



CARERS OF THE CARE-SEEKERS: THE LIVED EXPERIENCES OF PRIMARY CAREGIVERS OF PATIENTS WITH STROKE

Blaise B. Nieve

PhD in Nursing (cand.), PhD in Education major in Educational Leadership, MA Nursing, BS Nursing, RN, CMSRN, NEA-BC, MHFAider®

*Clinical Nurse II, Adult General Medicine Stepdown Unit, Duke University Hospital, Durham, NC, USA
Adjunct Professor, Graduate School – School of Nursing, San Pedro College, Davao City, Philippines*

<https://doi.org/10.5281/zenodo.11638449>

ABSTRACT

Despite extensive research on the impact of stroke on patients, the experiences of primary caregivers have not been given equal attention, particularly in terms of the long-term support they require. This phenomenological study was designed to develop an understanding of the lived experiences of the primary caregivers of patients with stroke, to discover what their experiences are as partakers of the burden of stroke, and to know how these experiences mean to them. Participants were selected purposively and were limited to caregivers who were at least 18 years old and had been a caregiver for at least six months. The stroke patients were those who had a stroke for at least six months and were living with some form of disability. Data were gathered through in-depth interviews conducted at a tertiary healthcare institution in Panabo City. Utilizing Colaizzi's method of qualitative data analysis, the study generated the following themes: Prologue: Taking Up the Mantle, The Adventure: Living the Life of a Hero, The Achilles' Heel, and Heroes Prevail. These themes revealed that as caregivers embodied the role of becoming carers for stroke patients, they perceived their experiences as akin to being heroic. They expressed initial hesitancy in accepting the role, gradually learned to live with and accept their responsibilities, faced numerous challenges, and ultimately found meaning and fulfillment in their caregiving journey.

Keywords: *Social Science, Primary Caregivers, Patients with Stroke, Phenomenology, Panabo City*

INTRODUCTION

Stroke, often referred to as a brain attack, is a critical medical condition that significantly impacts both the patients and their primary caregivers (National Stroke Association, 2012). According to the 2016 Heart Disease and Stroke Statistics Update by the American Heart Association (2016) and the Centers for Disease Control and Prevention (2015), stroke remains a leading cause of long-term disability worldwide. Each year, the World Health Organization (2014) reports that 15 million people suffer from stroke, with 5 million deaths and another 5 million left permanently disabled. In the Philippines, stroke stands as the second leading cause of death and disability, a statistic that shows no signs of decreasing (Navarro et al., 2014; Loo & Gan, 2012).

The increasing incidence of stroke globally and locally poses profound implications not only for the patients but also for their primary caregivers. These caregivers face substantial physical, emotional, and mental challenges as they support their loved ones through recovery. While extensive research has focused on the impact of stroke on patients, the experiences of primary caregivers have not received the same level of attention. Most studies emphasize acute care and early discharge support, with less focus on the long-term support required in community settings where caregivers play a crucial role (Aziz et al., 2016).

Caregivers become the primary support system for stroke patients after hospitalization and are integral to the healthcare team, contributing significantly to the rehabilitation and recovery of stroke survivors. However, caregiving can be stressful, and caregivers often experience various interrelated individual, interpersonal, and organizational issues in managing stroke-related deficits. This stress can lead to significant psychological distress, affecting caregivers' quality of life (Duncan et al., 2005; National Stroke Association, 2012; Lau et al., 2009; Plank et al., 2012).

Research has shown that stroke survivors and their caregivers face enormous challenges as they move through the phases of stroke management, including the stroke crisis, expectations for recovery, and the crisis of discharge. Caregivers often struggle to adapt to their new roles and responsibilities, which can strain familial relationships and personal well-being. Furthermore, caregivers frequently experience issues such as role changes, difficulties with social and leisure activities, communication challenges, financial problems, and physical and emotional health problems (Lutz et al., 2011; McGurk & Kneebone, 2013; O'Shea & Goode, 2015; Olai et al, 2014).

Studies have highlighted the high Caregiver Burden (CB) scores among stroke patient caregivers, attributed to factors such as low patient functional ability and insufficient municipal social service support. Significant burdens are also due to the time spent caring for stroke survivors and uncertainty about the future, particularly in the early post-stroke period. The health-related quality of life of spouses of stroke survivors decreases not only in the initial years but also in the long term, influenced by their age and the level of the stroke survivor's disability. Additionally, caregiving significantly impacts the domains of work, leisure, and friendships, with the negative effects closely

linked to the unmet needs of the stroke survivors (Andrew et al., 2015; Olai et al., 2014; Persson et al., 2015).

Despite these challenges, caregivers play a vital role in the health continuum of stroke survivors, influencing their rehabilitation and overall quality of life. Effective nursing interventions that provide caregivers with skills to manage physical, cognitive, emotional, and behavioral stroke-related problems are essential for both initial treatment and ongoing management throughout stroke recovery (National Stroke Association, 2012; Gillespie & Campbell, 2011; Grant et al., 2014; Rahman et al., 2017; Winstein et al., 2016; Yuki & Kudo, 2011).

Over time, caregivers learn to adapt to the demands of caring for stroke survivors. Studies have found that while a significant burden is experienced by caregivers in the post-acute and chronic phases of stroke, this burden tends to decline over time. Although stroke caregiving is initially associated with persistent psychological distress, by three years post-stroke, caregivers' life satisfaction, depression levels, and mental health quality of life become comparable to those of non-caregivers. Decreases in caregiver burden significantly correlate with improvements in caregivers' physical, psychological, and environmental quality of life, indicating that the quality of life for both stroke survivors and their caregivers is interlinked and significantly influenced by changes in the survivors' physical function over time (Jaracz et al., 2015; Haley et al., 2015; Pucciarelli et al., 2017).

Despite varying findings, these studies collectively emphasize that caregivers face substantial challenges but play a crucial role in the health and recovery of stroke patients. Recognizing their significant contributions and addressing their needs through further exploration of their experiences is essential for improving their well-being and the care they provide.

Given the critical role that primary caregivers play, it is imperative to develop a deeper understanding of their experiences. This study aims to explore the lived experiences of primary caregivers of stroke patients, highlighting their significant yet often overlooked contributions. By bringing these experiences to light, the study hopes to advocate for better support systems and recognition for primary caregivers, ensuring their needs are addressed alongside those of the patients they care for.

Research Questions

This study aimed to explore the following research questions:

Central Question:

- What are the lived experiences of primary caregivers of patients with stroke?

Sub-question:

- How do primary caregivers interpret and find meaning in their caregiving experiences?

METHODOLOGY

Study Design

This study utilized a phenomenological research design to explore and understand the lived experiences of primary caregivers of stroke patients (Creswell, 2013). Phenomenology is well-suited for this purpose as it aims to describe and interpret the essence of lived experiences, providing deep insights into the personal and subjective world of the participants. This approach allowed us to capture the rich, nuanced experiences of caregivers as they navigate their roles.

Setting

The data collection for this study was conducted at a tertiary healthcare institution in Panabo City. This institution, with a 173-bed capacity, offers a wide range of medical services to the residents of Panabo City and its neighboring areas. The setting provided a comfortable and private environment for in-depth interviews, ensuring that participants felt at ease while sharing their experiences. The study was conducted from January 2017 to March 2017.

Participants

Participants were selected using purposive sampling, focusing on primary caregivers who met specific criteria. Eligible participants were those who were at least 18 years old and had been caregiving for stroke patients for a minimum of six months. The stroke patients they cared for had experienced a stroke at least six months prior and were living with some form of disability. The study aimed for data saturation, which was achieved with eight participants.

Data Collection Procedure

Data collection involved conducting in-depth, one-on-one interviews with each participant. These interviews were guided by a validated questionnaire and were designed to elicit detailed and meaningful responses about the caregivers' experiences.

The procedure was as follows:

1. **Orientation and Consent:** Participants were thoroughly oriented about the study's nature, purpose, and procedures. They were informed of their rights, including voluntary participation, the right to refuse to answer questions, and the right to withdraw at any time. Informed consent was obtained from all participants.
2. **Interviews:** The in-person interviews were conducted at a location within the healthcare institution chosen for the comfort and privacy of the participants. Each session was audio-recorded with the participants' consent to ensure accuracy in data transcription. The interviewer used a researcher-made semi-structured interview guide which was validated by three research experts. Both the English and Visayan versions of the interview guide have been validated and deemed appropriate for the purpose of the study.

3. **Data Validation:** To ensure the reliability of the data, transcripts of the interviews were reviewed and validated by the participants. This reflective dialogue helped confirm that the participants' intended meanings were accurately captured.
4. **Thematic Analysis:** Data were analyzed using Colaizzi's method of qualitative data analysis. This involved extracting significant statements, formulating meanings, and identifying common themes across the participants' experiences.

Trustworthiness of the Study

Ensuring the trustworthiness of this phenomenological study was paramount to validate the findings and establish the credibility, transferability, dependability, and confirmability of the research. These criteria, proposed by Lincoln and Guba (1985), were meticulously applied throughout the study to ensure its rigor and reliability.

Credibility refers to the confidence in the truth of the data and the interpretations of the researcher. To achieve credibility, several strategies were employed. The study utilized Colaizzi's method of phenomenological data analysis, a well-regarded approach in qualitative research, ensuring that the analysis was systematic and thorough. The questionnaire guideline used for in-depth interviews was evaluated by experts in the field of research to ensure its relevance and effectiveness in capturing the lived experiences of caregivers. The researcher's prior employment at the participating organization facilitated an in-depth understanding of the organizational culture and the caregiving context, enhancing the credibility of the data collected. Eight participants were carefully selected to ensure a comprehensive exploration of the phenomenon. The study reached data saturation, meaning that no new information emerged from the additional data, ensuring a thorough understanding of the caregivers' experiences. Conducting a pilot study with four primary caregivers helped assess the feasibility of the research design and tools, ensuring that they effectively captured the necessary data. During interviews, participants were encouraged to be open and honest. They were assured of their right to withdraw from the study at any time without any repercussions, fostering a trusting environment. The researcher engaged with research experts to discuss the data analysis process. Peer debriefing helped identify any potential biases and provided an additional layer of scrutiny to the research findings. The findings were validated through related literature and theories, ensuring that the interpretations were grounded in existing knowledge.

Transferability pertains to the extent to which the findings can be applied to other contexts or groups. To enhance transferability, detailed descriptions of the research context, participants, and findings were provided. This comprehensive account allows readers to determine the applicability of the results to other settings or populations.

Dependability involves the stability and consistency of the research process over time. To ensure dependability, the study underwent external auditing by research experts who were not involved in the study. These experts reviewed the research process and findings to confirm that the data supported the conclusions drawn. The research process,

including data collection and analysis procedures, was meticulously documented. This transparency allows for the replication of the study and verification of the findings.

Confirmability ensures that the findings are shaped by the participants' experiences rather than researcher bias. To achieve confirmability, a clear audit trail was maintained, documenting every step of the research process. This included data collection methods, decisions made during analysis, and the development of themes. Participants reviewed the transcripts and the derived themes to verify that their experiences were accurately captured. This feedback loop ensured that the interpretations truly reflected the caregivers' perspectives. Throughout the data collection and analysis phases, reflective dialogue was used to cross-check the accuracy of the interpretations with the participants. This iterative process helped maintain the authenticity of the findings.

By rigorously applying these criteria, the study ensured that its findings were credible, transferable, dependable, and confirmable. This robust methodological framework provided a trustworthy account of the lived experiences of primary caregivers of stroke patients, offering valuable insights for healthcare professionals, policymakers, and support organizations.

Ethical Considerations

The study adhered to ethical principles to protect the rights and well-being of the participants. Ethical soundness of the study was evaluated by the technical panel of the Master of Arts in Nursing Program of Davao Doctors College, Inc. as well as the research board of the study's locale. This ensured that the research conformed to established ethical standards and guidelines.

Participants provided informed consent after being fully briefed about the study's purpose, procedures, and potential impacts. They were made aware of their rights, including the right to withdraw from the study at any time without any consequences. This informed consent process was crucial in ensuring that participation was voluntary and based on a clear understanding of what the study entailed.

Confidentiality was rigorously maintained throughout the study. Participants' privacy was protected by removing personal identifiers from the transcripts, and all data were securely stored to prevent unauthorized access. This approach safeguarded the participants' identities and the sensitive information they shared.

The principle of beneficence guided the study, which was conducted with the intent to benefit the caregivers. By bringing their experiences to light, the research aimed to highlight the challenges they face and inform better support systems for them. This focus on beneficence ensured that the study was not only ethically sound but also meaningful and impactful for the participants and the broader community of caregivers.

RESULTS

Profile of the Informants

The demographic profile of the study participants provides insight into the diverse backgrounds of primary caregivers of stroke patients. The participants include individuals with varying levels of healthcare experience, ranging from nurses and nursing assistants to those without any formal healthcare background.

Among the eight participants, four are nurses, reflecting a strong presence of individuals with professional healthcare training. These participants are aged between 23 and 32 years old, indicating a relatively young group of healthcare professionals.

Two participants are nursing assistants, both aged 24 years old. Their roles support the primary caregiving activities and highlight the involvement of ancillary healthcare staff in the caregiving process.

The remaining two participants do not have formal healthcare training. Participant 3, who is unemployed and 30 years old, and Participant 5, a 59-year-old self-employed individual, represent the segment of caregivers who may face additional challenges due to their lack of professional healthcare experience.

This demographic diversity underscores the varying degrees of preparedness and challenges faced by caregivers. It also highlights the need for tailored support systems that address the unique needs of both healthcare professionals and laypersons providing care to stroke patients.

Lived Experiences of Caregivers of Patients with Stroke

The study uncovered several key themes and subthemes that provide a comprehensive understanding of the lived experiences of primary caregivers of stroke patients. These themes reveal the practical realities and emotional journeys of caregivers, highlighting both the challenges they face and the sources of resilience and fulfillment they find in their roles.

Theme 1: Prologue: Taking up the Mantle

This theme captures the initial phase of the caregiving journey, where caregivers are confronted with the sudden need to take on the responsibility of caring for a stroke patient. It includes the subthemes of Call to Adventure, Refusal to the Call, Heeding the Call, and Meeting with the Mentor, reflecting the stages of acceptance and adaptation to the new role.

Call to Adventure. Caregivers often begin their journey suddenly, without prior warning. The moment a loved one suffers a stroke, caregivers are thrust into a new role, often out of necessity rather than choice. One participant recalled, "At the moment my aunt had a stroke, there was nobody else who could take care of her, and since I have a

nursing background, her family decided and asked my mother and me if I could be my aunt's caregiver" (Participant 1).

Refusal to the Call. Initial reactions to the caregiving role often include hesitation and reluctance. The overwhelming nature of the responsibility can lead some to initially refuse the role. "There were times when my cousins and I fought over whose turn it is to take care of my grandmother. I felt angry because I still had things to do other than caregiving" (Participant 4).

Heeding the Call. Despite their initial reluctance, many caregivers accept their roles out of love and duty towards their loved ones. They find a way to rise above their fears and hesitations. "Since he is my father, my family agreed to make me the primary caregiver. Actually, my sibling and I take turns in taking care of him, but it was I who really was with my father the most" (Participant 3).

Meeting with the Mentor. Caregivers often receive guidance and support from healthcare professionals, family members, and their own inner strength. This support is crucial in helping them navigate their new responsibilities. "St. Luke's had given us a diet plan, and his physical therapy was twice a week. He also had regular follow-up check-ups with Dr. P" (Participant 3).

Theme 2: The Adventure: Living the Life of a Hero

This theme describes the ongoing journey of caregiving, likened to a heroic quest. Caregivers cross into a new realm of experience, characterized by challenges and responsibilities, but also supported by others. The subthemes are Crossing the Threshold of Being a Hero, A Hero's Duty, and Heroes Assemble!, illustrating the day-to-day tasks and the support networks caregivers rely on.

Crossing the Threshold of Being a Hero. Once caregivers accept their role, they enter a new, challenging phase of life. This transition involves adapting to new routines and responsibilities. "The moment my grandfather had a stroke, we immediately brought him here because he was a regular here and because I work here as well. It seemed automatic that I was chosen to become his caregiver because I was a nurse and the only nurse in our family" (Participant 8).

A Hero's Duty. Caregiving involves a wide range of tasks, from basic daily care to complex medical procedures. The dedication required can be immense. "Usually by afternoons, I give her baths, turn her to her sides, change her clothes, change her catheter, and feed her through her NGT" (Participant 1).

Heroes Assemble! Support from family and friends is crucial. Caregivers often rely on their network to share the burden. "Yes, there were three of us siblings, and we have our cousins as well who help us in taking care of our father" (Participant 2).

Theme 3: The Achilles' Heel

This theme focuses on the vulnerabilities and struggles that caregivers face. It encompasses the significant physical, emotional, and social tolls of caregiving, highlighted by the subthemes "With Great Power Comes Great Responsibility," Heroes Bleed, and Facing the Big Battle. These subthemes address the immense stress and potential for burnout that caregivers endure.

"With Great Power Comes Great Responsibility" The role of a caregiver comes with significant responsibilities, often leading to feelings of being overwhelmed. "At the time I became the primary caregiver of my grandfather, the responsibility of being in-charge of his health was overwhelming for me" (Participant 8).

Heroes Bleed. Caregiving takes a toll on caregivers' physical and mental health. Social isolation and personal sacrifices are common. "My life was really affected. At the moment my father had a stroke, I was about to take exams at that time, and I was a graduating student at that. I was so busy meeting the ends of my requirements, even to the point of not being able to study because I'd allot my study and rest periods to taking care of him" (Participant 2).

Facing the Big Battle. The constant demands of caregiving can lead to significant stress and burnout. "As for the physical aspect, I just deemed that I needed strength to turn her to her sides because she was somewhat overweight" (Participant 1).

Theme 4: Heroes Prevail

The final theme celebrates the resilience and ultimate triumph of caregivers. Despite the myriad challenges, caregivers find meaning and fulfillment in their roles. The subthemes The Road Forward and Resurrection of the Hero describe the ongoing journey of personal growth and the renewed sense of purpose that many caregivers experience.

The Road Forward. Despite the hardships, caregivers find ways to move forward, often driven by the progress and recovery of their loved ones. They develop strategies and routines that help them manage their responsibilities more effectively.

Resurrection of the Hero. Ultimately, caregivers find a sense of purpose and fulfillment in their roles. The journey, while challenging, leads to personal growth and resilience. "For me, if you have children that aid you in caregiving, you'd have a breather, as if your burdens will lessen because of them" (Participant 5).

DISCUSSION

Life after stroke, for most patients, hadn't been an easy life to live with. In fact, it took them several months and, for some, even years before they recovered from and adjusted to the life of having a stroke. Although the complications that resulted from the

stroke event, and the changes it brought to them, varied from one person to another, these patients, owing to their decreased in or loss of their capacity to live their lives on their own, all faced the same brand of challenge – that is, taking on the role of being a care-seeker. However, these stroke patients aren't the only ones who faced big changes. Their caregivers faced them too. Their lives, much to what these stroke patients have had, haven't been an easy one to live with as well, and, in most cases, these caregivers, as they began to take up the role of being the carer of these care-seekers, did not have a good understanding of the mantle they were about to wear, of the role to which they were about to commit, and they were not well-prepared to take on even the basic tasks to meet the patients' needs after stroke. Furthermore, these patients and their caregivers did not have adequate time to deal with the shock and crisis of the stroke event, let alone the crisis of discharge and of all the new responsibilities with which they have dealt and continue to deal with after it occurred – an experience which has been reflected in other studies (Andrew et al., 2015; Byun & Evans, 2015; Haley et al., 2015; Lou et al., 2015; Lutz et al., 2011; McGurk & Kneebone, 2013; Persson et al., 2015; Olai et al., 2014; Timber & Smith, 2011). Simply put, their lives, in all its aspects, have never been the same after stroke.

Nevertheless, amidst all odds, these stroke patients and their caregivers found solace and support in the presence of their family and friends, in the teachings and insight of their healthcare providers, and, most importantly, in the sustenance of each other – as was underscored in several studies (Gillespie & Campbell, 2011; O'Shea & Goode, 2015; Plank et al., 2012; Grant et al., 2014). Together, living after stroke and with stroke had become a series of ups and downs, of trials and errors, and of frustrations and satisfactions.

The insights gained from this study are invaluable for healthcare professionals, policymakers, and support organizations, emphasizing the critical role of primary caregivers and the need for comprehensive support systems. Recognizing and addressing the multifaceted needs of caregivers is essential to improve their quality of life and, consequently, the health outcomes of stroke patients.

One of the primary insights from this study is the necessity for robust community-based support programs that offer both emotional and practical assistance to caregivers, as was suggested by the National Institutes of Health (2015). Such programs can provide a range of services, including help with daily tasks, transportation, and access to local resources. By integrating caregivers into the broader healthcare system, these programs can ensure they receive the comprehensive support needed to manage their caregiving responsibilities effectively. Emotional support through peer groups and counseling can alleviate the psychological burden, while practical assistance can ease the day-to-day caregiving load.

Moreover, implementing flexible work arrangements and respite care options is crucial to help caregivers balance their caregiving responsibilities with other aspects of their lives. Flexible work policies, such as adjustable work hours, remote work options, and extended leave provisions, can significantly reduce the stress and burnout associated

with balancing full-time employment and caregiving duties. Respite care options are equally important, providing temporary relief and allowing caregivers to take necessary breaks to maintain their well-being (Doty & Spillman, 2015; Swanke & Zennan, 2009).

In addition, offering comprehensive training programs is vital to equip caregivers with the necessary skills and knowledge to manage the complex needs of stroke patients effectively, as was suggested by Pitthayapong et al. (2017). These programs should cover practical skills, patient care techniques, and the use of medical equipment. Ongoing training is essential to address the evolving needs of both caregivers and patients, ensuring that caregivers are always prepared to provide the best possible care. Such training empowers caregivers, enhancing their confidence and competence in managing their roles.

Furthermore, incorporating Chada's (2014) recommendation of providing access to mental health services is critical to address the emotional and psychological challenges that caregivers face. Caregiving can be an isolating and emotionally taxing experience, leading to stress, anxiety, and depression. Access to professional counseling and mental health support can help caregivers cope with these challenges, improving their overall mental health and resilience. These resources should be readily available and tailored to meet the specific needs of caregivers, offering them the support they need to sustain their caregiving efforts.

By addressing these needs, the quality of life for both caregivers and stroke patients can be significantly improved. Enhanced support systems, flexible work policies, comprehensive education and training, and accessible mental health resources can ensure better health outcomes and more sustainable caregiving practices. The insights from this study highlight the resilience of caregivers and underscore the critical importance of providing them with the support they need to continue their vital work effectively. Investing in these areas not only benefits caregivers but also contributes to the overall well-being and recovery of stroke patients, fostering a healthier, more supportive community for all.

Limitations of the Study

This study provides valuable insights into the lived experiences of primary caregivers of stroke patients, but it has several limitations. The small sample size and specific geographic focus may affect the generalizability of the findings. Selection bias could also be present due to the purposive sampling method, and reliance on self-reported data may introduce recall bias. Additionally, the cross-sectional design captures only a single point in time, missing the evolving nature of caregiving, and the cultural context may limit applicability to other settings.

Despite these limitations, the study has notable strengths. The phenomenological design allows for an in-depth exploration of caregivers' experiences, providing rich and detailed insights. Colaizzi's method ensured rigorous data analysis, enhancing credibility. The diverse participant backgrounds add depth to the findings, and the focus on an under-

researched group addresses a significant gap in the literature. These strengths contribute to the study's overall value in informing support systems and interventions for primary caregivers of stroke patients.

Conclusions

This phenomenological study aimed to explore and understand the lived experiences of primary caregivers of stroke patients. Through in-depth interviews and qualitative data analysis, we uncovered four major themes that encapsulate the caregiving journey: Prologue: Taking up the Mantle, The Adventure: Living the Life of a Hero, The Achilles' Heel, and Heroes Prevail. These themes reveal the multifaceted nature of caregiving, highlighting both the immense challenges and the deep sense of fulfillment that caregivers experience.

The study found that caregivers often begin their roles with reluctance and hesitation, faced with overwhelming responsibilities and significant lifestyle changes. Despite these initial struggles, they adapt and grow, finding strength and resilience through their journey. The constant demands of caregiving take a toll on their physical, emotional, and social well-being, yet caregivers also find meaning and purpose in their roles, driven by love and duty towards their loved ones.

The findings of this study underscore the critical yet often overlooked role of primary caregivers in the rehabilitation and recovery of stroke patients. The study emphasizes the need for comprehensive support systems that address the physical, emotional, and social needs of caregivers, ensuring they are equipped to manage their responsibilities effectively while maintaining their well-being.

Recommendations

The research has drawn the following recommendations to nursing practice, education, and research from the findings of the present study. For nursing practice, to better support primary caregivers of stroke patients, it is essential to develop and implement integrated caregiver training programs. These programs should focus on practical skills, patient care techniques, and the use of medical equipment. Training must be ongoing to address the evolving needs of both caregivers and patients, ensuring that caregivers are equipped with the latest knowledge and skills necessary for effective care. Regular health assessments for caregivers are crucial to monitor their physical and mental health. By conducting these assessments, healthcare providers can identify signs of burnout and health deterioration early, allowing for timely interventions and support. Additionally, establishing counseling and mental health support services can help caregivers cope with the emotional and psychological challenges they face. Providing access to these services can significantly alleviate stress and improve caregivers' overall well-being.

In addition, nursing education programs should incorporate modules specifically focused on caregiver support. These modules should emphasize the importance of understanding and addressing the needs of caregivers, preparing future nurses to provide

holistic care that includes both patients and their caregivers. By integrating this perspective into the curriculum, nursing students will be better equipped to offer comprehensive support. Training in effective communication techniques is also essential. Educating nursing students on how to communicate empathetically and practically with caregivers ensures that they can provide the necessary guidance and support. This training will enable nurses to build strong, supportive relationships with caregivers, fostering a more collaborative and effective care environment.

For nursing research, there is a need for longitudinal studies to explore the long-term impacts of caregiving on physical and mental health. These studies should examine how the challenges and needs of caregivers evolve over time, identifying effective interventions that can support them throughout their caregiving journey. Research into the effectiveness of various support interventions is also critical. By evaluating programs such as caregiver training, support groups, and mental health services, researchers can determine the best practices for alleviating caregiver burden. Furthermore, studying the experiences of caregivers across different cultural and socio-economic backgrounds is essential to identify unique challenges and tailor support needs accordingly. This research will provide a more comprehensive understanding of caregiving dynamics, ensuring that support interventions are inclusive and effective for diverse populations.

Furthermore, it is the hope of the researcher that the following policy recommendations be implemented in healthcare systems to provide sustainable support to the primary caregivers of patients with stroke. First, advocating for policies that provide flexible work arrangements and respite care options is crucial to help caregivers balance their caregiving responsibilities with other aspects of their lives. Many caregivers face the challenge of juggling full-time employment and caregiving duties, which can lead to significant stress and burnout. Flexible work policies, such as adjustable work hours, remote work options, and extended leave provisions, can alleviate some of these pressures, allowing caregivers to manage their time more effectively. Respite care options, which provide temporary relief by arranging professional care for the patient, are also essential. These policies not only support caregivers' well-being but also ensure they can continue to provide high-quality care to their loved ones without sacrificing their own health or job security.

Moreover, promoting the development of community-based support programs is vital for offering practical assistance and emotional support to caregivers. These programs can provide a range of services, including help with daily tasks, transportation, and access to local resources. By integrating caregivers into the broader healthcare system, these programs can ensure that caregivers receive the comprehensive support they need. For example, community centers can host workshops and support groups, providing a platform for caregivers to share experiences and receive guidance from professionals and peers. These initiatives can create a supportive network, reducing feelings of isolation and enhancing caregivers' ability to manage their responsibilities effectively.

In addition, launching public awareness campaigns is essential to raise awareness about the critical role of caregivers and encourage community support and recognition of their contributions. These campaigns can highlight the challenges caregivers face and the invaluable service they provide, fostering greater empathy and understanding within the community. Public recognition can lead to increased support from employers, policymakers, and community members. Campaigns can utilize various media platforms, including social media, television, and community events, to reach a broad audience. By bringing attention to the importance of caregiving, these campaigns can drive societal changes that support caregivers, such as improved access to resources and better policy implementation.

Compliance with Ethical Standards

This study was conducted in full compliance with ethical standards. Informed consent was obtained from all participants, ensuring that they were fully aware of the study's nature, purpose, and procedures. Participants were informed of their right to withdraw from the study at any time without any repercussions. The anonymity of the informants was rigorously maintained, with personal identifiers removed from all data to protect their privacy. Throughout the study, the well-being of the informants was safeguarded, and every effort was made to minimize any potential distress or discomfort.

There were no conflicts of interest involved in the conduct of this study. The researcher adhered strictly to ethical guidelines to avoid plagiarism, ensuring that all sources were appropriately cited and credited. Additionally, there was no bias in the interpretation of the findings; the data were analyzed objectively to provide an accurate representation of the caregivers' experiences. The results of this study were used purely for research purposes, contributing to the body of knowledge on caregiving and informing better support practices for caregivers of stroke patients.

Acknowledgments

The author extends his deepest gratitude to the primary caregivers who participated in this study, sharing their invaluable experiences and insights. Special thanks are given to the faculty and staff of the Master of Arts in Nursing Program of Davao Doctors College for their guidance and support. The author also acknowledges the assistance of the participating institution with data collection. Finally, the researcher appreciates the unwavering support of his family and friends throughout this research journey. Thank you all for your contributions.

REFERENCES

- Andrew, N., Kilkenny, M., Naylor, R., Purvis, T., & Cadilhac, D. (2015). The relationship between caregiver impacts and the unmet needs of survivors of stroke. *Patient Preference and Adherence*, 1065. <http://dx.doi.org/10.2147/ppa.s85147>
- American Heart Association. (2016). *Heart disease, stroke and research statistics at-a-glance*. (2016). http://www.heart.org/idc/groups/ahamaph-public/@wcm/@sop/@smd/documents/downloadable/ucm_480086.pdf
- Aziz, N., Pindus, D., Mullis, R., Walter, F., & Mant, J. (2016). Understanding stroke survivors' and informal carers' experiences of and need for primary care and community health services—a systematic review of the qualitative literature: protocol. *BMJ Open* 2016; 6: e009244. <http://bmjopen.bmj.com/content/6/1/e009244.full.pdf+html>
- Byun, E. & Evans, L. (2015). Concept analysis of burden in caregivers of stroke survivors during the early poststroke period. *Clinical Nursing Research*, 24(5), 468-486. <http://dx.doi.org/10.1177/1054773814537060>
- Centers for Disease Control and Prevention. (2015). Heart disease and stroke statistics. *Morbidity and Mortality Weekly Report*, 64(11), 113-124.
- Chadda, R. (2014). Caring for the family caregivers of persons with mental illness. *Indian Journal of Psychiatry/Indian Journal of Psychiatry*, 56(3), 221. <https://doi.org/10.4103/0019-5545.140616>
- Creswell, J. (2013). *Qualitative inquiry & research design* (3rd ed.). Thousand Oaks: Sage Publications.
- Doty, P., & Spillman, B. (2015). Help for family caregivers available from government programs and policies. In J. E. Gaugler & R. L. Kane (Eds.), *Family caregiving in the new normal* (pp. 153-192). New York: Elsevier.
- Duncan, P. W., Zorowitz, R., Bates, B., Choi, J. Y., Glasberg, J. J., Graham, G. D., Katz, R. C., Lambert, K., & Reker, D. (2005). Management of Adult Stroke Rehabilitation care. *Stroke*, 36(9). <https://doi.org/10.1161/01.str.0000180861.54180.ff>
- Gillespie, D., & Campbell, F. (2011). Effect of stroke on family carers and family relationships. *Nursing Standard*, 26 (2), 39-46. <http://journals.rcni.com/doi/abs/10.7748/ns2011.09.26.2.39.c8707>
- Grant, J. S., Clay, O. J., & Glandon, G. L. (2014). Caregiving problems and feelings experienced by family caregivers of stroke survivors the first month after discharge. *International Journal of Rehabilitation Research*, 37(2), 127-135. <https://doi.org/10.1097/01.mrr.0000127639.47494.e3>
- Haley, W., Roth, D., Hovater, M., & Clay, O. (2015). Long-term impact of stroke on family caregiver well-being: A population-based case-control study. *Neurology*, 84(13), 1323-1329. <http://dx.doi.org/10.1212/wnl.0000000000001418>
- Jaracz, K., Grabowska-Fudala, B., Górna, K., Jaracz, J., Moczko, J., & Kozubski, W. (2015). Burden in caregivers of long-term stroke survivors: Prevalence and determinants at 6 months and 5 years after stroke. *Patient Education and Counseling*, 98(8), 1011-1016. <http://dx.doi.org/10.1016/j.pec.2015.04.008>

- Lau, D. T., Kasper, J. D., Hauser, J. M., Berdes, C., Chang, C., Berman, R. L., Masin-Peters, J., Paice, J., & Emanuel, L. (2009). Family caregiver skills in medication management for hospice patients: A Qualitative Study to define a construct. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 64B(6), 799–807. <https://doi.org/10.1093/geronb/gbp033>
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Sage. [https://doi.org/10.1016/0147-1767\(85\)90062-8](https://doi.org/10.1016/0147-1767(85)90062-8)
- Loo, K. W., & Gan, S. H. (2012b). Burden of stroke in the Philippines. *International Journal of Stroke*, 8(2), 131–134. <https://doi.org/10.1111/j.1747-4949.2012.00806.x>
- Lou, S., Carstensen, K., Jørgensen, C. R., & Nielsen, C. P. (2016). Stroke patients' and informal carers' experiences with life after stroke: an overview of qualitative systematic reviews. *Disability and Rehabilitation*, 39(3), 301–313. <https://doi.org/10.3109/09638288.2016.1140836>
- McGurk, R., & Kneebone, I. (2013). The problems faced by informal carers to people with aphasia after stroke: A literature review. *Aphasiology*, 27 (7), 765-783. <http://dx.doi.org/10.1080/02687038.2013.772292>
- National Institutes of Health (NIH). (2015). *Resources for Enhancing Alzheimer's Caregiver Health (REACH) II*. National Institute on Aging. <https://www.nia.nih.gov/health/reach-ii-intervention>
- Navarro, J. C., Baroque, A. C., Lokin, J. K., & Venketasubramanian, N. (2014). The real stroke burden in the Philippines. *International Journal of Stroke*, 9(5), 640–641. <https://doi.org/10.1111/ijis.12287>
- National Stroke Association. (2012). Caregivers and stroke. https://www.stroke.org/sites/default/files/resources/NSA_CaregiversAndStroke.pdf
- Olai, L., Borgquist, L., & Svärdsudd, K. (2015). Life situations and the care burden for stroke patients and their informal caregivers in a prospective cohort study. *Uppsala Journal of Medical Sciences*, 120(4), 290–298. <https://doi.org/10.3109/03009734.2015.1049388>
- O'Shea, R., & Goode, D. (2013). Effects of stroke on informal carers. *Nursing Standard*, 28(15), 43–47. <https://doi.org/10.7748/ns2013.12.28.15.43.e8095>
- Persson, J., Holmegaard, L., Karlberg, I., Redfors, P., Jood, K., Jern, C., Blomstrand, C., & Forsberg-Wärleby, G. (2015). Spouses of stroke survivors report reduced Health-Related quality of life even in Long-Term Follow-Up. *Stroke*, 46(9), 2584–2590. <https://doi.org/10.1161/strokeaha.115.009791>
- Pitthayapong, S., Thiangtam, W., Powwattana, A., Leelacharas, S., & Waters, C. M. (2017). A community based program for family caregivers for post stroke survivors in Thailand. *Asian Nursing Research*, 11(2), 150–157. <https://doi.org/10.1016/j.anr.2017.05.009>
- Plank, A., Mazzoni, V., & Cavada, L. (2012). Becoming a caregiver: new family carers' experience during the transition from hospital to home. *Journal of Clinical Nursing*, 21(13–14), 2072–2082. <https://doi.org/10.1111/j.1365-2702.2011.04025.x>
- Pucciarelli, G., Vellone, E., Savini, S., Simeone, S., Ausili, D., Alvaro, R., Lee, C. S., & Lyons, K. S. (2017). Roles of changing physical function and caregiver burden on

- quality of life in stroke. *Stroke*, 48(3), 733–739.
<https://doi.org/10.1161/strokeaha.116.014989>
- Rahman, R., Dewi, F. S. T., & Setyopranoto, I. (2017). Dukungan keluarga dan kualitas hidup bagi penderita stroke pada fase pasca akut di Kabupaten Wonogiri. *Berita Kedokteran Masyarakat/Berita Kedokteran Masyarakat*, 33(8), 383.
<https://doi.org/10.22146/bkm.22599>
- Swanke, J., & Zeman, L. D. (2009). Family Medical Leave as a resilience resource for family caregivers. *Care Management Journals*, 10(1), 8–13.
<https://doi.org/10.1891/1521-0987.10.1.8>
- Winstein, C. J., Stein, J., Arena, R., Bates, B., Cherney, L. R., Cramer, S. C., Deruyter, F., Eng, J. J., Fisher, B., Harvey, R. L., Lang, C. E., MacKay-Lyons, M., Ottenbacher, K. J., Pugh, S., Reeves, M. J., Richards, L. G., Stiers, W., & Zorowitz, R. D. (2016). Guidelines for adult stroke rehabilitation and recovery. *Stroke*, 47(6). <https://doi.org/10.1161/str.0000000000000098>
- Yuki, T., & Kudo, M. (2011). Factors related to continuation of health behaviours among stroke survivors. *Journal of the Japanese Physical Therapy Association*, 14(1), 1–11. https://doi.org/10.1298/jjpta.vol14_001

APA citation:

Nieve, B. B. (2024). CARERS OF THE CARE-SEEKERS: THE LIVED EXPERIENCES OF PRIMARY CAREGIVERS OF PATIENTS WITH STROKE. *Ignatian International Journal for Multidisciplinary Research*, 2(6), 1134–1150. <https://doi.org/10.5281/zenodo.11638449>

blaisenieve2@gmail.com