinelli Mazzi et al., 2020; Leggett et al., 2021; Soares et al., 2020; Stubbs et al., 2021).

Women caregivers were at higher risk for negative outcomes than males. Studies in the U.S, France, and Italy found that female caregivers of people with dementia experienced higher burden, stress, anxiety, and depression than male caregivers and reported problems caring for older relatives more frequently than men in private households (Brandt et al., 2021; Carpinelli Mazzi et al., 2020). A higher proportion of female caregivers experienced reduction in informal support (friends, co-workers) than male caregivers, while informal support among males exerted a protective effect against poor self-perceived health (Del Río-Lozano et al., 2022).

Racial and ethnic differences were also apparent in the literature. Caregivers aged 18 to 24 and those of



**Figure 1.** PRISMA flow diagram.

Hispanic or Latino ethnicity in the U.S. were more likely to experience anxiety or depression compared to White caregivers, with suicidal ideation being more prevalent among Black than White caregivers (Czeisler et al., 2021). In another study, Black caregivers were more likely than White caregivers to report higher caregiving-related financial strain, and Hispanic caregivers reported greater emotional stress than White caregivers (Longacre et al., 2021).

A study in France found that caregivers who resided with the care recipient experienced greater workload compared to caregivers whose care recipients lived in nursing homes (Borg et al., 2021). In addition, those living with recipients reported greater difficulty maintaining a regular sleep/wake rhythm due to around-the-clock care (Borg et al., 2021). Caregivers with long-term duties had greater burden than those with short care terms (Adelman et al., 2014; Park, 2021). A greater percentage of long-term caregivers reported headaches and abdominal discomfort than short-term caregivers, and long-term caregivers consistently reported more somatic symptoms than non-caregivers (Park, 2021). They were also more likely to provide extended hours of care than short-term caregivers which may heighten distress,

since higher work hours were shown to significantly predict anxiety, financial hardship, and physical strain in caregivers of people with dementia in the U.S. and UK (Giebel, Lord, et al., 2021; Greenberg et al., 2020).

Among studies in Italy, France, and the U.S., days spent in isolation had variable effects on caregiver well-being. Carpinelli Mazzi et al. (2020) found a significant association between days in lockdown and anxiety and depression among caregivers. Another study found that in home caregivers, no significant association was seen between time since lockdown and major depression, major anxiety, high perceived stress or severe burden (Borg et al., 2021). In France, Italy, and the U.S., length of time in lockdown and isolation had variable associations with major depression, anxiety, high perceived stress, and severe burden (Borg et al., 2021; Carpinelli Mazzi et al., 2020; Cohen et al., 2020).

Other sources of stress included financial strain and the caregiver's own health. Israeli caregivers with a net monthly income greater than or equal to the national average had a lower likelihood of forgone care for themselves (i.e., failing to see a doctor when needed) compared to those with net monthly incomes below average (Werner et al., 2021). Caregivers with a higher number

of chronic conditions were also more likely than non-caregivers to report reduced illness self-efficacy since the pandemic (Polenick et al., 2022).

### *Psychological Well-Being of Caregivers*

Studies of caregivers' psychological well-being examined the effect of the pandemic on mental health and caregiver distress. Caregiver distress includes the negative psychological perceptions by caregivers measured through self-reported anxiety, irritability, depression, nighttime disturbances, changes in weight or appetite, and hallucinations or delusions (Alexopoulos et al., 2021; Borelli et al., 2021; Guerrini et al., 2021; Manini et al., 2021; Park, 2021; Penteado et al., 2020). Caregivers of people with dementia experienced increased anxiety, depression, suicidal ideation, and overall poor mental health since pre-lockdown and compared to non-caregivers, in the U.S. and other countries (Borg et al., 2021; Carpinelli Mazzi et al., 2020; Czeisler et al., 2021; Hughes et al., 2021; Rainero et al., 2021; Soares et al., 2020). Even short-term caregivers were more likely to report psychological distress than non-caregivers (Park, 2021). In addition, most informal caregivers reported moderate to severe anxiety and depression symptoms, as well as overall increased stress levels (Borelli et al., 2021; Rusowicz et al., 2021; Sheth et al., 2021; Soares et al., 2020; Tam et al., 2021; Tsapanou et al., 2021). Caregiver concern for their own health and the health of their care recipients was a significant source of distress, as many felt added responsibility to shield recipients from the negative realities of the pandemic (Irani et al., 2021; Keng et al., 2020; Rusowicz et al., 2021; Todorovic et al., 2020). Novel pandemic concerns, such as adhering to public safety guidelines and accessing care for the recipient, may also compound caregiver stress (Lightfoot, Yun, et al., 2021). Feelings of depression were significantly associated with confusion on public health guidelines, and caregivers who were more worried about the pandemic were at greater odds of experiencing role overload than those who were less concerned (Leggett et al., 2021; Savla et al., 2021). Caregiver distress may, in turn, skew perceptions by caregivers of their own health as worsening during lockdown, even if they are not founded on clinical evidence (Rusowicz et al., 2021).

Declines in the mental health of caregivers during the pandemic likely contributed to poor physical health outcomes. In a study of family caregivers of people with dementia in Spain, 60% reported changes in body weight, 34% experienced sleep disorders, and 12% experienced eating disorders (Carcavilla et al., 2021; Rusowicz et al., 2021). Additionally, care complexity was a significant negative predictor of mental health during lockdown, while care intensity was associated with greater anxiety and depression during lockdown (Czeisler et al., 2021; Todorovic et al., 2020).

Social isolation typically negatively impacted caregiver mental health during lockdown (Hanna et al., 2021; Lightfoot, Moone, et al., 2021). Degree of social isolation was a major risk factor for caregiver burden, with the majority of caregivers feeling isolated at least some of the time during quarantine (Leggett et al., 2021; Tam et al., 2021). In the Leggett et al. study, around two-thirds of caregivers reported being isolated at least some of the time and largely attributed loneliness to being apart from friends and family, citing inability to leave home as the most difficult aspect of quarantine (Leggett et al., 2021). Caregivers with insufficient social support were at greater odds of experiencing role overload (Giebel et al., 2020; Hanna et al., 2021; Savla et al., 2021). In France, caregivers who lived with care recipients were more likely to feel isolated during lockdown, which was a risk factor for poor mental health (Borg et al., 2021). The association between social isolation and anxiety has been well-documented in the literature, likely explaining the worsened mental health of caregivers during lockdown (Santini et al., 2020). Loss of social activities such as sports and interest groups may also contribute to worsened mental health of caregivers in quarantine, as these provide regular opportunities for community and connection.

More advanced dementia was generally associated with higher caregiver ratings of emotional and social loneliness (Carbone et al., 2021). Confinement during COVID-19 increased caregiver stress at all levels of the patient's dementia stage (initial, intermediate, or severe dementia; Cohen et al., 2020). In Hwang et al, caregivers with anxiety reported lower functional status of care recipients compared to caregivers who did not report anxiety, suggesting an association between dementia stage and caregiver well-being (Hwang et al., 2021). This may be attributed to the fact that caregivers of adults with more advanced dementia had higher baseline stress levels, as they generally have higher personal involvement in the recipients' life (Cheng, 2017).

Family caregivers in particular reported higher anxiety, depression, fatigue, sleep disturbance, lower social participation, lower financial well-being, increased food insecurity, and increased financial worries compared to non-caregivers (Beach et al., 2021; Noguchi et al., 2021). In a study in Serbia, caring for a family member was found to be a significant predictor of caregivers' physical health (Todorovic et al., 2020). This is likely due to the greater emotional attachment shared between family members, as caregivers cited concern toward the recipients' health as a significant source of worry (Irani et al., 2021).

Among international family caregivers surveyed, words such as "sadness," "trauma," "anger," "frustration," and "helplessness" were most commonly used to describe their experience, reflecting the psychological toll of caring for a loved one in lockdown (Nash et al., 2021). In the first phase of the pandemic from spring to summer 2020, parental caregiving increased in almost

all European countries, suggesting a correlation with the increased strain reported by caregivers during this time (Bergmann & Wagner, 2021). In a study in Germany, caring for older relatives was also associated with a higher chance of missing pre-pandemic life than people who did not care for older relatives (Brandt et al., 2021).

Increased time together with care recipients also increased caregivers' distress during quarantine (Cravello et al., 2021). Greater facetime in lockdown allows caregivers to better witness patients' neuropsychiatric symptoms as well as declines in their functional status, which may be especially distressing for caregivers who share a strong bond with the recipient (Cravello et al., 2021; Maćkowiak et al., 2021). In a study in Italy, a modest yet significant association was found between caregiver distress and neuropsychiatric symptoms of recipients both before and during lockdown (Manini et al., 2021; Penteadó et al., 2020). Another study in Greece showed that perception of cognitive decline in people with dementia increased caregiver distress even if they were unfounded in reality, i.e. patient symptoms had not actually worsened since pre-lockdown (Alexopoulos et al., 2021). Unpaid caregivers reported the deterioration in emotional well-being of recipients as a new source of anxiety since lockdown, further supporting these findings (Hanna et al., 2021).

Studies found that the mental health of caregivers may affect not only themselves, but also the health of care recipients during quarantine. Caregivers may displace their anxiety and depression onto the care recipient via maladaptive behaviors, which range from impatience and irritability to elder abuse and neglect (Dang et al., 2020; Greenberg et al., 2020). Even mild forms of lashing out can exacerbate recipients' behavioral and psychological symptoms in dementia, causing "second-hand distress" (Keng et al., 2020; Moretti et al., 2021; Pongan et al., 2021; Soares et al., 2020). Caregivers with previous alcohol or drug use may increase dependency during lockdown while those in remission may experience relapse, increasing risk for abusive behavior (Makaroun et al., 2020). These issues pose serious risks for the health and safety of both parties if poor mental health of caregivers is unaddressed, highlighting the need for greater safeholds on caregiver well-being during lockdown.

Though findings indicate declines in caregiver mental health, it is hopeful that poor mental health does not appear to permanently impact caregivers once restrictions are lifted. In fact, just 2 months post-lockdown, Italian caregivers' psychological well-being improved significantly after spending 69 days in quarantine (Moretti et al., 2021). These findings are optimistic since they suggest caregivers have great capacity for psychological improvement as the pandemic lessens its grip over time.

### *Protective Factors for Caregiver Well-Being*

Healthy coping strategies, exercise, quality relationships with the care recipient, and social support services had beneficial effects on caregiver well-being (Greaney et al., 2021; Lightfoot, Moone, et al., 2021; Sánchez-Teruel

et al., 2022). In one study, caregivers cited enjoying the slower pace of quarantine, increased time with the care recipient, and a deepened relationship with the recipient (Lightfoot, Moone, et al., 2021). However in another study, roughly half (50.9%) of home caregivers felt their relationship with the care recipient had become more difficult since lockdown (Borg et al., 2021). These factors are more difficult to appraise than quantitative measures of caregiver well-being, but are nonetheless integral aspects of lockdown that should be considered in the conversation on caregiver well-being.

Coping strategies generally had a positive relationship with observed well-being in caregivers (Sánchez-Teruel et al., 2022). Self-efficacy and positive coping strategies played mediating roles independently and together on mental health of caregivers during lockdown, while education and social support were associated with lower anxiety and depression and greater perceived well-being among caregivers in Italy, the U.S., and the UK (Carpinelli Mazzi et al., 2020; Sánchez-Teruel et al., 2022). Social support was similarly predictive of higher well-being in UK caregivers, as was living in a large house (Sánchez-Teruel et al., 2022). These findings suggest caregiver interventions should aim to improve caregivers' self-efficacy and adoption of positive coping strategies while avoiding negative ones. Among caregivers in Jamaica, positive coping strategies included faith, spirituality, and gardening, which caregivers said gave their lives purpose as they navigated the uncertainties of the pandemic (Stubbs et al., 2021).

Physical activity, whether of moderate or high intensity, has also been a protective factor of caregiver well-being during the pandemic. In one study in the U.S., the majority of caregivers reported an increase in sedentary behavior and screen time, but 48% also reported increased vigorous physical activity while 55% reported increased moderate physical activity (Greaney et al., 2021). Caregivers who lived with the care recipient were more likely to report increased sedentary behavior, increased weekday screen time, and to provide care for more days per month than those who did not live with the recipient, supporting other findings that residence with the care recipient was associated with greater burden (Greaney et al., 2021; Vislapuu et al., 2021).

Social services played a key role in supporting caregivers during lockdown. These include adult day care centers, support groups, and community activities for people with dementia and their caregivers (Giebel, Pulford, et al., 2021). In a study in the UK, social service use dropped significantly in April 2020 at the start of lockdown, then increased from July to August 2020 (Giebel, Pulford, et al., 2021). Caregiver well-being also increased from July to August 2020, suggesting it may be associated with greater use of social services (Giebel, Pulford, et al., 2021). Caregiver anxiety likewise decreased during this period while cases of depression actually increased, possibly due to caregiver burnout toward the end of lockdown (Giebel, Pulford, et al., 2021).

Resilience was another protective factor explored in multiple studies. Resilience can be understood as a multidimensional construct explaining how individuals adjust to experiences they perceive as threatening to their sense of self, especially in ways that favor a positive outcome (Palacio et al., 2020). Interestingly, though resilience typically has protective effects against depression and anxiety, this was not consistently observed during the pandemic (Altieri & Santangelo, 2021; Sánchez-Teruel et al., 2022). A strong positive relationship between well-being and resilience was observed in one UK study, while an Italian study found caregivers with high resilience actually experienced a greater increase in anxiety than those with low resilience (Altieri & Santangelo, 2021; Sánchez-Teruel et al., 2022). These findings may be explained by the fact that unprecedented global events such as the pandemic can alter or void pre-existing advantages of high resilience, changing our previous understandings of caregiver burden (Altieri & Santangelo, 2021). Another explanation is that higher resilience in caregivers during lockdown may decrease willingness to ask for help, disposing them to higher mental burden.

### Support for Caregivers

With findings largely illustrating the negative effects of the pandemic on caregiver well-being, studies are exploring interventions to better support caregivers. Interventions may include family support programs, telehealth video-conferencing, team based approaches to homecare, and targeted patient referrals by healthcare staff (Dang et al., 2020; Paplikar et al., 2022).

A family support intervention developed by the Alzheimer's Regional Center of Rhodense in Italy was shown to decrease caregiver burden, in spite of caregivers' witnessing declines in the care recipient's functional status, suggesting that greater caregiver support may lessen the negative effects of recipient health on caregiver distress (Cravello et al., 2021). In interventions of telephone-based reality orientation therapy, people with neurocognitive symptoms of dementia were found to improve during lockdown, subsequently lowering caregiver burden (Panerai et al., 2021). Programs such as Coordinated Care At Risk/Remote Elderly (CCARRE) at The Montefiore–Einstein Center for the Aging Brain in New York ease caregiver burden by providing social services for utilities, food, and housing since the start of the pandemic (Weiss et al., 2020).

In patient-caregiver dyads exposed to telehealth video-conferencing, varying improvements were seen in the physical/mental health, perceived burden, and self-efficacy of caregivers (Lai et al., 2020). One caveat of telehealth support is that caregiver presence during virtual visits may hinder the care recipient from disclosing neglect or abuse, preventing them from receiving the help they need (Makaroun et al., 2020). As such, care must be taken in the health settings occupied by both

caregiver and recipient to ensure the recipient receives proper care.

These interventions, in conjunction with the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act, which seeks to provide support for more than 43 million unpaid family caregivers by the U.S. Department of Health and Human Services, provide hope for increased levels of well-being among caregivers, especially caregivers for people with dementia (Dang et al., 2020). Policy recommendations include offering a condition-specific approach for dementia types and providing support bubbles with other families for resource sharing (Onwumere et al., 2021). In addition, greater emphasis should be placed on community resource allocation of social services (case workers, food and utilities assistance) to informal caregivers when possible. Hospitals should offer expanded telehealth services to older adults with dementia and aid in coordinating contactless appointments and medication distribution, as these interventions showed improvements in caregiver well-being and decreased burden.

### Discussion

In this review of informal caregivers to people with cognitive impairment or dementia during lockdown, we found pandemic-related challenges that increased caregiver burden and impacted their psychological state. Not all findings represent novel risk factors of caregiver burden, but the pandemic appears to have heightened pre-existing risk factors while introducing some new ones. Overall, the strain on caregiver burden and psychological well-being reflects the general decline in mental health during the pandemic among individuals with and without pre-existing mental illness (Dubey et al., 2020). Mass-scale social isolation, herd behavior, and spread of the social media "infodemic" have increased adverse mental health outcomes in much of society since the pandemic began (Dubey et al., 2020). The fact that female, Hispanic, and non-Hispanic Black caregivers experienced greater anxiety and depression also highlights pre-existing disparities in the caregiver workforce, which is predominantly female and people of color (Adelman et al., 2014; Czeisler et al., 2021). Other demographic factors associated with poor mental health, such as living in a smaller house or with a greater number of individuals per household, reflect inequities in income and housing that may be exacerbated by lockdown (Sánchez-Teruel et al., 2022).

The cultural context of studies is another consideration of our review. In countries like Serbia, greater emphasis on elderly assistance from youth may alleviate caregiver burden, though Serbia's higher proportion of female and family caregivers may have other implications on burden (Todorovic et al., 2020). Most studies examined were from the U.S. and the UK, highlighting a need to better compare caregiver experiences among countries.

Almost all papers included in this review were cross-sectional and conducted in the first year of lockdown, before vaccines were available. Caregivers during the first year of the pandemic faced the most limited resources and stringent public health measures. Such extenuating circumstances may have exacerbated the effects of the pandemic on caregiver well-being. Lack of longitudinal information at this time limits our ability to identify broader impacts of the pandemic on caregiver well-being, though its impacts within the first year are significant enough to warrant greater telehealth, social services, and axillary health support to caregivers at this time.

## Appendix

Article (N=64)	Design	Sample
<i>Caregiver Burden (N=28)</i>		
Beach et al. (2021)	Cross-sectional	N=576
Borelli WV et al. (2021)	Cross-sectional	N=58
Borges-Machado et al. (2020)	Cross-sectional	N=36
Budnick A et al. (2021)	Cross-sectional	N=1000
Carcavilla et al. (2021)	Cross-sectional	N=106
Cohen G et al. (2020)	Cross-sectional study	N=80
Hughes et al. (2021)	Rapid review	N=10
Hwang et al. (2021)	Cross sectional	N=34
Irani et al. (2021)	Cross sectional	N=69
Keng a et al. (2020)	Descriptive article	NA
Leggett et al. (2021)	Cross-sectional	N=311
Lightfoot et al. (2021)	Cross-sectional	N=52
Longacre et al. (2021)	Cross-sectional	N=285
Mackowiak ete al. (2021)	Cross sectional	N=21
Makaroun LK et al. (2020)	Descriptive article	NA
Nash WA et al (2021)	Cross-sectional descriptive study	N=512
Panerai S et al. (2021)	Nonrandomized interventional comparison study	N=27
Polenick C et al. (2021)	Cross-sectional	N=105 caregivers, 590 non-caregivers
Rajovic et al. (2021)	Cross-sectional	N=798
Rusowicz J et al. (2021)	Cross-sectional	N=85
Salini et al. (2022)	Literature review	N=13
Sheth K et al. (2021)	Cross-sectional	N=221 caregivers (Jan 2020); N= 177 caregivers English and N=144 Spanish (April-June 2020)

## Conclusion

The COVID-19 pandemic has greatly impacted all aspects of our daily lives, especially those of caregivers. Our findings emphasize the urgency of addressing COVID-19's effects on caregiver well-being, a crisis of mental and physical strain running parallel to the course of the global pandemic. While these studies demonstrate the significant role caregivers play in recipients' lives, the onus of caregiving does not fall solely on them. Through systems-based solutions, aid to caregivers can hopefully reduce burden and facilitate greater wellbeing in caregivers, and by extension, their loved ones.

Stubbs M et al. (2021)	Cross-sectional	N=19
Tam MT et al. (2021)	Cross-sectional	N=417
Todorovic N et al. (2020)	Cross-sectional	N=112
Tsapanou A & Papatriantafyllou et al. (2021)	Cross-sectional	N=204
Tsapanou A & Zoi P et al (2021)	Cross sectional	N=339
Werner P et al. (2021)	Cross-sectional	N=73
<b>Caregiver Mental Health (N=23)</b>		
Alexopoulos P et al. (2021)	Cross-sectional	Caregivers of patients with mild (N = 13) and major (N = 54) neurocognitive disorders
Altieri & Santangelo (2020)	Quantitative cross-sectional study	N=84
Bergmann & Wagner (2021)	Cross-sectional	N=51,983
Borg et al. (2021)	Cross-sectional	N=389 home caregivers; 159 nursing home caregivers
Brandt M et al. (2021)	Cross-sectional	N=425
Carbone et al. (2021)	Cross-sectional	N=35
Carpinelli M et al. (2020)	Cross-sectional study	N=239
Czeisler G et al. (2021)	Cross-sectional	N=1362
Daley et al. (2022)	Cross sectional nested study	N=16
Dang S et al. (2020)	Letter to the editor	NA
Del Rio-Lozano et al. (2022)	Cross sectional	N=261
Dubey et al. (2020)	Literature review	NA
Giebel C & Lord K et al. (2021)	Cross-sectional	N=569 (61 people with dementia, 285 unpaid carers, 223 older adults)
Greenberg NE et al. (2021)	Descriptive article	NA
Guerrini CJ et al. (2021)	Cross sectional	N= 1,366
Noguchi et al. (2021)	Cross sectional	N=957
Park S (2021)	Cross-sectional	N=4784
Penteado C et al. (2020)	Cross-sectional study	N=100
Pongan E et al. (2021)	Cross-sectional	N=389
Rainero et al. (2021)	Cross sectional	N=4913
Sanchez-Teruel et al. (2021)	Cross-sectional	N=310
Santini et al. (2020)	Cross sectional	N=3005
Soares WB et al. (2020)	Descriptive article	NA

Figure A1. continued



<i>Protective Factors on Caregiver Well-being (N=7)</i>		
Giebel C & Pulford D et al. (2021)	Cross sectional	N= 337
Greaney et al. (2021)	Cross-sectional study	N: 835
Hanna K et al. (2021)	Cross sectional	N=15 unpaid carers, 4 patients
Lightfoot et al. (2021)	Cross sectional	N=52
Manini A et al. (2021)	Cross-sectional	N=94
Moretti et al. (2021)	Longitudinal study	N=221
Savla J et al. (2021)	Cross-sectional	N=53
<i>Caregiver Support (N=6)</i>		
Cravello L et al. (2021)	Interventional study	N=34
Lai FH et al. (2020)	Nonrandomized interventional comparison study	N=60
Onwumere et al. (2021)	Descriptive article	NA
Paplikar et al. (2022)	Literature review	N=37
Vislapuu et al. (2021)	Prospective study	N=105
Weiss EF et al. (2021)	Cross sectional	N=85

**Figure A1.** Articles.

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