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## Being a Caregiver in the Time of a Pandemic: An Integrative Review

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**Being a Caregiver in the Time of a Pandemic: An Integrative Review**

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## COVID-19 AND CAREGIVER BURDEN

### Abstract

**Aim:** To review and analyze research to better understand the effects of COVID-19 on informal caregivers and the strategies that could be employed to help the caregiver cope with any additional stress or burden of care.

**Background:** Informal caregivers are not paid for their services and often are not medically trained but provide care for their care recipients. Caregivers deal with stress while managing their care recipient's health, financials, and social adjustments. The impact of COVID-19 and quarantine compounded the stressors of the caregiver. During stressful times, the health and well-being of the caregiver needs to be preserved.

**Evaluation:** A comprehensive search was performed for research conducted between March 2020 and November 2021. Key search terms were *COVID-19*, *pandemic*, *caregiver(s)*, and *caregiver burden*. This methodological review was conducted using the Whittemore and Knafl integrative approach.

**Key Issues:** Changes implemented with the emergence of COVID-19 contributed to additional mental and physical conditions in the informal caregiver including increase in stress, financial concerns, somatic symptoms, and depression. Strategies employed to help the caregiver cope are increasing physical activity, offering emotional support, and the use of telehealth.

**Conclusion:** This review provides information about the impact COVID-19 had on the informal caregiver. Understanding how to support the informal caregiver during a time of the pandemic can help with the outcomes and quality of life for the patients and caregivers.

**Implications for Nursing:** Shifting focus from patient-centered care to family-centered care can change the outcomes of the over-burdened caregiver.

Keywords: COVID-19, pandemic, caregiver(s), caregiver burden

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### **Being a Caregiver in the Time of a Pandemic: An Integrative Review**

Those individuals that take on the role of caregiver (CG) are often plagued with mental and physical strain, likely caused by feeling overwhelmed or underprepared for their role (Holland, et al, 2020). Per the National Alliance on Caregiving (2020), approximately 53 million adults were reported to be informal CGs within the United States. These CGs are not paid for their services and often are not medically trained but provide care for their loved ones, family, or friends while putting their lives on hold (Kent, 2020). Many forego their life plans to provide support and maintain a household for someone with a life-limiting disease (Kent, 2020). Caregiving is a difficult undertaking without the consideration of the influence of a pandemic. The emergence of the pandemic COVID-19 compounded the difficulties of caring for someone with a disability due to the isolation of the family and the scarcity of healthcare resources. These changes, among others, effect the ability of the valued, informal CG to provide for their loved ones.

### **Clinical Problem**

According to Sabella and Suchan (2019), those individuals assuming the CG role take on more than health management but also medication management, financial burdens, and social adjustments. They also have a lower quality of life due to elevated stress, social isolation, disturbances of sleep patterns, lack of privacy, and increased physical illness combined with many mental health issues (Sabella & Suchan, 2019). Isolation can also contribute to the feelings of loneliness and a decrease in mental well-being. Many CGs provide for those who suffer from aphasia or dementia making it difficult to communicate (Leaman & Azios, 2021). This lack of communication may compound their feelings of isolation making them a greater risk for both mental and physical health issues. According to Leaman and Azios (2021), CGs who

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experience isolation are at an increased risk for coronary artery disease, diabetes, cerebrovascular accident (CVA), and mental health conditions such as depression and anxiety.

The wellness of the CG can reciprocally decrease the outcomes for their ailing care recipients (CRs) especially if the CR has a more profound disability (Coxe, et al, 2020). A study referenced by Sutter-Leve, et al (2021) concluded that after CVA, a CR's health and functional outcomes reduced when their CG suffered from mental health issues. Kuzuya et al. (2011) reported increased stress in CGs being associated with increased hospitalization and mortality rate in older CRs. Additionally, Isik et al. (2019) found similar results in the CRs diagnosed with Alzheimer's disease whose CG had declining mental health, further illuminating the importance of the informal CG's health and well-being.

With COVID-19, the CG burden compounded drastically due to the decrease in access to resources and the increase of isolation (Holland, et al, 2020). Many facilities had to go on diversion, and some closed completely with more than three dozen hospitals filing bankruptcy in 2020 per the American Hospital Association (2020). With the lack of hospital resources, CGs may turn to home health or care aids to assist with the care. These resources were also removed or at least diminished with the shelter-in-place ordinances (Kent et al., 2020). Without the help of an intact healthcare system, the CG had increased responsibility. Those that would turn to their friends or family to assist them had additional barriers with the shelter-in-place guidelines (Kent et al., 2020) increasing the burden and responsibility of providing care.

One of the largest changes in healthcare since the emergence of COVID-19 has been the absence or limited number of family or support persons to be allowed in the medical facility with their loved one (Bainter, et al, 2020). When a CR was hospitalized or needed medical attention, the CG may not have been allowed to enter the facility with them. According to Sutter-Leve et

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al (2021), concerns for their loved one's ability to cope in a new environment without them can increase the CG's anxiety. This also increased the CG's frustrations with communication between themselves and the medical staff (Sutter-Leve et al., 2021). It has been reported that when CGs were unable to witness the progression of their loved one while at the facility, they felt inadequate to care for them once discharged (Sutter-Leve et al., 2021). The CG reported feelings of uncertainty about the abilities of their CR and felt they lacked understanding to what assistance would be needed (Sutter-Leve et al., 2021). A narrative inquiry study performed by Karpa, et al (2020) suggests that collaborating with the CGs can address the needs of the family unit and increase satisfaction of the continuum of care post discharge. The education of the CGs should be inclusive of items that could minimize their stress while their care recipient (CR) is the hospital system (Newcomb & Hymes, 2021). Other strategies could include encouraging self-care or facilitating the communication with other clinicians (Newcomb & Hymes, 2017).

The purpose of this integrative review is to review and analyze previously conducted research on informal CGs changes in stress and burden of care during COVID-19. To further assist the CGs during COVID-19 and any future pandemics, the author investigated possible interventions to increase coping strategies of the CG.

### **Scope of the Review**

While there are many studies on the strain of informal caregiving, there is paucity in the changes of the role and burden since the emergence of COVID-19 in the United States. Because of the lack of research in this arena, the author conducted an integrative review of peer-reviewed literature on CGs of adults with varying health conditions during the time of COVID-19. This methodological review was conducted using the Whitemore and Knafl (2005) integrative approach allowing for inclusion of many different research designs, specifically non-

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experimental research to further investigate the mental and physical transformations a CG might experience. Following Whitemore and Knafl's (2005) framework, the author addresses the five stages of an integrative review: problem identification, literature search, data evaluation, data analysis, and presentation. Literature on changes in CG burden and stress during COVID-19 was studied to develop conclusive ideas to better prepare clinicians to understand how CGs respond and cope to changes during a pandemic.

### **Problem Identification Stage**

Utilizing the Whitemore and Knafl (2005) integrative approach, the first stage is to identify a well-defined problem to focus the review. To better understand the implications of COVID-19 on the informal CG, this integrative review was created to analyze the research that has been conducted on the changes in the stress and health of informal CGs during the time of this pandemic. Additionally, the examination of the research was intended to reveal insight on strategies clinicians could employ to support informal CGs and prepare for any future pandemics. Conducting an integrative review utilizing research questions to guide the process allowed the author to synthesize current research in CG stress and burden during COVID-19 while identifying the gaps in literature to steer future research initiatives.

The research questions that directed this review were:

- What mental and physical health changes have occurred in CG and CR population since the emergence of COVID-19?
- What changes during COVID-19 had the greatest impact on informal CGs' mental and physical health?
- What strategies did researchers suggest to relieve stressors on informal CGs?

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### Literature Search

The data search stage was conducted from March 2020 to November 2021 to ensure a sizeable collection of articles were included. During this time, the electronic databases that were searched were Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and PsycARTICLES. Key search terms were *COVID-19*, *pandemic*, *caregiver(s)*, and *caregiver burden*. Publications were included if the topic addressed CG burden during COVID-19, participants were informal CGs who were caring for adults, the research design was either qualitative or quantitative, the study was conducted within the United States, the article was written in English, and the articles were published after March 2020. The rationale for focusing on literature from March 2020 forward was to review the research conducted after the emergence of COVID-19 in the United States and analyze how this pandemic altered the lives of informal CGs. Publications were excluded if they were not published (e.g., theses and dissertations), the articles were not written in English or not conducted within the United States, participants were formal CGs (e. g., nurses), the participants of the study were under the age of 18 or caring for someone under 18, and the studies were not empirical research.

A total of 665 articles were ascertained in the initial search using the defined search terms. After removing the duplicate articles, the remaining 634 title and abstracts were reviewed to determine if the publication met the criteria. Most of the articles focused on populations other than informal CGs (e.g., healthcare workers or lesbian gay bisexual transgender queer + community) resulting in 483 articles being eliminated. An additional 118 articles were eliminated due to the participants either being under the age of 18 or caring for someone under 18. Of the remaining articles, 26 were not empirical studies conducted within the United States

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and were omitted. Seven abstracts met the inclusion criteria and the studies were reviewed.

Figure 1 details the data search or collection process.

### **Data Evaluation Stage**

Within the data evaluation stage, the author worked independently to review the quality of the identified articles by first reviewing the abstracts followed by the extensive appraisal of each publication to determine that the content focused on informal CG burden during COVID-19. Publications that met the inclusion criteria were then reviewed independently by another researcher to prevent bias. The seven articles were then evaluated to determine whether the study was either qualitative or quantitative. The author then assessed the research level and quality using the John Hopkins Nursing Evidenced-based Practice (JHNEBP) appraisal tools (Dang et al, 2022). Refer to Table 1 for article limitations, level, and quality rating. All seven articles were identified as a Level VI as they were single descriptive studies or qualitative. Due to the personal nature of the research, qualitative studies are an appropriate source of data. The narrative provided by qualitative studies is valuable in understanding the CGs experiences during a pandemic. While these studies are considered low level of evidence, the sample size of each study was sufficient. Given that the emergence of COVID-19 within the United States was March 2020, there is little experimental research available. Therefore, all seven articles (Beach et al., 2021; Greaney et al., 2021; Larson et al., 2021; Macchi et al, 2021; Park, 2021; Salva et al., 2021; Sheth et al., 2021) are included to fulfill the purposes of this integrative review.

### **Data Analysis Stage**

The author organized, grouped, and summarized the data into a matrix so that it may be compared to identify patterns, relationships, and themes (Whittemore & Knafel, 2005). To complete the matrix, the author analyzed each article multiple times searching for commonalities

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and outliers within the research. Utilizing a constant comparative method allowed the researcher to organize and sort the data into categories according to attributes. During this stage, the researcher extracted a) the population of participants in the study, b) changes identified with the emergence of COVID-19 on a CG, and c) strategies suggested by the researchers to employ that could benefit a CG. Content relating to these categories was extracted and aggregated to be further analyzed for discovering useful information in the final stage of this integrative review.

### **Review Presentation Stage**

During the final stage of the integrative review process, Whitemore and Knalf (2005) suggests amalgamating details from each identified study to present evidence in support of a conclusion. The data compiled into a table was author, year, study design, sample population, and findings of research (Table 2). This provided a final summary of the findings regarding what is known of the effects of COVID-19 on informal CG burden.

### **Results**

The results section discusses the findings of the seven articles (Beach et al., 2021; Greaney et al., 2021; Larson et al., 2021; Macchi et al., 2021; Park, 2021; Salva et al., 2021; Sheth et al., 2021) and how it relates to CG stress after the emergence of COVID-19. The findings include characteristics of the study participants, changes the CG experienced after COVID-19, and strategies suggested by the researchers to benefit the CG.

### **Research Populations**

The demographics of the study participants varied throughout the studies. Except for Greaney et al. (2021), each study that identified the gender of the CG participants reflected that a majority of them were female. Seventy-five percent of the CG participants were female in three of the studies (Beach et al., 2021; Larson et al., 2021; Sheth et al., 2021). Macchi et al. (2021)

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reported 74.4% female CG participants while Park (2021) surveyed 56.1% female long-term CGs and 59.6% female short-term CGs. Only one study did not report the gender of the CG participants (Salva et al., 2021). The largest representation of male CGs at 69% was reported by Greaney et al. (2021). Out of the seven articles, only one did not report the race of the participants. Those that did report race, had a majority of white participants ranging from 55% to 93.3% (Beach et al, 2021; Greaney et al, 2021; Macchi et al, 2021; Park, 2021; Savla et al, 2021; Sheth et al, 2021). Income of participants was reported in four studies with three articles reflecting that a majority of participants made between \$15,000 to \$50,000 annually (Greaney et al, 2021; Macchi et al, 2021; Park, 2021). Beach et al (2021) had outlier data regarding income reporting that 36.8% of their CG made between \$50,000-\$99,999 annually. Two studies explored the employment status of the participants classifying the CGs that are unable to work due to COVID-19, working from home, or working on a job site (Beach et al., 2021; Larson et al., 2021).

All CR populations were adult but those defined differed in diagnosis and level of required care. Two studies defined a CR as someone who received assistance with personal care and required caregiving (Larson et al., 2021; Park, 2021) while other studies had stricter parameters. Beach et al. (2021) defined their CR population as those having a long-term physical condition, cognitive or memory decline, or those with behavior, emotional, or development disorders. Another study reported that the CR common diagnoses were hypertension, diabetes, dementia, cardiac disease, and CVA (Sheth et al., 2021). The remaining two articles narrowed the focus of their study by defining the CR as those that have dementia (Savla et al., 2021) or those with a probable diagnosis of Parkinson's disease, Alzheimer's disease, or related disorder (Macchi et al., 2021).

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While each study has participants within the United States, there were two studies that included other territories (Larson et al., 2021; Sheth et al., 2021). One study did not define the geographical setting of the study yet recruited participants who were members of Mturk online services (Greaney et al., 2021). Three studies were narrowly focused on a region within the United States. Singularly, the only quantitative study to focus on a smaller region was conducted by Beach et al. (2021) who surveyed participants in Pittsburg and the surrounding regions. The two qualitative studies were located in smaller geographical areas. Savlta et al. (2021) was set in rural southwest Virginia and Macchi et al. (2021) focused their study in outpatient palliative care facilities at the University of Colorado and University of California San Francisco.

### **Changes During COVID-19**

Due to the isolation precautions employed during COVID-19, CGs reported an increase in stress (Beach et al., 2021; Macchi et al., 2021; Savla et al., 2021) compared to those that do not have the role of CG within their household. Stressors could be increased due to many factors. One such factor reported was difficulties obtaining the supplies, medical treatment, and support needed to properly care for the CR (Beach et al., 2021, Macchi et al., 2021). Another contributing factor was the financial change many CGs underwent during the shelter-in-place stage of COVID-19. Many CGs had to change locations of their employment or were even laid off from their jobs increasing their financial concerns (Beach et al., 2021; Larson et al., 2021).

The health of the household was also at risk with the implementation of quarantine during COVID-19. Both the mental and physical health of the CG decreased (Beach et al., 2021; Macchi et al., 2021; Park, 2021) with long-term caregivers reporting an increase in symptoms such as headache, abdominal discomfort, and body aches (Park, 2021). The changes not only occurred in the CG as many respondents reported changes in the CR health as well. The

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participants in two studies reported a decline in the mental health of the CR which increased the difficulty of providing care (Beach et al., 2021; Macchi et al., 2021). In addition to the already compounding health issues of this pandemic, the fear of contracting COVID-19 was also reported (Macchi et al., 2021; Savla et al., 2021). Savla et al. (2021) had 62% CG report concerns about the suggested guidelines for protection and the risk of illness from COVID-19. One study further examined this phenomenon and found that both CG and CR participants feared to travel for medical care due to the increased risk of contracting the disease (Macchi et al., 2021). This could potentially delay treatment causing further health injuries.

Noteworthy to mention is one study which was an outlier in this integrative review. Sheth et al. (2021) results differed from all other studies showing little to no change from pre-pandemic in January 2020 to after isolation precautions were employed in April 2020 in the CG's reports of depression or self-worth but did report an increase in the CG stress. The discrepancy in reports of depression or self-worth could be attributed to the already high reports of depression pre-pandemic so the CG felt little to no change with the emergence of COVID-19 (Sheth et al., 2020). Another factor could be the timing of the study. Three articles reported conducting their studies later into the pandemic, thereby resulting in higher reports of depression and lower self-worth (Beach et al., 2021; Larson et al, 2021; Macchi et al., 2021).

### **Strategies to Benefit Caregivers**

Alternatives to traditional medical and support services sought out during quarantine were telehealth (Macchi et al., 2021; Savla et al., 2021) and utilizing personal relationships to aid in services such as food delivery (Savla et al., 2021). Fifty-nine percent of respondents reported that formal services of telehealth and meal deliveries were sufficient to assist the CG during the time of quarantine (Savla et al., 2021). One study had respondents that were not as satisfied with

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telehealth reporting that it was a good short-term substitute for traditional medical care, but the participants eventually lost motivation to continue the appointments (Macchi et al., 2021).

Utilizing the strengths developed by the CG/CR relationship living within the same household could also assist with coping. Although increased conflict within the households were reported, Larson et al. (2021) found that homes with a CG/CR relationship had better cohesion than that of a non-CG household. These families reported increased flexibility and adaptability, open communication with each other, and an increased sense of purpose (Larson et al., 2021) during the time of a pandemic. Other coping strategies were reported to decrease the stressors of a CG (Savla et al., 2021). Active strategies such as gardening or painting were utilized in 57% of the respondents versus passive strategies such as playing games or using social media in 43% of CGs (Salva et al., 2021). One study explored activity levels of the CG to see what changes had occurred during the pandemic to their daily schedule (Greaney et al., 2021). Greaney et al., 2021 reported that CGs had a decrease in physical activity and increase in sedentary behavior including screen time during the pandemic to cope with the changes (Greaney et al., 2021). While the research studies did not define which coping strategies were more successful in decreasing stress for the CG, Greaney et al. (2021) did suggest that a decrease in the active coping strategies may contribute to the physical deterioration of the CG.

### **Discussion**

There are many similarities found in research literature regarding the effects of being an informal CG such as an increase in mental health disorders and deterioration in physical health. According to Sabella and Suchan (2019), those assuming the CG role have a lower quality of life due to elevated stress, social isolation, disturbances of sleep patterns, lack of privacy, and an increase in physical illness combined with a multitude of mental health issues. Reciprocally, the

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CG's health can impede the progress of the patient. The restrictions following the COVID-19 outbreak have increased many complications experienced by the CG (Beach et al., 2021; Larson et al., 2021; Macchi et al., 2021; Park, 2021; Savla et al., 2021).

### **Implications for Nursing**

Nurses can make a large difference in the outcomes and quality of life for both the CG and their CR. Both populations need additional assistance and support during this pandemic (Beach et al., 2021). Multiple strategies such as family centered care, telenursing, and utilization of coping strategies may be implemented to serve CGs during the time of a pandemic and beyond.

### ***Family Centered Care***

A common mantra within healthcare is to treat the patient, not the illness (Centor, 2007). The focus for those receiving informal care should be expanded to include family centered care and the CG. Karpa et al. (2020) states that nurses understanding of the CG's needs and emotional support aids in making the CGs more effective collaborators of care by increasing the CGs willingness to participate in care. Nurses need to recognize that informal CGs are a vital part of the healthcare team and that the demands of providing that care can be considerable (Jadalla et al., 2020). Asking the CG how they are doing, using direct observation, or an informal assessment tool will assess the CGs needs (Jadalla et al., 2020) as well as establish trust between the nurse and the CG (Newcomb & Hymes, 2017). Beyond assessment of the CG, education is essential to increase the confidence of the CGs ability to care for their loved-one (Jadalla et al., 2020). Without education about the CR, CGs reported that they had difficulty understanding medical terminology and struggled adjusting to their role as CG thereby increasing the CG's

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stress (Newcomb & Hymes, 2017). Education may be conducted in-person, by telecommunication or virtually (Jones, 2021).

To bridge the gap between the patient and their CG, some facilities have utilized nurse-driven telecommunication (also referred to as telenursing) (Goudarzian et al., 2018) by nurses contacting the CG at regular intervals to give updates (Newcomb & Hymes, 2017) while others introduced “Get to Know Me” white boards with personal details about the CR to humanize the patient and establish trust with the CG (Jones, 2021). Nurses also facilitated the use of technologies such as telephone, computer, or telemonitoring to care for chronic patients at home (Goudarzian et al., 2018). The use of the aforementioned technologies also allows the nurse the ability to keep communication open between the CG, the CR, and other clinicians (Jones, 2021) ensuring that the team was corresponding and informed of any changes in treatment plans.

### *Utilization of Telehealth and Home Health*

Some researchers choose to look at the COVID-19 outbreak with optimism to push healthcare into a new era (Coxe et al., 2020; Goudarzian et al., 2020; Rivaz et al., 2020). The optimism is mostly focused on the use of technology as a method for nurses to conduct assessments remotely and provide support. When a CG does not feel comfortable sending the CR into a medical facility due to the risk of getting COVID-19 (Rivaz et al., 2020) or because the CG was not allowed to accompany them (Macchi et al., 2021), technology could be utilized to conduct visits. The use of telehealth may not reach all populations, but it could allow a large portion of those in the United States to get the treatment needed. When delaying or foregoing treatment, there is a risk that the CR may develop a severe illness or complications that may lead to hospitalization or death (Rivaz et al., 2020). With the available of telenursing options to the CG, nurses may be able to prevent illness and complications of the CR (Goudarzian et al., 2018).

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Telehealth is not only beneficial for the patient but has been shown to relieve some of the CG stressors. Both Goudarzian et al. (2018) and Coxe et al. (2020) conducted studies of the benefits of telehealth for CGs. Both studies resulted in a significant improvement on the CG's anxiety. Additionally, 88% of the participants claimed a reduction of depression symptoms by utilizing computer-based videoconferencing with therapists (Coxe et al., 2020) which could be utilized by nurses when assessing the CR or providing emotional support for the CG. Signal et al. (2020) reported cost effectiveness as an advantage of implementing telerehabilitation sessions versus a traditional in-person session potentially decreasing one of the financial obligations on the CG (Beach et al., 2021, Larson et al., 2021). The research suggests encouraging the development of programs and applications that could be embedded into all of healthcare to allow greater access to rehabilitation, counseling, and medical assistance in general.

For those that do not have access to telehealth, the reinstatement of home health visits adhering to infection control measures or telecommunication may be required (Macchi et al., 2021). This is especially true for those that are older and in rural areas (Kent et al., 2020). These populations may experience gaps in critical health care that need another solution. Community nurses are uniquely positioned to allow the CG the opportunity to express and voice their concerns (Burdett et al., 2020).

### *Support and Coping Strategies*

After determining the existing coping mechanisms used by the CG, nurses should reinforce the positive coping strategies while supporting them to change the negative coping mechanisms (Dinç & Erdoğan, 2021). In Greaney's et al. (2021) study, most participants reported a decrease in physical activity instead choosing a sedentary lifestyle. Promotion of the physical activity should be incorporated with strategies to assist the CG in meeting their goals

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(Greaney et al., 2021). Savla et al. (2021) suggest encouraging the outlets that a CG enjoyed prior to pandemic whether it was an active or passive coping strategy.

In addition, clinicians may choose to teach new methods of self-care for CG to increase their mental and physical wellbeing. Many of the self-care strategies that nurses utilize may also be applied to the CG. Practicing mindfulness and performing breathing exercises have been shown to decrease stress by strengthening the parasympathetic nervous system (Hossain & Clatty, 2020). Reinforcing that it is necessary and not selfish for a CG to take time for oneself may be needed for the betterment of their health (Burdett et al., 2020). There are also many CG advocacy programs that can be suggested. The Family Caregiver Alliance and National Alliance for Caregiving are in the forefront of providing guidance during COVID-19 (Kent et al., 2020). Nurses need to know the local community organizations that may provide support (Savla et al., 2021) so that they can suggest CGs utilize these resources such as meal delivery (Kent et al., 2020) or peer support groups (Burdett et al., 2020).

### **Limitations**

There were several limitations to this study: primarily, the lack of experimental research. The research design for the seven articles were mostly quantitative surveys or qualitative interviews. While surveys are an appropriate tool to quantify the variables of CG stress, most of the surveys conducted were cross sectional and only investigated the CG changes within one period of time (Beach et al., 2021; Greaney et al., 2021; Larson et al., 202; Park, 2021). Due to the short time frame to conduct research on the effects of COVID-19, the ability to suggest the long-term impact on CGs is limited. Longitudinal surveys could give a clearer idea of how COVID-19 has affected the CG's mental and physical wellbeing throughout the different phases of COVID-19 including the "shelter-in-place" stage. Longitudinal studies could explore how a

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CG felt not only during the different stages of the pandemic but also investigate the changes in stress related to the availability of vaccines.

Within two of the articles (Greaney et al., 2021; Larson et al., 2021), the instruments used had strong validity and reliability. Validity of instruments used in surveys is required to ensure the concept is accurately being measured (Heale & Twycross, 2015). For example, the use of a tool measuring depression would not be valid for measuring stress of a CG. Reliability is defined as the replicability of the study meaning that when a participant retakes a survey, they would get similar results consistently (Heale & Twycross, 2015). The use of the two instruments COVID-19 Household Environment Scale (CHES) (Larson et al., 2021) and Caregiver Burden Index (CBI) (Greaney et al., 2021) offer validity and reliability to these two studies regarding the short-term effects of COVID-19 on CG. The success of these instruments could be used in collaboration to further research CG burden during COVID-19.

There were many other limitations including demographics, health conditions, and situational context. Information related to CG demographics and the CR health conditions were lacking in some of the articles. Contextual variables such as specific caregiving tasks and living arrangements were often not addressed in the research studies.

Of the seven articles, two articles defined the CR by diagnoses (Macchi et al., 2021; Savla et al., 2021). Per Larson et al. (2021), the type and severity of the CG disability has been noted within previously conducted research to have an impact on the care demands and CG burden. The author found limited information about the CR's level of dependency describing assistance needed to perform daily functions such as eating, dressing, and bathing. Level of dependency along with the hours of caregiving duties performed each day could further define the pre-pandemic stressors the CG is experiencing. Without the contextual variables defined

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above, researchers are not provided with a clear picture of the different intensities of daily care that have been included in the studies.

Additionally, the living arrangements of the CR were not clearly defined in all of the articles (Beach et al., 2021; Park, 2021; Sheth et al., 2021). Only one article stated that the CR must be living in the household (Larson et al., 2021). The stress of the CG may vary depending on the living situation of the CR resulting in different challenges and inconsistencies in the data of CG burden. If the CR is living in a facility, this would suggest that the CG participant is not the sole CG and has assistance potentially decreasing their burden and stress. The results of a study for a CG receiving help versus someone who is the sole CG could vary drastically (Park, 2021).

### **Recommendations**

The need for further research as COVID-19 progresses is imperative to prepare clinicians for future pandemics. Additional studies conducted to determine the CR level of independence, living situation, and diagnosis could further define the stressors of the CG. Longitudinal studies could be beneficial to show what successes were implemented during COVID-19 and what still needs to be improved upon. Furthermore, research needs to be continued to explore the long-term effects of the pandemic on the stress and burden of the CG. New consequences of this pandemic are bound to emerge that could affect the CG's financial status, mental health, and physical wellbeing (Park, 2021).

Prior to the pandemic, many studies have been conducted regarding CG burden (Goudarzian et al., 2018; Isik et al., 2019; Kuzuya et al., 2011; Newcomb & Hymes, 2017; Sabella & Suchan, 2019). Furthermore, the author found during the literature search of this integrative review, that much research has been completed about the impact of COVID-19 on the

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general population as well as healthcare workers, but little is known about how the changes implemented affected informal CGs (Beach et al., 2021). The health of the CGs alone could be reassessed over longer periods to ascertain any residual implications of the isolation and stressors caused by COVID-19. Additionally, future studies could narrow the parameters of their research. Prior research has focused on limited outcomes, CR populations, and/or has not included contextual variables (e.g., CG-CR relationship, specific caregiving tasks, and CR health conditions) which has been shown to change the CG's level of burden (Larson et al., 2021). Studies regarding short-term effects are in its infancy and research will need to continue as this pandemic progresses.

### **Conclusion**

With the ever-changing landscape of healthcare due to COVID-19, clinicians should be aware of not only the patient's well-being but that of the CG as well. This integrative review provides information to healthcare workers about the risks of additional stress to CG during the time of a pandemic. The research reviewed implied that CG stress has escalated from factors such as financial concerns and access to healthcare resources. Understanding the importance of the CG's physical and mental well-being and how to alleviate additional stressors can increase the quality of life and outcomes of the patients. Utilizing tools such as telenursing, educating the CG regarding coping strategies, and supplying the CG with additional community resources have been successful at easing CG stress. It is important for nursing to shift their focus from patient-centered care to family-centered care to change the outcomes of the over-burdened CG in this time of a pandemic and in the future.

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**Figure 1***PRISMA Flow Diagram*