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Impact of COVID-19 on Informal Caregiver Stress

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Senior Project in Nursing

NURS 499

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Abstract

The onset of the COVID-19 pandemic forced the entire world to isolate, as no one knew exactly what it was, how it was spread, or who was most vulnerable to fatal consequences. This global lockdown cut people off from a lot of necessary resources, including access to any healthcare that wasn't deemed essential. While priorities shifted to protect vulnerable populations, the system failed to fully prepare their informal caregivers for taking over all of their physical, psychological, and social needs. An informal caregiver is anyone providing care for another individual outside of a professional setting. This literature review aimed to determine the impact of the COVID-19 pandemic on informal caregivers and to find out what healthcare professionals can do to better prepare them for future emergencies. Caregivers described feeling unsupported by healthcare professionals, anxious about transmitting the virus to their care recipients, and more depressed during the pandemic. In addition, participants in several studies stated there was a need for increased tele-health services, thorough caregiver teaching, and opportunities for their care recipients to safely socialize. These findings emphasize the important role of evidence-based nursing in patient care. By ensuring thorough mental and physical assessments, consistently reinforced caregiver teaching, and facilitation of family-centered care, nurses can reduce a lot of the stressors faced by informal caregivers.

Background & Aim

Since the beginning of the COVID-19 pandemic, one of the greatest concerns for healthcare professionals has been caring for vulnerable populations. A commonly overlooked aggregate are the people caring for the vulnerable populations outside of a healthcare setting. Barber (2018) defines informal caregiving as anyone who provides care to someone without receiving formal training, financial compensation, or professional recognition. Extensive research has linked informal caregiver stress to adverse health outcomes including increased cardio- and cerebrovascular complications and premature mortality (Waligora et al., 2019). The onset of the COVID-19 pandemic decreased available resources for informal caregivers or ICGs, during a time of increased need. Prolonged isolation and the lack of health, family, and social support has increased ICG stress exponentially (Willner et al., 2020). The aim of this literature review is to analyze the impact of the COVID-19 pandemic on the mental and physical health of ICGs on a global scale. Additional analysis will determine the most effective nursing interventions to combat ICG stress.

Method

A literature review was conducted using online allied health databases including CINAHL, Cochrane Library, and PUBMED. Keywords in the literature search included: “COVID-19,” “informal caregiver,” “family caregiver,” “stress,” and “nursing interventions.” Selection criteria was further limited to literature published between the years 2011 and 2021 and peer-reviewed. For this review to be representative of the entire ICG population, the selected articles were chosen to be varied in content, country of origin, and characteristics of the subject being cared for.

Literature Review

Ten articles meeting selection criteria were chosen. An article by Barber (2018), discusses the infinite characteristics of ICGs to emphasize the importance of thorough social history assessments on all patients. The article states that even children can act as ICGs. Barber also examines appropriate nursing interventions for this population. Some of the evidence-based recommendations include offering a flexible appointment schedule or piggybacking caregiver and care recipient appointments, hosting support groups, and offering home health support.

Beach et al. (2021) conducted a cross-sectional study of over 500 ICGs in the United States using an online survey instrument. The purpose of this study was to compare the impact of the COVID-19 pandemic on ICGs and non-caregivers to determine how informal caregiving played a role in the experience. The study found that the COVID-19 pandemic led to increased challenges for informal caregivers. Some of the negative effects related to long-term isolation and high transmission rates included ICG depression, anxiety, loneliness, and loss of sleep. A significant finding from this study was that on a standardized anxiety scale, ICGs scored more than a half a standard deviation above national levels. It was also found that ICGs had significantly more financial problems during the pandemic than non-caregivers. Demographic analysis revealed that several characteristics placed ICGs at a greater risk for complications during the pandemic. These characteristics include female gender, living in low-income households, younger caregivers, ICGs providing care for younger care recipients, and those caring for people with cognitive or behavioral alterations.

In a study by Cohen et al. (2020), 80 ICGs of people with Alzheimer's disease and related dementias were surveyed in Argentina with the aim to analyze the impact of a 4-week mandatory isolation on this particular population. The study found a statistically significant

increase in both family-reported anxiety and level of burden after the 4-week intervention. Most common factors relating to these findings included suspended rehabilitation programs, decreased family-visitation, and fear of spreading COVID-19 to the care recipient.

A study by Dhiman et al. (2020) surveyed over 250 ICGs of children with developmental disabilities in India. The purpose of this study was to find the correlation between the COVID-19 pandemic and caregiver anxiety, depression, and stress. An additional aim was to determine the prevalence of tele-rehabilitation services made available to this population. Statistical analysis revealed that half of study participants had increased symptoms of anxiety and depression related to COVID-19 isolation. The reported lack of community resources left participants with increased ICG stress and other related mental health complications.

Farajzadeh et al. (2021) conducted a cross-sectional study of 160 ICGs of children with cerebral palsy in Iran. The study aimed to find the correlation between ICG stress and the COVID-19 pandemic. This study found that ICG stress has physical and emotional consequences, which can lead to low-quality care of the care recipient and poor health outcomes for both the ICG and recipient. The study also stated that many caregivers worry their inability to socially distance from the care recipient will lead to virus transmission and serious health complications. It emphasized that family-centered support such as caregiver teaching and empowerment can lead to a reduction in anxiety and depression among this population. Authors of this study also stressed the importance of having a plan of care in-place from healthcare personnel, as doing so can help reduce isolation-induced caregiver stress. Important components of this plan include mental health support and thorough patient and caregiver teaching.

In a study by Grumi et al. (2021), 84 ICGs of children with neurodevelopmental disabilities in Italy were surveyed with the intention of finding the effect of a COVID-19 related

lockdown on the mental health of ICGs. One of the biggest concerns for this population was the lack of available tele-rehabilitation services. Without access to these services, a lot of ICGs felt lost in their attempts to support their care recipients. Another large concern for this population was the fear of their vulnerable care recipient contracting COVID-19. This study concluded by emphasizing the importance of tele-health resources and family-centered approaches for vulnerable populations such as informal caregivers.

Irani et al. (2021) surveyed 69 ICGs of adults with disabilities and chronic diseases in the US about their experiences during the COVID-19 pandemic. The study participants stated that their typical ICG tasks included performing medical interventions such as wound care, ostomy care, and critical monitoring as well as providing assistance with activities of daily living and social support to the care recipients. A majority of ICGs reported feeling increasingly overwhelmed with the responsibilities associated with caregiving during the COVID-19 pandemic. With much of the professional healthcare assistance shifting to telehealth, informal caregivers reported feeling uncertain about health decisions they made for the care recipients. The study also found that the COVID-19 pandemic reduced support services for ICGs, leading to the addition of several responsibilities. Numerous caregivers also mentioned that due to the pandemic, they had become the sole caregiver for their care recipient. There were also reports of caregivers being nervous about transmitting COVID-19 to their vulnerable care recipients.

In a multicenter parallel randomized control trial, Shariati et al. (2021) studied the effect of web-based family communication by nurses in a COVID ICU on subjective stress in Iran. This study found that reported stress of family members of patients hospitalized during the pandemic has been increased. After implementing web-based communication for 10-15 minutes

per day, the study found a statistically significant decrease in stress levels. This emphasizes the importance of communicating with families and ICGs during times of restricted visitation.

In a study by Waligora et al. (2019), it was found that ICGs report low rates of engagement in self-care activities which is associated with adverse health outcomes. The study discusses the importance of educating healthcare professionals about self-care behaviors for ICGs of individuals with Alzheimer's and related dementia. It lists important self-care activities for ICGs including adequate sleep, leisure time, social support, spiritual practice, and scheduled breaks from caregiving responsibilities.

Using an online survey instrument, Willner et al. (2020) measured the impact of the COVID-19 pandemic on the mental health of ICGs of children with intellectual disabilities in the UK. In comparison to caregivers of people without intellectual disabilities, this study found that ICGs had a 4- to 10-fold increase in diagnoses of major depression. Compared to studies conducted pre-pandemic, these numbers are significantly higher. ICGs also have an increase in reports of feeling defeated and entrapped, descriptors that are associated with increased rates of suicidal ideation. This study also found that ICGs reported having decreased support during the pandemic despite an increase in need. The needed support included services from healthcare, family, and social entities.

Analysis

Several themes arose from the selected material. Seven of the articles found a correlation between increased ICG stress and the COVID-19 pandemic. Each of the seven articles also mentioned that a major stressor was increased responsibility related to a decrease in support from healthcare personnel (Beach et al., 2021; Cohen et al., 2020; Dhiman et al., 2020; Farajzadeh et al., 2021; Grumi et al., 2021; Irani et al., 2021; Willner et al., 2020). This emphasizes the

important role nurses and other healthcare professionals play in reducing ICG stress. One suggestion to improve support for this population is increased availability of tele-health services. Several studies discussed how the lack of access to tele-health contributed to ICG stress levels (Beach et al., 2021; Dhiman et al., 2020; Grumi et al., 2021; Shariati et al., 2021). Another major concern for ICGs was an increased risk of infecting the care recipient with COVID-19 (Cohen et al., 2020; Grumi et al., 2021; Irani et al., 2021). Giving ICGs and their care recipients the option of receiving healthcare from the safety of their home is one way to mitigate the risk of transmission without compromising quality of care.

Only two articles mentioned that the pandemic affected their ability to financially support their care recipient (Beach et al., 2021; Farajzadeh et al., 2021). However, this is assumed to be misrepresentative of the broader ICG population. Several articles mentioned their study was limited to people of average income and as research has shown, a majority of ICGs are living in poverty (Willner et al., 2020). Additional stressors mentioned within the articles include worsening mental health for the care recipient, working from home while performing ICG duties, decreased support from family and friends, closure of childcare and adult daycare centers, concerns for care recipients falling behind in school, and decreased opportunities for the care recipient to safely socialize (Beach et al., 2021; Dhiman et al., 2020; Farajzadeh et al., 2021; Grumi et al., 2021; Irani et al., 2021). Some of these additional concerns were limited to the age and type of disability of the care recipient and are not representative of the entire ICG population.

Several studies also discussed the mental health impact of prolonged stress on the ICG. Common mental health disorders stemming from COVID-19 related stressors include anxiety and depression. Six studies found an increase in symptoms of anxiety in ICGs during the

pandemic (Beach et al., 2021; Cohen et al., 2020; Dhiman et al., 2020; Farajzadeh et al., 2021; Grumi et al., 2021; Willner et al., 2020). Whereas only five found an increase in symptoms of depression (Beach et al., 2021; Dhiman et al., 2020; Farajzadeh et al., 2021; Grumi et al., 2021; Willner et al., 2020). The slight difference in findings is presumably related to the aim of the study by Cohen et al. (2020). The increase in mental disorders among the ICG population stresses the importance of thorough mental health assessments during routine appointments with ICGs.

Four articles concluded that there is an increased need for family-centered care for ICGs (Barber et al., 2018; Farajzadeh et al., 2021; Grumi et al., 2021; Willner et al., 2020). Family-centered care is a collaboration between the patient, the patient's family or ICG, and several healthcare professions (Kuo et al., 2012). This holistic approach to healthcare can decrease care fragmentation and can help prepare ICGs to independently care for their recipients. Seven articles discussed the need for policy change to better support ICGs (Barber et al., 2018; Beach et al., 2021; Cohen et al., 2020; Dhiman et al., 2020; Farajzadeh et al., 2021; Grumi et al., 2021; Willner et al., 2020). By implementing policy changes, informal caregivers can get the financial, medical, and psychological support they need to properly care for their recipients.

Nursing Implications

There are several recommendations for nurses caring for ICGs. The first step in a therapeutic relationship with any patient is to find the source of the patient's stress. This will ensure a thorough understanding of any influencing factors before giving suggestions and referrals. This is especially important for ICGs because they are a very diverse population with care recipients who need varying degrees of assistance. Due to ICGs tendency for anxiety and depression, it is important that nurses perform a thorough assessment of every patient's mental

health. Since the onset of the COVID-19 pandemic, ICGs should be reevaluated to detect any change from baseline.

In addition, nurses should collaborate with other healthcare professionals to find resources aimed at alleviating any possible causes of stress and anxiety for ICGs. Many times, ICGs require assistance from many different healthcare entities to ensure their care recipients are receiving well-rounded care. If there is fragmentation, the ICG may be required to step into rolls that they are unprepared for, possibly putting the care recipient in danger and leading to increased stress and anxiety on the ICG's end (Irani et al., 2021). Many ICGs described feeling unprepared when the pandemic caused them to isolate with their care recipient. By preparing ICGs with thorough patient teaching on medical, emotional, and rehabilitative care, nurses can help them feel more confident in their ability to independently care for the recipient in case of emergency, such as the COVID-19 pandemic.

For ICGs of hospitalized individuals, there are several recommended interventions to help alleviate stress. One suggestion is effective communication strategies. Even with visitor restrictions, nurses can talk to approved contact persons of hospitalized patients. Describing the patient's known status and their plan of care can help the ICG feel more comfortable with the care their recipient is getting. Even though the hospitalized patient's ICG is not present with them at the facility, nurses can schedule times of telephone communication with them so they can express concerns and ask questions. Answering any outstanding questions that the ICG may have about the patient has also been shown to alleviate stress (Shariati et al., 2021).

Literature Gaps

According to the selected articles, further research is required to fully understand the COVID-19 pandemic's effect on ICGs. Farajzadeh et al. (2021), suggests that future studies find

the current healthcare interventions available to ICGs and determine their efficacy in reducing ICG stress. This would ensure ICGs are receiving the best support for their individual circumstances. It is also recommended that there be additional studies conducted on long-term effects of the COVID-19 pandemic on ICGs (Irani et al., 2021). With many hospitals limiting visitation for every patient, future research should be conducted on alternative communication methods between healthcare personnel and families and ICGs of hospitalized patients (Shariati et al., 2021). Dhiman et al. (2020) states that future studies should analyze and compare the difference in reported ICG stress for varying degrees of disability in care recipients. Limitations within several of the studies revolved around the financial status of the ICGs, further research should include a more financially representative sample of participants (Willner et al., 2020).

Conclusion

Regardless of geographic location and age or disability of care recipient, it has been shown that the COVID-19 pandemic negatively impacted informal caregivers. The literature indicates that the healthcare system left ICGs unprepared and alone during the pandemic. There are several ways that nurses can help alleviate some of the stress and anxiety that ICGs face including thorough assessments, therapeutic relationships, collaborative care, and in-depth education. In addition to following the recommendations discussed in the articles, nurses can practice compassion by taking the time to talk to ICGs to find out what they can do to help. Nurses should also be familiar with local resources so they can make the proper referrals for each individual situation. Additional emphasis should be placed on family-centered care for ICGs and their care recipients. Family-centered care has a lot of benefits for this population as they report feeling less alone, more prepared, and more confident in their ability to care for their care recipients (Kuo et al., 2012).

Nurses can also assist in the reduction of ICG stress by petitioning for policy changes. Some policy amendments include advocating for paid family leave for ICGs in times of crisis and financial reimbursement for ICGs providing care for individuals on Medicaid (Irani et al., 2021). Policies should also focus on making healthcare more equitable for low-income families. Some suggestions include financial aid to assist ICGs in affording the needed technology to engage in tele-health services and increased occupational opportunities for ICGs to be able to afford care for their recipients' complex medical needs (Farajzadeh et al., 2021). In addition, more policies need to be in place to protect vulnerable populations against COVID-19 transmission in public, including stricter and more consistent mask mandates, social distancing and capacity restrictions, and more access to virtual healthcare and social events.

References

- Barber, C. (2018). Working with informal caregivers: Advice for nurses. *British Journal of Nursing*, 27(19), 1104-1105. <https://doi.org/10.12968/bjon.2018.27.19.1104>
- Beach, S. R., Schulz, R., Donovan, H., & Rosland, A. M. (2021). Family caregiving during the COVID-19 pandemic. *Gerontologist*, 61(5), 650-660. <https://doi.org/10.1093/geront/gnab049>
- Cohen, G., Russo, M. J., Campos, J. A., Allegri, R. F. (2020). Living with dementia: Increased level of caregiver stress in times of COVID-19. *International Psychogeriatrics*, 32(11), 1377-1381. <https://doi.org/10.1017/S1041610220001593>
- Dhiman, S., Sahu, P. K., Reed, W. R., Ganesh, G. S., Goyal, R. K., & Jain, S. (2020). Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. *Research in Developmental Disabilities*, 107. <https://doi.org/10.1016/j.ridd.2020.103790>
- Farajzadeh, A., Dehghanizadeh, M., Maroufizadeh, S., Amini, M., & Shamili, A. (2021). Predictors of mental health among parents of children with cerebral palsy during the COVID-19 pandemic in Iran: A web-based cross-sectional study. *Research in Developmental Disabilities*, 112. <https://doi.org/10.1016/j.ridd.2021.103890>
- Grumi, S., Provenzi, L., Gardani, A., Aramini, V., Dargenio, E., Naboni, C., Vacchini, V., Borgatti, R. (2021). Rehabilitation services lockdown during the COVID-19 emergency: The mental health response of caregivers of children with neurodevelopmental disabilities. *Disability and Rehabilitation*, 43(1), 27-32. <https://doi.org/10.1080/09638288.2020.1842520>

- Irani, E., Niyomyart, A., Hickman, R. L. J. (2021). Family caregivers' experiences and changes in caregiving tasks during the COVID-19 pandemic. *Clinical Nursing Research*, 30(7), 1088 – 1097. <https://doi.org/10.1177/10547738211014211>
- Kim, H., Chang, M., Rose, K. & Kim, S. (2011). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, 68(4), 846-855.
- Kuo, D. Z., Houtrow, A. J., Arango, P. Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal*, 16(2), 297-305. <https://doi.org/10.1007/s10995-011-0751-7>
- Shariati, E., Dadgari, A., Talebi, S. S., Shan, G. R. M., & Ebrahimi, H. (2021). The effect of web-based communication between a nurse and a family member on the perceived stress of the family member of patients with suspected or confirmed COVID-19: A parallel randomized clinical trial. *Clinical Nursing Research*, 30(7), 1098-1106. <https://doi.org/10.1177/10547738211017688>
- Waligora, K. J., Bahouth, M.N., & Han, H.R. (2019). The self-care needs and behaviors of dementia informal caregivers: a systematic review. *Gerontologist*, 59(5), 565-583. <https://doi.org/10.1093/geront/gny076>
- Willner, P., Rose, J., Kroese, B. S., Murphy, G. H., Langdon, P. E., Clifford, C., Hutchings, H., Watkins, A., Hiles, S., & Cooper, V. (2020). Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 33, 1523-1533. <https://doi.org/10.1111/jar.12811>