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# Availability and Burden of Family Caregivers in Caring for a Recurrent Stroke Survivor in the Community During a Pandemic

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## ABSTRACT

Family caregivers significantly influence the ability of stroke survivors to thrive in the community despite of their disability. Recently, family caregivers are faced with the challenges of fulfilling their domestic duties while acting as the coordinators of medical and nursing care to their patient. Caring for a family member with disability is already a challenging task that may even be magnified by the presence of calamities and state emergencies. This paper examined the burdens and challenges experienced by family caregivers during the COVID-19 threat. This research utilized an illustrative case study approach, which typically focuses on one or two instances of an event to illustrate a phenomenon while highlighting the contextual elements of the case. It was discovered that the emergence of a highly contagious and deadly virus required a major adjustment in the lives of family caregivers caring for family members with disabilities, especially in communities where local transmission is rampant. Despite having local policies that have been set in place to prevent the continuing transmission of new COVID-19 infections, these restrictions highly affected the way of life in the communities and accentuates the lack of community resources for medical emergencies.

***Keyword: Family Caregiving; Pandemic; Stroke Survivor; Recurrent Stroke; Community Health; Case Study***

## INTRODUCTION

Stroke is one of the major challenges in healthcare for being a leading cause of death and disability worldwide (Katan & Luft, 2018; Khoshnam *et al*, 2017) where most survivors live with some degree of permanent disability (Grefkes & Fink, 2020; Papanagiotou & Ntaios, 2018) that require the assistance of a family caregiver (Caro, Costa, & Da Cruz, 2018). Family caregivers (usually composed of family members and adopted family) significantly influence the ability of stroke survivors to thrive in the community despite of their disability (Camicia *et al.*, 2019; Pitthayapong *et al*., 2017). The presence of an available caregiver is highly important in the care and rehabilitation of stroke survivors (Ahmad *et al.*, 2018) as it positively influences the functional recovery of stroke survivors and may be an important element to successful rehabilitation (Ludin & Othman, 2019; Mirkowski *et al.*, 2018).

Although family members may not consider themselves as caregivers, this term is commonly used in the literature to represent family or informal/unpaid caregivers (Morelli *et al.*, 2019). For the context of this paper, family caregivers pertain to a relative, partner, friend, or neighbor who aids an adult with a chronic or disabling condition such as stroke. Recently, family caregivers are faced with the challenges of fulfilling their domestic duties while acting as the coordinators of medical and nursing care without the necessary training and professional help (de Sousa *et al.*, 2022). As the burden of care for stroke patients has been transferred from healthcare institutions to community-based setup, family caregivers are likely to carry heavier responsibilities without enough professional support and expert services (Phillips *et al.*, 2020).

Aggravated by the uncertainty of the patient's condition, the family caregivers of stroke survivors tend to suffer from high levels of stress (Hamzah, Masingboon, & Duengpaeng, 2018). Family caregiver stress often leads to other negative outcomes for both survivors and their caregivers (McCurley *et al.*, 2019). For instance, caregiver stress has been found to be associated with social isolation (Jellema *et al.*, 2019), declining health (Hekmatpou, Baghban, & Dehkordi, 2019) and increased risk of mortality among the caregivers (Sutter-Leve *et al.*, 2021), and at the same time interfere with the

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rehabilitation of the survivor (Em *et al.*, 2017). Moreso, depression has also been found to be common among stroke family caregivers, with some studies reporting higher depression rates among family caregivers as compared to the stroke survivors (Wan-Fei *et al.*, 2017).

Regardless of the stroke survivor's dependence, caregivers experience physical and emotional distress not mainly because of the stroke survivor's physical disability, but by the challenges caused by the emotional and behavioral consequences of stroke to the survivor (Rohde *et al.*, 2019; Wan-Fei *et al.*, 2017). Stroke survivors often experience a sense of profound personal failure owing to the sudden, debilitating experiences resulted from stroke (Chow, 2018). And since the current focus of rehabilitation received by stroke survivors is primarily on physical recovery, while their psychosocial and emotional needs are often left unaddressed (Chow, 2018; Ludin & Othman, 2019; Pindus *et al.*, 2018), stroke survivors may experience denial, hopelessness, and frustration (Wenzel *et al.*, 2021) that may sometimes be vented out to the family caregivers (Tong & Ke, 2021).

## Experiencing Stroke in the Community During a Pandemic

The CORONAVIRUS-19 pandemic has brought changes to everyone's personal and professional lives. Globally, the number of confirmed cases had been increasing daily at varying rates in different countries (Maleki *et al.*, 2020) accompanied by hundreds and thousands of deaths around the world. Despite this global catastrophe, the prevalence of the "traditional" healthcare problems remains consistent, where certain conditions warrant emergency treatment (Baracchini *et al.*, 2020).

Due to the global outbreak the situation seems to be out of hand, various hospitals around the world have utilized triage protocols for emergency cases to identify patients with suspected or confirmed COVID-19 infection (Baracchini *et al.*, 2020). However, protocols and algorithms like these are feasible in hospitals mostly because the settings are controlled, and the right resources are usually available. Such system in dealing with emergencies may not be entirely feasible in community settings where resources are not immediately available, infection control protocols are not well defined, and the risk of local disease transmission remains to be a threat.

In the Philippines, an Enhanced Community Quarantine (ECQ) and local travel restrictions were set in place as early as March 2020 as more cases of local disease transmission had been noted (Vallejo & Ong, 2020). Under such scenario, only transportation (by land, by air or by sea) for essential services were allowed, while medical personnel and goods, sanitation operations and emergency cases were exempted from these restrictions (Vallejo & Ong, 2020). Despite the said exclusions, limitations remain in communities as most of the manpower and facilities available were dedicated to preventing local transmission of the disease (i.e., restricting the movement of people, imposing curfews and lockdowns, sanitation, etc). This sudden shift of community priority and the reallocation of resources have led to a crippled emergency management in most local government units (LGUs).

There is a growing concern that patients with stroke symptoms are not seeking medical attention because of fear of being exposed to COVID-19 in the hospitals or during transport (Bullrich *et al.*, 2020). Due to their underlying comorbidity, getting exposed to COVID-19 leads to poor outcomes and mortality, and requires longer time for clinical care and treatment (Zhang *et al.*, 2020). And since time remains of key importance in responding to the acute phase of an ischemic stroke, issues that delay emergency medical response in the community may lead to poor patient outcomes, and even death among stroke patients.

Caring for a family member with disability is already a challenging task that may even be magnified by the presence of calamities and state emergencies. The emergence of COVID-19 as a major threat, not only to the stroke survivor, but also to his family caregivers triggers their collective anxiety as a family and tests their resilience (Sya'diyah *et al.*, 2022). This paper explored the experiences of family caregivers in taking care of a stroke survivor in the community during a pandemic. Specifically, this paper examined the burdens and challenges experienced by family caregivers during COVID-19 threat.

## Theoretical Framework

The Bowen's Family Systems Theory (as cited in Keller & Noone, 2019) proposes that every member of a family plays an important role that influences how each family member operates in connection with each other. This theory also posits that a family is an internally dynamic system where any functional change on one member causes a compensatory change on the functional roles of other family members (Bowen, 1974, as cited in Keller & Noone, 2019). This interrelationship is presumed to cause cohesion and cooperation among family members in their common goal of protecting and providing for one another (Kerr, 2019). On the other hand, this interrelatedness is also the cause of increased pressure among family members who absorb most of the burden, thereby leading to anxiety, isolation, depression, alcoholism, extramarital affairs, tension, and health problems (Kerr, 2019).

This theory was used to guide the analysis of this study by considering family caregivers as part of a family unit, who assume compensatory roles as a response to the needs of a family member with disabilities. Furthermore, this theory shall guide this study based on the assumption that each family is unique in terms of its composition, the characteristics and roles of its members, the developmental and non-developmental stages of each family member and the interrelationship dynamics within the family.

## METHODOLOGY

### Research Design

This study utilized the qualitative case study research approach, which is an "intensive, systematic investigation of a single individual, group, community or some other unit in which the researcher examines in-depth data relating to several variables" (Heale & Twycross, 2018). This approach is best used to examine complex topics or phenomena in the natural setting and narrow it down into manageable research questions by increasing the researcher's understanding of them (Heale & Twycross, 2018). Specifically, this paper used an illustrative case study approach, which is primarily descriptive in nature, as it typically uses one or two instances of an event to illustrate a phenomenon by focusing on the contextual elements of the case (Mohajan, 2018).

### Case Selection

Nita (not her real name), A 69-year-old family caregiver to her 79-year-old husband, who is a long time diabetic and a restroke survivor, was chosen as the case under study. Together, they have four children (three of whom have already migrated abroad and have their own families, while one died five years ago). Her husband initially had his first ischemic stroke attack back in February 2020, just before the imposition of community quarantines and restrictions in the country due to the local transmission of COVID-19. Her husband survived another stroke incident in December 2020. Nita lives alone with her husband, while her two granddaughters (who are both in their mid-20s) live one block away. For her husband's medical treatment and rehabilitation, they receive financial support from their children abroad.

She was chosen as the informant of this study as she has been the primary caregiver for her husband since he survived his first stroke attack. Furthermore, she continued to be the primary caregiver after her husband survived a recurrent stroke during a pandemic when strict community restrictions are already in place. As a housewife, she had to use effective coping strategies to adapt, minimize stress and protect her mental health (Ping, Natalia, & Hurai, 2022). Supplemental data for this study were obtained from the stroke survivor's two granddaughters (Paula and Lyra- also not their real names) who act as the secondary caregivers for when their grandmother needs assistance in looking after her husband.

### Data Gathering

Information was gathered through a series of one-on-one interviews and group discussions after securing an informed consent. Data was obtained using the informant's local language and underwent a two-way translation with the help of an expert who is very familiar with the English language, and the language used in the interview. The informants were kept anonymous for this study while the field notes were kept confidential. Any recorded session of the interviews that helped in the accurate data transcription and analysis were saved in a password-encrypted device.

### Data Analysis

Since qualitative studies demand that the researchers reflect on the data being gathered (Maher *et al.*, 2018), the data analysis in this study was conducted simultaneously with the data collection. Stake, as cited in Boyce (2017), suggested two strategic ways in analyzing case studies -- "through direct interpretation of individual instance, and through aggregation of instances until something can be said about them in a class". Meticulous reflection and thorough description of the data, followed by proper thematization in which certain processes or patterns would fit in are the essential steps (Nowell *et al.*, 2017) applied in this study. The qualitative data in this study were thoroughly evaluated to ensure their thematic fitness (Nowell *et al.*, 2017). After identifying the central themes, they were analyzed based on the Family Systems Theory with relation to the settings in which the case occurred. The researcher then scrutinized all elements of the social setting to produce a more general interpretation of the situation.

### Data Validation

After categorizing the data according to patterns, construct validity was established though member checks. This was done by sharing the researcher's interpretations and findings to the key informants for them to discuss and clarify the details, and even elucidate more issues that were not yet tackled (Candela, 2019).

### Ethical Consideration

The paper reflects the author's own research and analysis in a truthful and complete manner, and is not being considered for publication elsewhere. The necessary ethical review and institutional permission was granted by Capitol University College of Nursing on December 8, 2021

## RESULTS

### Challenges of a Family Caregiver During a Pandemic

Few of the common challenges experienced by family caregivers who are caring for a stroke survivor is the feeling of uncertainty when they faced new care situations at home which could be due to a lack of preparation prior to the patient's discharge from confinement and the lack of accessible and timely in-home services after discharge (Farahani *et al.*, 2020; Mohammadi *et al.*, 2019).The limited time to acquire the necessary skills for this new care-giving role, particularly where the stroke was severe with a high demand for personal care is one of the identified barrier in caring for stroke survivors (Chen *et al.*, 2021; Sheehan *et al.*, 2022). During the initial interviews, the primary caregiver shared,

*NITA: "During his first stroke attack, we really had difficulty. That was because we were not able to prepare. Who would expect that he would have a stroke attack? But that incident was still bearable because we didn't have COVID-19 [restrictions] at the time. But during his second stroke attack, we really faced difficulties. That is because I cannot just go out to run errands because of my age. I am at high-risk, and I cannot just be exposed to COVID-19. But we don't have a choice. We really must find ways to accomplish what needs to be done."*

Nita compared her experiences as the primary caregiver to her husband before and after the COVID-19 pandemic. Her personal circumstances added more challenges to the already challenging role of a being family caregiver. Due to the increasing rates of local transmission, local governments have imposed restrictions and prohibited high-risk groups (which include the older persons above 60 years old and those with comorbidities, among others) from going out in public. These restrictions made her dependent on her grandchildren to do errands on her behalf. She further added,

*NITA: "When he had another stroke attack, I really panicked because he really needed to be brought to the hospital, but I could not go with him because I might get infected with COVID-19 in the hospital. Luckily, we have neighbors who are young enough to lift him and bring him to the hospital. If not, I don't know what I will do."*

Her advanced age places her at high-risk for developing severe COVID-19, symptoms thus prohibiting her from going into public places where the possibility of exposure to the virus is very high. Her sense of helplessness due to the COVID-19 restrictions during a medical emergency made her rely solely on her neighbors.

*NITA: "Even in buying his medications, I had to ask another person to do it. Fortunately, it is now possible to have the medications delivered at home, so I don't have to go have to the pharmacy. Sometimes, I will ask our neighbors to buy our grocery supplies and buy his diapers."*

Due to her age, Nita had to rely on community resources, her access to technology and improved essential services may have helped meet some of her needs, but she still had to rely on community support for her other needs.

### Limited Community and Family Resources

Pindus *et al.*, (2018) claimed that caregivers of stroke survivors in the community consider it very important to know what community resources are available and to have access to those resources. Furthermore, the availability of someone to watch over their loved one, even for a few hours, was perceived as very beneficial to family caregivers (Achilike *et al.*, 2020; Kavga *et al.*, 2021). This may be particularly true among caregivers with increasing personal needs.

*NITA: "I also need to rest, especially that I am old. I am also afraid that I might get sick. Who will take care of my husband if I also get sick? That's why I really feel happy when my grandchildren can come over at night so they can watch over their grandfather while I get some sleep. At dawn, I must wake up early so they can get some sleep. They also need some sleep because they must go to work in the morning."*

The lack of available family members to act as an alternate caregiver is perceived as a major challenge for Nita. Given that her husband needs tube feedings every four hours, along with regular diaper changes to prevent the worsening of her husband's bedsores, having a consistent and reliable caregiver is pertinent.

*NITA: "Back then, when there weren't many people infected with COVID-19, we availed the services of a housemaid who watched over my husband and did our laundry. However, ever since our housemaid left, we have had difficulty looking for a replacement. There are others who are available, but they can only do stay-out services. We cannot allow a stay-out housemaid who goes home every day, as she might carry the COVID-19 [virus]. She might even get us infected. That is why we cannot just trust other people to watch over my husband."*

The fear of interacting with and being exposed to an asymptomatic carrier of the virus is one of the main concerns for the family caregiver of a stroke survivor. The risks involved in receiving help from other people are considered a major hindrance to family caregivers' reaching out for social support and availing of community services.

*NITA: "As for my grandchildren, they also have day jobs. That's why I cannot just rely on them all the time. It's a good thing that we have neighbors that I can trust, who care to help us."*

### Emotional, Cognitive and Physical Effects of Stroke

Brain injuries (i.e., stroke) commonly lead to emotional disorders known as catastrophic reactions (Tsarkov & Petlovanyi, 2019). This pertains to the abrupt onset of emotional symptoms of frustration, depression, and embarrassment lasting from a few seconds to a few minutes, and is characterized by a display of emotion (shouting, swearing, pounding fists, and throwing things) followed by a return to the previous calm emotional state (Carota & Bogousslavsky, 2018; Choi-Kwon & Kim, 2022). Although many professionals speculate that these behaviors should be encouraged or at least tolerated as a way of promoting the patient's "adjustment" to his condition (Kirkevold *et al.*, 2018), the memory and behavior changes of stroke survivors and the family conflict surrounding stroke recovery are important considerations during the post-stroke recovery period (Ramazanu *et al.*, 2022; Tyagi *et al.*, 2020).

*PAULA: "My grandfather gets upset easily. He wants us to follow all his preferences. Even though he knows that we are having a hard time caring for him, he wants us to follow his preferences. He doesn't want to wear a diaper because he prefers that we carry him to the toilet. But we are having difficulties because he is too heavy for us to lift. We are worried that we might slip or fall on the floor while lifting him."*

*LYRA: "He gets upset if we don't give in to his wishes. He already knows that it is dangerous, or it is prohibited due to his condition. But he still insists. And he gets frustrated if he doesn't get what he wants. He scolds me every day because he wants me to feed him rice, even though he knows that he is incapable of swallowing food. He even gets upset if we help him in get up, because he prefers to stand up on his own, even though he already knows that he cannot move his legs. We are afraid that he might fall or get injured."*

*NITA: "My husband used to work as a manager back then. That's why he is used to having all his instructions followed. He wants people to always listen to him. And now that he is dependent on the people around him, he always gets frustrated when his preferences are not being followed. Sometimes he would curse at us. And it hurts us. But we don't have a choice because we cannot just leave him on his own."*

On top of the emerging challenges caused by the community restrictions due to the pandemic, the usual physical, behavioral, and cognitive impact of stroke on the survivors intensifies the burden experienced by family caregivers. The stroke survivor's inability to accept his current condition and cope with his disability contributes to the burden carried by his family members. The impact of the pandemic on the communities, along with the existing internal family issues, has forced the family caregivers to face challenges and assume roles beyond their capacity.

## DISCUSSION

Caring for a family member with a debilitating disability is already a burden by itself. It disrupts the usual family functioning by assigning new roles to the remaining members and sometimes undermine the personal issues of some family members, which eventually might put pressure on the family relationship. The emergence of a highly contagious and deadly virus requires a major adjustment in the lives of people, especially in the community where local transmission is rampant. New policies have been set in place to prevent a sudden and continuing surge of new infections. These policies involve restrictions which highly affect the way of life in the communities and worsens the lack of resources for medical emergencies.

## CONCLUSION

The family caregivers of stroke survivors are already burdened by their new responsibilities in dealing with the physical, cognitive, and emotional impacts of stroke. These challenges are made more difficult because of the emergence of a contagious disease, which requires restrictions and adjustments in the communities, which further limit the family members' access to the resources needed in medical emergencies, caregiving, and patient rehabilitation.

### Recommendation

It is highly recommended to develop community policies and programs that ensure a systematic workflow for emergencies, even during a pandemic crisis. Furthermore, it is essential to ensure continuous access to community resources for the family caregivers.

### Conflict of Interest

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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