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Poststroke Depression and the Lived Experiences of the Family Caregiver and Care Recipient Dyad

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Walden University

College of Social and Behavioral Sciences

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Tiffany Gurley-Nettles

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Walden University
2021

Abstract

Poststroke Depression and the Lived Experiences of the Family Caregiver and Care Recipient Dyad

by

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M.S. University of the District of Columbia, 1997

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

Walden University

May 2021

Abstract

Poststroke depression in stroke survivors is a more common occurrence than once believed as the survivor of stroke must contend with the loss of their former self and with residual physical, communicative, cognitive, and/or psychological changes. Family members who become informal caregivers, with minimal to no training in some cases, may experience stress from having to adjust to new family roles and responsibilities. Limited information is available on the lived experiences of the family caregiver and the survivor of stroke. The objective of this study was to explore the lived experiences of the survivor or stroke with poststroke depression and family caregiver stress within the dyad. This transcendental phenomenological study was conducted using semistructured interviews with six dyads, twelve participants in total. Interviews were transcribed and coded manually. Data analysis resulted in twelve themes, seven themes from interviews with the family caregivers and five themes from the interviews with the survivor of stroke with post-stroke depression. The key findings of this study indicate that time and commitment, lack of preparedness, family caregiver burden, lack of balance, isolation, and the challenges of managing the depression of the recipient of care are factors that contribute to family caregiver stress. Furthermore, lack of self-efficacy, grieving of former self, isolation, lack of depression coping skills, and difficulty with communication are all factors that contribute to poststroke depression. Study findings may inform allied health practitioners of strategies for managing the role of family caregiving, stress, poststroke depression and coping, thereby creating a positive social change impact for this community.

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Dedication

I dedicate my dissertation to my two amazing children, Tejah and Trevor Nettles. You two were my inspiration through this entire journey as you graciously sacrificed your mommy time and allowed me to work, on most days anyway, until I found a way to balance it all. You were patient, kind, and forgiving as I went through all the emotions that came with this process. The struggle was real as life seemed to be challenging me at times, and you both helped me push pass those obstacles. When I wanted to quit, all that I had to do was to remember who was watching, and that kept me going. At one point, the word "dissertation" became the equivalent to a four-letter word in the house, and often at the mention of the word, eyes would roll but we made it though. Thank you so much for being the best kids a mom could ever be blessed with. Thank you, Tejah and Trevor; I love you to infinity and beyond!

I also dedicate my work to my mom. I tried to keep it a secret from you at first because I wanted to surprise you at the end. As time moved forward, the work became more intense, and I had to explain why I was always so busy. You were so happy and supportive of my pursuit of my PhD, and I was happy that I shared the news with your early. I, however, had no idea that I would lose you before I was done. I was devastated. Your loss hit me like a ton of bricks, and it stopped me in my tracks. I no longer wanted to continue, but I could hear your words "you go girl, you've got this" and I noticed your grandchildren were watching. I took some time off to get myself together and jumped back in with extra motivation. You and Dad modeled the importance of education and have always been a source of encouragement. To my dad, thank you making education a priority in our house and for being the best father ever! You and Mom laid a great foundation for me, and you both will live forever in my heart. Thank you, Beverly and Leon Gurley, for all that you instilled in me. May you continue to rest in peace.

Acknowledgements

I would first like to acknowledge my family and friends who supported and encouraged me along this process. Those of you who provided technical assistance and let me borrow computers and printers when I was having technical difficulty. To those who let me cry when life along this journey became extremely rough with the loss of four family members, including my mom and a very dear friend. To my niece Jasmine Gurley who predicted this journey for me before I even decided to apply. I also would like to acknowledge Jamil Smart, Clarke Perry, and Joan Jones who helped me prepare for my proposal, and final defense, proofread papers, and were my study buddies. To my friends who let me come to their social gatherings and family events with my books in tow. I appreciate every ounce of support that you all provided.

I would also like to acknowledge Ms. Devon Dee who helped me lay the groundwork to get me off to a good start at the beginning of this journey. Dr. Shameka Johnson who took time out of her busy schedule to spend a day with me to ensure that I had complete understanding of Advanced Quantitative Statistics, my most feared course, thank you so much. To my fellow classmate Deidre Butts who was there for me when times were tough, and for the midnight work and study sessions. Whew! I owe you a debt of gratitude! Dr. Katina Clarke, we made it! Thank you for the monthly check-ins, advice, suggestions, and the work/life balance tips for my kids. I remember our first residency when we could not see the light at the end of the tunnel but were determined to make it though. To the rest of my residency cohorts, thanks for all the brainstorming sessions, tips, and tricks to make it through this process and write a quality paper. To all of my family and friends who spread the word to help me obtain participants for my study, thank you from the bottom of my heart.

To my awesome committee members, you were amazing (insert applause here). Dr. Brent Robbins, I appreciate all your enthusiasm, wisdom, feedback, and support. To my dissertation chair, Dr. Jay Greiner, words cannot express the level of gratitude that I have for you. You were more than a mentor, you were my therapist, supporter, my shoulder to cry on, my encourager, physician assistant, and more! My personal life was all over the place, and you remained patient, supportive, and encouraging the entire way. For every setback, obstacle, and unexpected life challenge that came my way, you were right there to offer support and a reassuring word. Thank you for your patience and guidance and for sharing your knowledge with me; you are the absolute best, and I cannot thank you enough. Finally, I would like to thank my family caregivers and stroke survivor participants. I appreciate the time you took from your very busy lives to share your personal experiences with me. I salute you!

Table of Contents

List of Figures

Chapter 1: Introduction to the Study

Informal caregivers are a valuable resource to their care recipients and play a critical role within the U.S. healthcare system. Stroke survivors, for instance, rely on informal caregivers to provide care and assistance with daily tasks (Wan-Fei et al., 2017). Over 40 million American provide informal care each year (Family Caregiver Alliance National Center on Caregiving, 2009), and they include spouses, partners, children, siblings, other family members, friends, and even neighbors. Many informal caregivers feel a sense of reward in caring for a loved one, and their work affects recovery outcomes poststroke; however, the heavy demands can become burdensome and lead to stress, exhaustion, anxiety, and depression (American Heart Association, 2019; Family Caregiver Alliance National Center on Caregiving, 2014). The demands of caregiving are impacted by the type of illness, cultural approach, distance, setting, and severity of deficits poststroke.

Poststroke depression is a common occurrence and is directly associated with the quality of life of the survivor of stroke. (Wan-Fei et al., 2017). Other factors related to poststroke depression are the severity of the stroke, the impact on physical and communication ability, and family support. The depression often experienced by stroke survivors and caregivers has an adverse impact on the dyadic relationship (Wan-Fei et al., 2017). As Wan-Fei et al. (2017) observed, the emotional state of family caregivers and care recipients affects each individual within the dyad. Further research is indicated to explore the lived experiences within the family caregiver and care recipient with poststroke depression dyad, to glean insight and understanding of the dyad along with contributing factors to negative emotions.

Background

Stroke continues to be the foremost cause of long-term disability with numerous survivors of stroke being discharged from acute care and rehabilitation facilities to the home and community with the family responsible for providing extended or long-term care (Mozaffarian et al., 2015). Because most survivors of stroke return home, the family caregiver is likely to experience the emotional and social effects of the stroke (Bucki et al., 2019). There are also changes to relationships in some dyads, along with the accompanying stress and burden. Stroke care recipients, with a resulting physical impact, tend to underestimate the disturbance to the relationship with the caregiver (Bucki et al., 2019). Furthermore, the family caregiver tends to overestimate the relationship disturbance and the survivor of stroke's personality changes (Bucki et al., 2019).

Poststroke depression affects the quality of life of the family caregiver and the survivor of stroke (Wan-Fei et al., 2017). Many stroke survivors have symptoms of depression that would be recognized by a health care provider but not by an untrained family caregiver. In one study, care recipients with poststroke depression who had a supportive family caregiver displayed fewer symptoms of depression and a higher number of good functional outcomes (Ahn et al., 2015). The authors of the study, Ahn et al. (2015), concluded that depression is a significant problem for stroke survivors and caregivers and that factors related to care matter in terms of the distress of the patient. Furthermore, there was an association between the distress levels in survivors of stroke and the psychological distress levels of the family caregiver. There are numerous studies that address caregiver stress, poststroke depression, and the caregiver dyad (e.g., Bucki et al., 2019; DeRyck et al., 2014; Torrisi et al., 2018) however, research is limited with regard to lived experiences within the dyadic relationship between the stroke survivor with poststroke depression and the family caregiver. This study may have implications in the fields of allied health, nursing, and rehabilitation medicine.

Problem Statement

The informal or family caregiver is essential to the survivor of stroke, as it is the family caregiver who will aid the stroke survivor during rehabilitation and activities of daily living such as bathing, dressing, and grooming. Also included in the caregiver’s lists of new tasks are instrumental activities of daily living such as cooking, cleaning, and money management. Many family caregivers are not prepared for this new role and added responsibility, which leads to higher levels of emotional distress (Cameron et al., 2006). Family caregivers encounter stress given the new challenges of assuming many new caregiving duties in addition to their own personal responsibilities and daily routines. Numerous studies confirm the burden, burnout, reduced quality of life, and depression that is often experienced by family caregivers (Barbic et al., 2014).

Previous researchers have reported an association between impairment in stroke survivors and caregiver stress and depression (Pendergrass et al., 2017). Results affirm that informal caregiving has a major impact on the caregiver’s emotional, physical, and social health and that this impact will influence the caregiver’s ability to maintain the role over a long period of time (Barbic et al., 2014). In a study of the impact of the stroke survivor’s behavioral and psychological symptoms on the family caregiver’s experiences of depression, researchers found that the behavioral and psychologic symptoms contributed to the family caregiver’s depression (Cameron et al., 2006). Although these studies contribute valuable information to the field, limited information is available on the lived experiences of the family caregiver and the survivor of stroke. In this study, I explored the lived experiences of the family caregiver with stress and recipient of care within the family caregiver and survivor of stroke dyad.

A major cause of rehabilitation and long-term disability in the United States is stroke (Ma et al., 2014). Many stroke survivors experience the psychological problem of poststroke depression, defined as a mood disorder secondary to stroke with depressive and mixed mood features. (McCarthy et al., 2011). There are many factors that are associated with the risk of post-stroke depression. In a meta-analysis study, Shu et al. (2017) identified risk factors such as a history of mental illness, including depression and anxiety; having a family history of mental illness; and neuroticism, which is a tendency to respond to frustration, threat, or loss with negative emotions. Stroke severity, level of resulting disability, level of independence, female sex, and age less than 70 years are also reported risk factors for poststroke depression (Shu et al., 2017). Poststroke depression is a psychiatric complication that is common. It often goes undiagnosed and is known to decrease the effectiveness of rehabilitation and increase the mortality rates for patients after a stroke (Belokoskova & Tsikunov, 2010).

Many survivors of stroke are able to return to the community; however, most will go through difficult and demanding rehabilitation over a lengthy period (Palmer & Glass, 2003). Successful community reentry and resumption of daily activities, as well as psychosocial roles and psychological recovery, will largely depend on the emotional support from family (Palmer & Glass, 2003). Post-stroke depression can have a major negative impact on the stroke survivor's quality of life (Kleindinst et al., 2013). Reporting the symptoms of depression to health care providers has been found to be beneficial in the recovery. Kleindinst et al. (2013) also suggest that further exploration is needed to explore stroke survivor awareness of depressive symptoms and how to cope with the feelings experienced to assist in the resolution of this phenomenon (Kleindinst et al., 2013).

It appears that perceived stress of the family caregiver can be projected on the care recipient, in this case the stroke survivor, and negatively impact their recovery from depression as well as from other deficits incurred as a result of the stroke (Rashid et al., 2013). Survivors of stroke, who have caregivers who are distressed, may have poorer outcomes thus leading to the need for interventions for caregivers, which will lead to optimal recovery following stroke (Grant et al., 2013). Landerville et al. (2009) concluded that there was a significant relationship between stroke severity and activity restriction, as both related to symptoms of depression poststroke. Also noted were changed social roles, which were related to depressive symptoms (Landerville et al., 2009). However, a gap in the literature remains on research involving the lived experiences of family caregiver stress and care recipient experiences related to poststroke depression. . I explored caregiver stress and stroke survivors' experiences of depression in the context of the relationship between caregiver and care receiver.

Purpose of the Study

The purpose of this qualitative study was to explore the lived experiences of stroke survivors with poststroke depression within the caregiver-care recipient dyad. I sought to (a) identify what factors contribute to family caregiver stress, (b) identify what factors contribute to stroke survivors' depression, and (c) explore how both caregivers and stroke survivors cope with family caregiver stress and how stroke survivors cope with depression. I conducted semistructured interviews to document the lived experiences and perceptions of family caregivers and stroke survivors.

Research Questions

The research questions (RQs) for this qualitative study center on understanding the lived experiences of the family caregiver and care recipient with poststroke depression dyad. The overarching RQ was, What are the experiences of the care recipient after stroke and the family caregiver as it relates to post-stroke depression and caregiver stress? The secondary RQs were as follows:

RQ1. How do caregivers and stroke survivors describe the factors that contribute to caregiver stress?

RQ2. How do caregivers and stroke survivors describe the factors that contribute to stroke survivors' depression?

RQ3. How do caregivers and stroke survivors cope with caregiver stress?

RQ4. How do stroke survivors cope with stroke survivors' depression?

RQ5. What is the experience with the caregiver and care recipient with reciprocity?

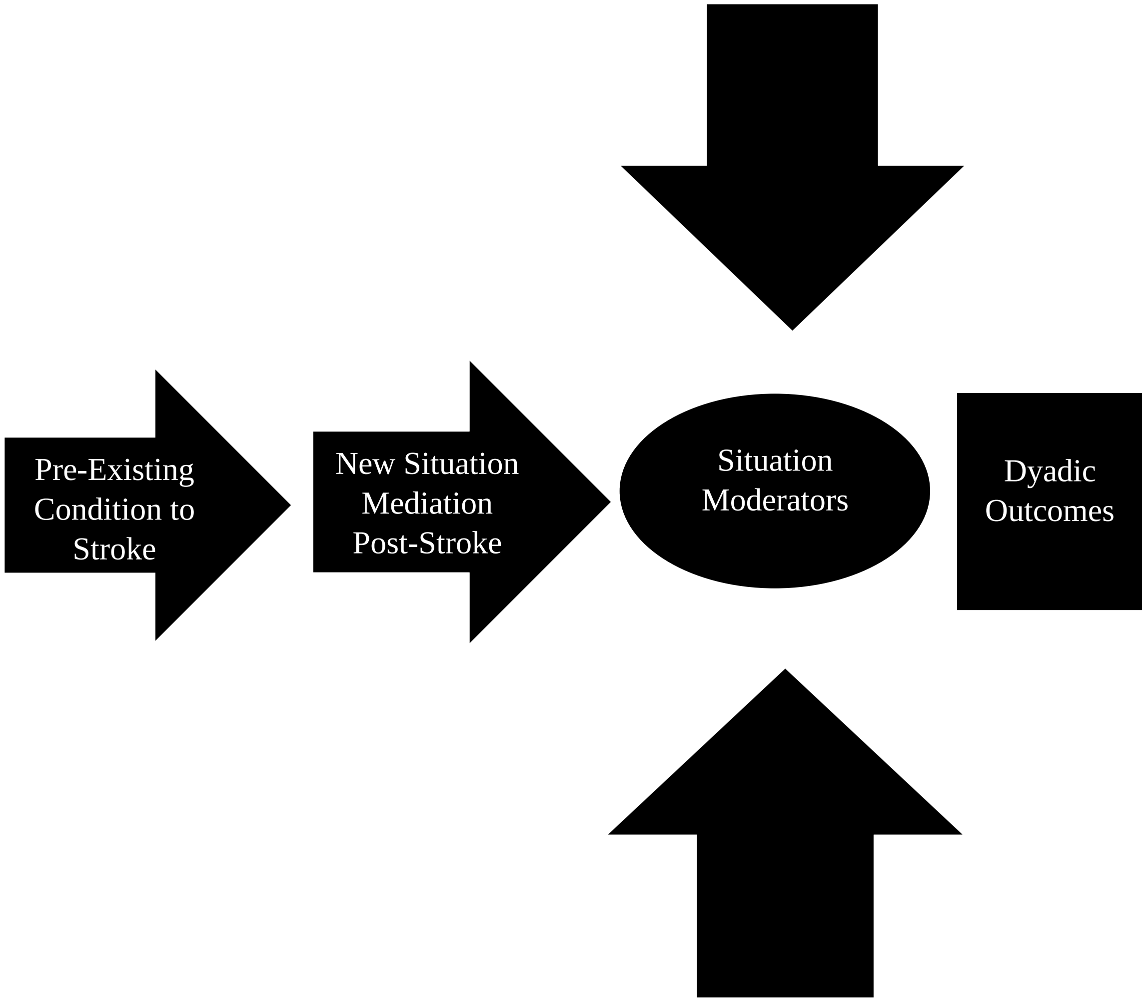
Conceptual Framework

Figure 1 represents the conceptual framework for this study. I drew from Savini et al.’s (2014) adaptation of Lazerus and Folkman’s (1984) and McCubbin et al.’s (1983) conceptual models and from existing literature. Savini et al. suggested that in the caregiver-survivor of stroke dyad, that quality of life in the new situation poststroke is influenced based on the preexisting stroke condition of the relationship and is mediated by the variables of the new situation poststroke. Based on the literature, a direct influence on poststroke situation is based on the preexisting condition of the relationship (Stipancic et al., 2019). Moderators include available rehabilitative support and social support which are said to impact the relationship (Stipancik et al., 2019).

In this study, I documented the lived experiences of stroke survivors with depression and their family caregivers with stress and depression. Findings of this study may contribute to caregiver education and instruction models based on the relationship of the dyad prior to the stroke. Discharge preparation that is successful and effective begins at admission to the facility (Robeznieks, 2017). Family caregiver education is designed to prepare the caregiver for the needs and care of the survivor of stroke and may have a positive impact on patient outcomes. Family and other caregivers who are actively engaged in the process create a support system for in-home family care immediately postdischarge as well as for long-range planning (Robeznieks, 2017).

Figure 1

Conceptual Framework



Note. from “Quality of Life in Stroke Survivor-Caregiver Dyads: A New Conceptual Framework and Longitudinal Study Protocol,” by S. Savini, H. G. Buck, V. V. Dickson, S. Simeone, G. Pucciarelli, R. Fida, M. Matarese, R. Alvaro, and E. Vellone, 2014, *Journal of Advanced Nursing, 71*(3), p. 678 (https://doi.org:10.1111/jan.12524).

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Nature of the Study

I used a phenomenological research design for this study. This type of inquiry allowed for the participants to describe their lived experiences as a family caregiver or survivor of stroke with poststroke depression (see Creswell, 2013). Understanding the lived experiences of the caregiver and the poststroke survivor within their dyadic relationship is aligned with research involving qualitative inquiries. Caregivers were included in the study based on the completion of a background questionnaire to validate their stress associated with the care of a family member with poststroke depression. Family caregivers in the study were full-time, live-in family caregivers such as a spouse, relative, or significant other. Full-time caregiving, in this study, equates to 6 or more hours per day. Interviews allowed for the participants to express their individual experiences; they were conducted face-to-face and recorded with permission. The interviews contained semistructured questions with open-ended prompts (e.g., “tell me more about that”). Interview questions for family caregivers included items such as “what are your stressors in caregiving?” and “describe how you were prepared for your duties of caregiving?” Survivors of stroke were also interviewed, and items included “describe your interaction with your family caregiver” and “describe the ways you feel that you can be more independent.” The current study included six caregiver-care recipient dyads for a total of 12 total participants.

Definitions

I have defined the following terms used throughout this dissertation:

Acquired communication disorders: “Impairment in the ability to receive, send, process, and comprehend concepts or verbal, nonverbal and graphic symbol systems. A communication disorder may be evident in the processes of hearing, language, and/or speech” (American Speech-Language-Hearing Association, 1993, para. 2).

Activities of daily living: Tasks of everyday life related to personal care. These activities include dressing, bathing, showering, transferring from bed to chair, transferring from sitting to stand, walking, eating and toileting (Centers for Medicare & Medicaid Services, 2008).

Care recipient: An adult who is receiving ongoing assistance with daily tasks to function, secondary to a disabling condition(s) resulting from a stroke (Family Caregiver Alliance National Center on Caregiving, 2014).

Family caregiver stress: The physical and emotional strain that the caregiver may feel as a result of caregiving. The symptoms of stress because of providing care to a loved one can include anger, denial, exhaustion, depression, anxiety, irritability, sleeplessness, reduced concentration, health issues, and social withdrawal (Alzheimer's Organization, 2018).

Family caregiver: A spouse, relative, friend, or neighbor who, due to a personal relationship with the recipient, delivers a wide range of assistance to an individual with a disability condition or chronic illness (Family Caregiving Alliance National Center on Caregiving, 2014). Assistance includes dressing, bathing, grooming, communicating, eating, swallowing, walking, cooking, transportation, coordination of medical care, and other personal household duties. A family caregiver is also known as an *informal caregiver*.

Full-time family caregiver: For this study, a live-in family caregiver who provides care for 6 or more hours per day.

Instrumental activities of daily living: Daily tasks that involve higher, intact cognitive abilities such as cooking, shopping, managing finances, using the telephone, and housework (Brown et al., 2014).

Poststroke depression: A mood disorder secondary to stroke that involves depressive features, mixed-mood features, or major depressive-like occurrences (Robinson & Jorge, 2015).

Stress: How the body and brain respond to any demand or collection of events that causes a brain reaction by which a physiological response is activated in the brain (Contrada & Baum, 2011).

Stroke: A brain injury that is caused by a cessation of blood flow to a portion of the brain, preventing nutrients and oxygen from reaching brain tissue and causing brain cells to die, also called a *cerebral vascular accident* (The Mayo Clinic, 2018). Strokes can be ischemic, caused by narrowing of the arteries; thrombotic, caused by a blood clot; or hemorrhagic, caused by a weak blood vessel that leaked or a burst aneurysm (The Mayo Clinic, 2018).

Assumptions

I based this study on the assumption that the stress and burden experienced by the family caregiver are, in part, due to lack of caregiver education. Also, the stress and burden experienced by the family caregiver, along with the lack of education, influence post-stroke depression experienced by the care recipient within the dyadic relationship. Additionally, it is assumed that the study participants have personally experienced family caregiver burden and stress in the provision of care and the care recipient has experienced some level of depression after returning to their home environment. There is also the assumption that if the care recipient experiences a communication disorder that this too will contribute to post-stroke depression. Furthermore, I assume that the study participants within each dyadic relationship are capable of being truthful in sharing their experiences, perceptions, and feelings unique to this form of caregiving and receiving of care secondary to a stroke.

These assumptions are critical for the study as receiving care from a loved one post-stroke provides a unique set of circumstances in the possible loss of physical and communicative functioning. Another critical element in the assumptions is also in the provision of care as the family caregiver may have to assume the responsibilities of instrumental activities of daily living along with providing a range of assistance with regular activities of daily living. There is very little information known about the lived experiences of the family caregiver and the care recipient post stroke within the dyadic relationship. My resulting assumption is that exploring the lived experiences of the family caregiver and the care recipient with post-stroke depression will aid in the reduction in the knowledge gap concerning this type of dyad primarily for allied health professionals.

Scope and Delimitations

The focus of this study was selected secondary to the risk factors associated with post-stroke depression and the frequency of stress and burnout incurred by informal caregivers providing care to loved one's post-stroke (Shi, Yang, & Wu, 2017; Draper, et al., 2007) Additionally, the interrelationship and interdependence among the informal caregiver's and the stroke survivor's well-being and related emotional responses based on the stroke survivor's impairments and problems (Grant, et al., 2013; Wan-Fei, et al., 2017). Furthermore, communication impairments resulting from a stroke and the barriers that arise between the family caregiver and the care recipient in their lived experiences and their role in the dyadic relationship (Winkler, Bedford, Northcott, & Hilari, 2014; Draper, et al., 2007).

The participants in this study will be of the populations of struke survivor/caregiver dyads that are at least three months post-stroke, residing in the community within their home environment. Caregivers must be informal caregivers (non-paid) family member or friend. Stroke survivors must have adequate auditory comprehension and verbal expression abilities to actively and accurately participate in the interview process.

Limitations

This study of family caregivers and recipients of care with post-stroke depression had its limitations due to the difference in experiences by each dyad. Furthermore, each dyad experience varies by the degree of challenges, disabilities, deficits, and tolerance secondary to the severity of the stroke and the perceived attitudes of the two individuals within the dyad. The general limitation of qualitative research also applies to this study. Personal interviewing may yield inhibited responses secondary to lack of anonymity and fear of image tainting. There is also the lack of ability to generalize the results secondary to the small sample size.

As a researcher, my individual experiences could lead to bias thereby influencing the outcomes. My experience as a family caregiver, first-hand knowledge of stroke, possible outcomes, stress and burden of the caregiver and the care recipient is potential for ideological and personal bias. These biases will be addressed with the use of semi-directed open-ended questions to gather rich descriptions and detailed accounts during the interview process.

Significance

Symptoms of post-stroke depression are damaging to the quality of life and overall recovery in the survivor of stroke (Kleindinst, Clark, & Dunbar, 2013). The family caregiver and stroke survivor with post-stroke depression is a critical dyad that may be of dire importance in understanding recovery from stroke, especially in the community re-entry phase of rehabilitation. Stroke is a disease that is disabling and requires family involvement for the success of the stroke survivor (Alexander & Wilz, 2010). The concern surrounding the recovery of victims of stroke include the importance of supportive family or network of friends and other social support (Tompkins, Schulz, & Rau, 1998). This study will contribute significantly to the fields of allied health, social work, rehabilitation psychology, health psychology, and nursing by increasing the understanding of experiences of the caregiver and care recipient with post-stroke depression. This study will also benefit the participants in the study as well as other family caregivers and individuals with post-stroke depression given the new knowledge in the field and program development specific to this phenomenon.

Exploring the influence of family caregiver stress on post-stroke depression will also add to practical applications for family caregiver needs in education, training, and transition programs, as well as the longer-term continuance of the needs of the family caregiver and the needs of the survivor post-stroke. Implications will also increase of quality of life for the survivor of stroke with post-stroke depression by obtaining a clearer understanding of factors related to the influences within the dyad, with information on the regulation of stress to offset effects on the care recipient. With this understanding of the influences in the dyad, post-stroke depression education programs will be equipped with strategies using meaningful and appropriate education, support, and resources for caregivers and the stroke survivors allowing for better adaptation to physical changes and community re-entry. This study will explore the lived experiences of the caregiver that influence their stress levels which may contribute to the severity of post-stroke depression, thus leading to new field knowledge for education, prevention, and wellness programs geared specifically to this dyad.

Summary

Stroke is one of the leading causes of disability in the United States. Disabilities can range from mild communication, physical, and/or cognitive deficits to severely debilitating requiring total care by a formal or informal caregiver (American Stroke Association, 2018). Following a stroke, many survivors experience depression that is often the result of biochemical changes which can cause the survivor to have limited to no ability to feel positive emotions (American Stroke Association, 2018). The depression can also be a result of grieving the loss of one’s former self. Family caregivers are often thrust into this role as the onset of stroke is sudden and the need for care for the survivor of stroke extends beyond the acute medical setting (Tsai et al., 2015). This dyadic relationship is believed to be critical to the recovery and stability of health for the survivor or stroke as well as having an effect on the health and wellbeing of the family caregiver. Using semi-structured interviews, this study is designed to capture the thoughts, feelings, and perceptions of the survivor of stroke with post-stroke depression and the family caregiver and their lived experiences. In Chapter 2, I will review the literature surrounding stroke, post-stroke depression, and family caregiving.

Chapter 2: Literature Review

Introduction

Informal caregiving is a bidirectional process involving the care provider and the recipient of care. Once an illness occurs, and a family member is needed to provide care, there is an immediate change in the role from a spouse, son, daughter, relative, or family friend to the informal caregiver (Godwin et al., 2013). Stress and burden of the informal caregiver is a well-researched phenomenon; however, knowledge of the caregiver and care recipient dyad poststroke is limited as well as the dyad with a resulting poststroke depression. Investigation of these dyads will allow for a more accurate view of the caregiver and care recipient poststroke and the mental health within the relationship for more vigorous interventions (Godwin et al., 2013).

In this chapter, I will provide a detailed review of the literature that will support the need to evaluate the lived experiences of the family caregiver and recipient of care with poststroke depression. In the chapter, I will also describe the research strategy used for the literature review and rationale for the selection of the conceptual framework. Also included will be a synopsis of current literature on the family caregiver and care recipient with poststroke depression, its historical background, and current developments in caregiver and care-recipient dyadic relationships.

Literature Search Strategy

To find journal articles and other relevant literature, I searched databases such as PsycInfo, PsycArticles, SAGE Premier, CINAHL & MEDLINE Combined Search, EBSCOhost, EBSCO Discovery Service, ProQuest Central, BMJ Journals, Google

Scholar, and Walden's Thoreau Multi-Database Search, focusing on psychology, health sciences, and nursing literature. I also searched government and medical websites and other credible websites that are topic relevant. Key search words included *stroke*, *cerebral vascular accident*, *family caregiver*, *informal caregiver*, *caregiver dyad*, *stress*, *depression*, and *post-stroke depression*. I also used word combinations such as "emotional changes in stroke," "stroke and communication," "poststroke depression," and "family caregiver stress." My literature search concluded as the contents of the literature became repetitive with regards to my topic.

Literature Review Related to Key Variables and/or Concepts

Stroke

A stroke, medically known as a cerebrovascular accident or brain attack, occurs when the blood flow to the brain is obstructed (National Heart, Lung, and Blood Institute, n.d.; Robinson & Jorge, 2015). A stroke can also occur secondary to a ruptured blood vessel in the brain causing bleeding and damage of brain cells (National Heart, Lung, and Blood Institute, n.d.). It can occur at any point when blood flow ceases to an area of the brain (American Heart Association, 2018). Brain cell death occurs during a stroke, and bodily functions controlled by that damaged area of the brain are weakened, impaired, or lost. The impact of stroke can cause many challenges as there are physical effects, communication disabilities, swallowing impairments, emotional and behavioral changes, and cognitive deficits that can occur as a result of stroke, making stroke the foremost cause of disability in the United States (Byun et al., 2017). A stroke can occur at any age; however, after the age of 55 the likelihood of having a stroke doubles every 10 years (American Stroke Association, 2018).

Types of Stroke

Hemorrhagic stroke occurs when blood spills around or into the brain, that causes pressure and swelling that damages brain tissues and cells. (American Heart Association, 2018). An intracerebral hemorrhage is the most common type of hemorrhagic stroke with the most common cause being aging blood vessels and high blood pressure (American Heart Association, 2018). A subarachnoid hemorrhage consists of bleeding in the areas between the brain and the subarachnoid space, which is the tissue that covers the brain (American Heart Association, 2018).

When a blood vessel that carries blood to the brain is blocked by a blood clot, an ischemic stroke occurs (American Heart Association, 2018). A blood clot can travel through the body, and once it reaches a blood vessel that is small enough to block it, the blood flow ceases and a stroke occurs (American Heart Association, 2018). A thrombotic stroke is another form of stroke that is caused by a blood clot that forms inside one of the brain's arteries (American Heart Association, 2018). Large vessel thrombosis is the most common form of a thrombotic stroke and atherosclerosis, a buildup of cholesterol, fats, and other substances, is the most common cause of this type of stroke (American Heart Association, 2018; The Mayo Clinic, 2018). Small vessel disease is another type of thrombotic stroke; this occurs due to small vessel blockage also called a lacunar infarction (American Heart Association, 2018).

A transient ischemic attack occurs from a temporary blockage (American Heart Association, 2018). Stroke-like symptoms can occur; however, the symptoms last less than 24 hours and do not cause permanent damage to the brain (American Heart Association, 2018). Although these symptoms are short-lived with typically no resulting damage, a transient ischemic attack is considered a warning sign of a future stroke, with 40% of individuals who suffer an attack subsequently having a stroke and nearly half of strokes occurring within several days of an attack (American Heart Association, 2018). Of the two major types of stroke, hemorrhagic stroke is the least common. Most (87%) of strokes are ischemic; however, hemorrhagic stroke is deadlier (American Heart Association, 2018; Robinson & Jorge, 2015).

Stroke risk can be classified in three ways: medical conditions, behavior, and family history. The leading medical condition is high blood pressure, which occurs when the pressure of blood on the arteries and other blood vessels is too high (Centers for Disease Control and Prevention, 2018). When additional cholesterol builds up in the arteries, it is high cholesterol that is diagnosed. This causes the arteries to narrow resulting in stroke and other problems (Centers for Disease Control and Prevention, 2018). Common heart disorders such as coronary disease, which occurs when plaques build up within the arteries blocking blood flow to the brain, increases the risk of stroke (Centers for Disease Control and Prevention, 2018). Other heart conditions include defects of the heart valve, irregular heartbeat, and enlarged heart chambers that can lead blood clots to break loose and cause a stroke (Centers for Disease Control and Prevention, 2018). Diabetes and sickle cell disease also increase the risk of stroke. A buildup of sugar in the blood prevents nutrients and oxygen from circulating properly with diabetes, and the abnormal sickle shape blood cells from sickle cell disease and can lead to stroke (Centers for Disease Control and Prevention, 2018).

Unhealthy behaviors can also contribute to the risk of stroke. Lack of physical activity can lead to the health conditions that lead to or increase the risk of stroke (Centers for Disease Control and Prevention, 2018). Unhealthy diets are those that are high in cholesterol, trans fat, and saturated fats; these linked to heart disease and thereby increase the risk for stroke and can lead to obesity, which is also classified as a behavior that can increase the risk of stroke (Centers for Disease Control and Prevention, 2018). Excessive alcohol also raises blood pressure and the risk of stroke. Triglycerides are increased with too much alcohol and can harden arteries increasing the stroke risk (Centers for Disease Control and Prevention, 2018). First- and secondhand smoke reduces the blood’s ability to carry oxygen and damages the heart and blood vessels (Centers for Disease Control and Prevention, 2018).

A family history of stroke is also a risk factor. Having a sibling or parent who has had a stroke increases the risk of stroke along with the possibility of genetic disorders that can increase the risk (American Heart Association, 2018). The most common symptoms of ischemic stroke are subjective arm weakness, self-reported speech disturbance, subjective leg weakness, subjective facial weakness, arm paresthesia, leg paresthesia, nonorthostatic dizziness, and headache (Yew & Cheng, 2015). Arm paresis, leg paresis, dysarthria, dysphagia, facial paresis, ataxic gait, abnormal eye movement, and visual field defect are the most common signs of ischemic stroke. (Yew & Cheng, 2015).

Stroke and Gender

Women have a greater risk of stroke than men as women have more strokes each year (American Heart Association, 2018). There are factors that increase the risk for women such as pregnancy, gestational diabetes, oral contraceptive use which increases when combined with smoking, history of preeclampsia, and post-menopausal hormone therapy (American Stroke Association, 2018). Approximately 60% of deaths from stroke are women with stroke taking twice as many lives as breast cancer. (Centers for Disease Control and Prevention, 2018). Stroke increases with age and as women live longer than men, 6 in 10 deaths from stroke are women (Centers for Disease Control and Prevention, 2018). Mental health issues also increase the risk of stroke and women are twice as likely the experience anxiety and depression (Centers for Disease Control and Prevention, 2018).

In men, stroke is the fifth leading cause of death and although women are at greater risk, men have strokes at younger ages (Centers for Disease Control and Prevention, 2018). In American men, stroke serves as the foremost cause of long-term disability with African American men having a greater risk than any other male group (American Heart Association, 2018). High blood pressure and smoking place men at risk for stroke along with obesity as more men are likely to smoke than women and three out of four men are within weight ranges that increase their likelihood for stroke (American Heart Association, 2018). Diabetes, overuse of alcohol and inactivity can increase stroke risk in men and statistically men have a higher possibility for these risk factors (American Stroke Association, 2018).

Complications After Stroke

There are many complications that occur following a stroke creating barriers to recovery (Langhorne, et al., 2014). Complications post-stroke, during the acute phase, are manage while still in the hospital, however, these same complications can occur after discharge (Langhorne, et al., 2014). Stroke survivors and caregivers report falls, pain, frequent infections, symptoms of depression, and anxiety along with miscellaneous illness, unexplained blackouts with readmissions to the hospital being common (Langhorne, et al., 2014). Most complications develop within the first 6 weeks post-stroke including infections, pain and pressure sores (Langhorne, et al., 2014). Langhorne et al (2014) also found that depression and falls seemed to develop more gradually creating hesitancy in early diagnosis of depression. Other complications include recurrent stroke, epileptic seizures, deep pain thrombosis, pulmonary embolism, confusion, and emotionalism (Langhorne, et al., 2014).

Quality of Life After Stroke

Two thirds of individuals require rehabilitation post-stroke to maximize the quality of life for the most optimal long-term outcome (National Institute of Health National Institute of Neurological Disorders and Stroke, 2014). Depending on the part of the brain that is damaged, many skills are lost. The five major types of disabilities are paralysis or movement control difficulties, difficulty with use or comprehension of speech or language, difficulties with memory and thinking abilities, sensory deficits, and emotional disturbances (National Institute of Health National Institute of Neurological Disorders and Stroke, 2014).

A common disability following a stroke is paralysis on one side of the body by which the face, arm, leg or the entire side of the body has a loss of motor function known as hemiplegia (National Institute of Health National Institute of Neurological Disorders and Stroke, 2014). Hemiparesis can also occur in which there is a weakness on one side of the body leaving the stroke survivor with difficulty with grasping objects, walking, dressing, bathing, and grooming (National Institute of Health National Institute of Neurological Disorders and Stroke, 2014). Walking, balance, and body posture can also be impaired with damage to the area of the brain responsible for the coordination of movement (National Institute of Health National Institute of Neurological Disorders and Stroke, 2014).

Loss of sensation or the ability to feel pain, touch, and temperature or to feel your position in space can be affected by stroke (Bolognini, Russo, & Edwards, 2016; National Institute of Health National Institute of Neurological Disorders and Stroke, 2014). These sensory deficits can also impair an individual's ability to control unitary continence, bowel control as well as the ability to recognize objects within their hand and one’s own limb (National Institute of Health National Institute of Neurological Disorders and Stroke, 2014).

Depression

Depression is a mood disorder that is common yet serious as it causes symptoms that affect how one thinks and feels (National Institute of Mental Health, n.d.; World

Health Organization, 2019). The symptoms and severity of depression vary and affect how one handles everyday activities such as working, eating, and sleeping (National Institute of Mental Health, n.d.). Worldwide, over 300 million individuals are affected by depression and it is a serious health condition (World Health Organization, 2019). Depressive symptoms include sadness, pessimism or feelings of hopelessness, irritability, anxiety, fatigue, loss of interest in hobbies and other activities, decreased concentration, difficulty sleeping, oversleeping, appetite changes, headaches, aches, or pains unrelated to a physical cause, and thoughts of death, suicide attempts, and suicide (National Institute of Mental Health, n.d.; World Health Organization, 2019). The cause of depression is a combination of biological, genetic, environmental, and psychological factors that can occur at any age (National Institute of Mental Health, n.d.).

In midlife and older adults, depression may co-occur with serious medical illnesses including heart disease, Parkinson's disease, cancer and diabetes which in turn can make the medical conditions worse (National Institute of Mental Health, n.d.). Additionally, individuals who have endured adverse events of life such as bereavement, unemployment, and psychological trauma are also likely to develop depression (World Health Organization, 2019).

Poststroke Depression

Major depression is experienced by approximately one third of stroke survivors and can have an opposing effect on functional recovery, cognitive function, and survival (Alajbegovic, . Djelilovic-Vranic, Alajbegovic, Nakicevic, & Tiric-Campara, 2014). Post-stroke depression (PSD) is a common neuropsychiatric occurrence and is of great clinical significance as it is a critical factor for the quality of life, rehabilitation, as well as a source of family caregiver stress (Jyotirekha & Rajanikant, 2018). PSD is defined as a mood disorder secondary to stroke with depressive features, mixed-mood features, or major depressive-like episode (DSM-V, 2015). Diagnosis of PSD occurs after the individual has a depressed mood, loss of pleasure or interest along with four other depressive symptoms that last for at least two weeks (Robinson & Jorge, 2015).

Historically, PSD was described as a psychological reaction that is expected after one acquires disabilities and activity restriction (Folstein, Maigerger, & McHugh, 1977). Researchers began to doubt this theory following the stroke of 72-year-old physician became depressed and irritable following a stroke, that persisted for two years who, after psychiatric services and antidepressant medication depressive symptoms were relieved, returned to interest and enjoyment of life (Folstein, Maigerger, & McHugh, 1977). From that point, studies began to emerge seeking to discover changes in emotions post-stroke. Folstein, Maigerger, and McHugh, (1977) believed that depressive symptoms in stroke patients were disregarded due to the belief that the unhappy circumstance made the symptoms inevitable. Shi, Yang, and Wu, (2017) conducted a meta-analysis to identify PSD risk factors at varied time periods following the stroke. It was found that stroke severity was a major factor in the development or occurrence of PSD along with a history of mental health disorders and these factors could be used as an indicator (Shu, Yang, Zeng, & Wu, 2017).

In a study by Wilkins, et al., (2018), researchers also set out to determine factors associated with depression including sex, level of education, nationality, cognitive deficits, cardiovascular risk factors, stroke severity, and stroke symptoms. During the item analysis the most frequent issue found in the depressed participants was, lost of interest or pleasure (anhedonia), feeling tired, trouble sleeping, and changes in appetite (Wilkins, et al., 2018). Dysarthria or slurred speech that is difficult to understand was also found by the researcher in this study to be associated with depression (Wilkins, et al., 2018). Additionally, nationality was found to be a significant factor for post-stroke depression in this study the study by Wilkins, et al., (2018), as the Middle Eastern and African participants had higher numbers with depression than the Southeast Asian and Western Pacific participants. The researchers postulated that the difference between the numbers among the nationalities may be the conflict in the middle east may be a potential cause of increased depression (Wilkins, et al., 2018). Researchers in this study did not take into account any pre-stroke depression rates.

Wei et al. (2014) concluded that post-stroke depression is of increased risk with strokes occurring in the right hemisphere following a systematic meta-analysis. Brown, Hasson, Thyselius, and Almborg, (2012) concluded in their study on post-stroke depression that the degree of functional independence is associated with post-stroke depression.In a cross-sectional study by Angelelli, et al., (2004) researchers found that manifestations of depression were significantly associated with gender as female patients were at higher risk post-stroke. Researchers also found that depressive symptoms are present within 2 months post-stroke and was accompanied by concomitant neuropsychological disorders such as anxiety, irritability, eating disorders, and euphoria (Angelelli et al., 2004).

Patients with aphasia in Angelelli et al.'s (2015) study were more more likely to have agitation and irritability than those without language deficits. Poststroke depression is a primary factor in limited patient recovery in rehabilitation along with the increasing mortality rates and most cases go undiagnosed and therefore untreated (American Speech-Language and Hearing Association, 2019c; Llorca et al., 2015). Ahn et al. (2015) sought to analyze the effects of poststroke depression on rehabilitation outcomes along with the role caregivers play in stroke patients. More than half of the participants displayed symptoms of depression, and patients with poststroke depression had functional outcomes that were rated as poor (Ahn et al., 2015). Similar to other studies, patients who had right hemisphere lesions and lower rates of depression and patients who had informal or family caregivers displayed lower frequencies of depression (Ahn et al., 2015). In this study, however, geneder did not play a role or did not show statistical significance to post-stroke depression.

Ahn et al. (2015) were the first to explore the caregiver type as a risk factor and to determine that family members are key importance to post-stroke patients as they provide emotional encouragement and aid in compliance of rehabilitation services. Ahn, Lee, Jeong, Kim, and Park, (2015) concluded that post-stroke depression can be improved caregiver support and early identification and treatment of the depression. Ayerbe, Ayis, Crichton, Wolfe, and Rudd, (2013) found additional predictors of PSD such as pre-stroke depression and disability following the stroke. Although previous studies have been conducted to determine PSD predictors, constraints such as weak analyses, small sample size, and short follow-up, a definitive conclusion has been difficult to achieve (Jyotirekha & Rajanikant, 2018).

Communication

Communication is the method by which individuals express their wants, needs, feelings, and preferences as well as how they understand others (American Speech-Language and Hearing Association, 2019c). Functional communication is inclusive of speech, gestures, personalized movements, words, pictures, signs, and augmentative and alternative devices output (American Speech-Language and Hearing Association, 2019c). All components of communication enhance an individual's level of independence (American Speech-Language and Hearing Association, 2019c). Communication deficits post-stroke are common with approximately one-third of survivors having some degree of difficulty with speech production or understanding what is being said (Stroke Association, 2012). Communication disorders can be divided into three categories, speech disorders, language disorders, and cognitive disorders (American Speech-Language and Hearing Association, 2019a).

Aphasia

Aphasia is a language disorder that occurs secondary to damage to the brain including stroke, head trauma, infections, or brain tumors (American Speech-Language and Hearing Association, 2019a). For most individuals, language skills are house within the left side of the brain and with damage in this hemisphere of the brain, deficits may occur creating difficulty with speaking, understanding, reading, and writing (American Speech-Language and Hearing Association, 2019a). There are seven types of aphasia range from mild in severity to so profound in that the individual is unable to communicate basic needs (American Speech-Language and Hearing Association, 2019a).

Broca’s aphasia occurs from damage in the left hemisphere, frontal lobe in the Broca’s area (American Speech-Language and Hearing Association, 2019a). Broca’s aphasia is considered a non-fluent, expressive aphasia (American Speech-Language and Hearing Association, 2019a). Sound production and finding the right words to convey meaning may be difficult, with verbs being more difficult to produce than nouns (American Speech-Language and Hearing Association, 2019a). With Broca’s aphasia, the ability to comprehend speech is preserved with simple language structures and speech is primarily limited to utterances that are short with four to five words (American Speech-Language and Hearing Association, 2019a). Broca’s aphasia can also have a negative impact on the person’s ability to write, however, the ability to read may be maintained (American Speech-Language and Hearing Association, 2019a).

Like Broca’s aphasia, transcortical motor aphasia is also a non-fluent aphasia in that speech production is effortful with impaired grammatical construct (Goodglass & Kaplan, 1972). The damaged area of the brain superior to Broca’s area in the left hemisphere and the deficits are similar however the ability to repeat words, phrases, and sentences are preserved (American Speech-Language and Hearing Association, 2019a). Mixed non-fluent aphasia, results in speech that is effortful but also difficulty with comprehension of speech is present and the reading and writing ability is at an elementary level following the stroke (American Speech-Language and Hearing Association, 2019a).

The most severe form of aphasia is global aphasia. Global aphasia results in the production of very few recognizable words and severe comprehension deficits, and individuals with global aphasia cannot write or read (American Speech-Language and Hearing Association, 2019a). Global aphasia is caused by injuries to the areas of the brain responsible for comprehension of spoken language, producing words and sentences, and accessing grammar and vocabulary (American Speech-Language and Hearing Association, 2019a). Wernicke's aphasia is a fluent aphasia where speech is produced and connected with ease, correct rate, and prosody (American Speech-Language and Hearing Association, 2019a). However, the speech is jargon-filled with irrelevant words, and comprehension, reading, and writing are also impaired (American Speech-Language and Hearing Association, 2019a). In Wernicke's aphasia, individuals are unaware that their sentences do not make sense or that their words have no meaning. Wernicke's area is in the left posterior temporal area of the brain which is responsible for processing word meanings and spoken language (American Speech-Language and Hearing Association, 2019a).

Anomic aphasia is a mild form of aphasia that results in difficulty finding the correct word yet comprehension and the ability to repeat words remain undamaged (American Speech-Language and Hearing Association, 2019a). Grammar is intact in anomic aphasia, yet their sentences can be filled with vague words and circumlocutions in attempt to find the target word (American Speech-Language and Hearing Association, 2019a). Reading is generally intact however the word-finding difficulty will also manifest in writing (American Speech-Language and Hearing Association, 2019a).

Conduction aphasia is a rare type of aphasia with its most salient feature being the impairment in repetition (American Speech-Language and Hearing Association, 2019a). Damage is in the left parietal region of the brain with speech characteristics of good verbal expression, good comprehension but with noted difficulty repeating phrases of increased length and complexity and some word-finding difficulty (American Speech-Language and Hearing Association, 2019a). There are also syndromes that occur secondary to stroke that does not fit in a specific aphasic category yet carry a characteristic or two of complex aphasia such as alexia, or alexia and agraphia, also impairments of calculation may appear independently (American Speech-Language and Hearing Association, 2019a).

Dysarthria

Dysarthria is a motor speech disorder that involves the oral muscles of speech, lips, tongue, throat, face, and respiratory musculature (American Speech-Language-Hearing Association, 2019d). During verbal expression, your oral muscles move and make precise movements to produce each sound therefore when the muscles used to speak are weekend, often occurring after a stroke, the ability to talk becomes difficult and can often co-occur with other communication disorders, such as aphasia, following a brain injury (American Speech-Language-Hearing Association, 2019d). Characteristics of dysarthria are often noted as slurred or mumbled speech, however other signs include slow speech, fast-paced speech, soft-spoken speech, the inability to move the jaw, lips, tongue, properly, robotic-sounding speech and changes in voice (American Speech-Language-Hearing Association, 2019d).

Difficulties with dysarthria post-stroke are found to lead to social and emotional disruption, changes in relationships and self-identity and perceived stigmatization (Stipancic, Borders, Brates, & Thibeault, 2019). In this recent study by Stipancic, Borders, Brates, and Thibeault, (2019), to examine incidence and co-occurrence of aphasia, dysarthria, and dysphagia in stroke survivors following their first stroke, of the ischemic type, the researchers found that 28% of the participants had at least two of the aforementioned disorders, and 4% had all three of the disorders. Dysarthria has been found to be associated significantly with depression post-stroke independently (DeRyck, et al., 2014). Central facial palsy, also common post-stroke and is often a co-occurrence with dysarthria, is facial weakness that causes facial asymmetry post-stroke (Chang, et al., 2016). Central facial palsy results in a greater negative impact than dysarthria in regards to the quality of life in individuals post-stroke (Chang, et al., 2016).

Acquired Apraxia of Speech

Apraxia of Speech, also known as a neurological disorder, caused by a disruption to the motor planning pathways of the brain secondary to stroke or head injury (National Institute on Deafness and Other Communication Disorders, 2016). Individuals with apraxia of speech have difficulty sequencing the movements of speech to accurately produce the intended speech sound (National Institute on Deafness and Other Communication Disorders, 2016). Apraxia of speech is also known as verbal apraxia or dyspraxia can be comorbid with aphasia and/or dysarthria (American Speech-Language-Hearing Association, 2019b). Apraxia differs from dysarthria in that it does not involve paralysis or muscle weakness, nor does it involve language comprehension (American Speech-Language-Hearing Association, 2019b).

Other forms of apraxia involve oral apraxia, apraxia of gait, limb apraxia, and apraxia of swallowing (American Speech-Language-Hearing Association, 2019b). The severity spectrum of apraxia can range from mild, difficulty with a few sounds, to very severe that an alternative method of communication is required (National Institute on Deafness and Other Communication Disorders, 2016). Symptoms of apraxia of speech include inconsistent distorted sound production, difficulty with complex words, the substitution of sounds, groping for sounds, and stress, rhythm, and tone errors (National Institute on Deafness and Other Communication Disorders, 2016). Ryck et al., (2014) concluded in their study that aimed to determine prevalence and risk factors for post-stroke depression at varying intervals up to 18 months post-stroke that apraxia and aphasia were proven consistently associated with post-stroke depression however not most often considered as a factor in other studies.

Cognitive Communication

The processes of knowing and thinking are part of the cognitive processes. The domains of cognition are attention, orientation, memory, problem-solving and executive function (Northeastern University Traumatic Brain Injury Resource for Survivors and Caregivers, 2010). A right hemisphere stroke may result in cognitive-communication deficits. The awareness of person, time, place and situation is the domain of orientation that can be impaired as a result of a brain injury, such as stroke (Northeastern University Traumatic Brain Injury Resource for Survivors and Caregivers, 2010). Attention is the cognitive ability to concentrate which has four sub-domains: focused, sustained, alternating, and divided attention. The capability to briefly respond to a specific stimulus whether auditory, visual, or tactile (Northeastern University Traumatic Brain Injury Resource for Survivors and Caregivers, 2010). Sustained attention refers to single activity concentration, and the ability to shift attention between different tasks is alternating attention (Northeastern University Traumatic Brain Injury Resource for Survivors and Caregivers, 2010). Divided attention refers to simultaneously responding to multiple tasks (Northeastern University Traumatic Brain Injury Resource for Survivors and Caregivers, 2010).

Memory is the process by which information is remembered, stored and retrieved and is be categorized by short-term, long-term, procedural, prospective, and sensory memory (Northeastern University Traumatic Brain Injury Resource for Survivors and Caregivers, 2010). Short-term memory refers to the ability to recall information after a few minutes, and long-term is the capability to recall information for hours, days, or longer (Northeastern University Traumatic Brain Injury Resource for Survivors and Caregivers, 2010). The ability to remember how to do physical actions or motor activities is procedural memory with prospective memory being the ability to remember plans and what needs to be done (National Institute of Health National Institute of Neurological Disorders and Stroke, 2014). Sensory memory is related to the senses of touch, taste, vision and hearing and the ability to remember information surrounding these senses (Northeastern University Traumatic Brain Injury Resource for Survivors and Caregivers, 2010). Problem-solving is how individuals make decisions, think and reason and executive function is how one initiates, plans, and completes behavior that is goal-directed and coordinates all of the components of cognition (Northeastern University Traumatic Brain Injury Resource for Survivors and Caregivers, 2010).

Despite the frequency of depression following both left hemisphere and right hemisphere stroke, early research revealed an increase in overall psychological symptoms in those with right hemisphere infarcts, and depressive symptoms often unrecognized (Folstein, Maigerger, & McHugh, 1977). Ghaffari, Akbarfahimi, and Forough, (2017) found a correlation that was significant between the cognitive deficits of attention and memory, affected motor side of arm and leg and basic activities of daily life and depression. Depressed patients, in this study, had cognitive deficits that were moderate to severe in severity in the domains of attention, memory, concentration, working memory, recent memory, and executive function, which also aligned with prior studies (Ghaffari, Akbarfahimi, & Forough, 2017). Ayerbe, Ayis, Crichton, Wolfe, and Rudd, (2013) concluded with cognitive impairment, along with stroke severity, anxiety, and lack of family support and lack of social involvement as predictors of PSD.

Informal Caregiving

Informal caregiving involves providing unpaid assistance to someone who has a disabling, chronic, or serious health condition or has a condition that limits their ability to independently handle the demands of daily living activities (Family Caregiver Alliance National Center on Caregiving, 2009). Informal caregiving is unpaid work and can involve full-time or part-time care depending on the condition of the care recipient (Pfender, 2018). Along with being unpaid, informal caregivers are not medically trained yet still provide support to their care recipients because of medical conditions. Family caregivers are also challenged with communicating with providers, navigating the health system, and performing medical tasks that are often challenging and complex (Friss Feinberg & Spillman, 2019). Woodford, Farrand, Watkins, and Llewellyn, (2018) studied the difficulties that caregivers face who experience anxiety and depression and found that difficulties adjusting to the losses and changes that accompany the life of a caregiver, along with social isolation and the feelings of worry. Informal caregivers providing care for stroke survivors have health problems reported in areas such as anxiety, depression, and hypertension following the stroke event (King, et al., 2012 ; Byun, Riegel, Sommers, Nancy, & Evans, 2017).

Loss of independence and freedom created feelings of being “a prisoner in your own home” and feelings of being trapped by the informal caregiver (Woodford, Farrand, Watkins, & Llewellyn, 2018). Informal caregivers often reported feeling overwhelmed by the assumption of new responsibilities previously carried out by the stroke survivor, now that the care recipient is no longer able to perform secondary to reduced physical and/or cognitive capability (Woodford, Farrand, Watkins, & Llewellyn, 2018). Tsai and Pai, (2016) sought to evaluate the role of cognitive appraisal and burden as mediators of stroke survivor and caregiver outcomes. Tsai and Pai, (2016) found that cognitive appraisal and burden mediate the relationship between caregiver depression and the functional status of the survivor of stroke. This same study also revealed that the severity of the disease in the recipient of care has a direct impact on the cognitive appraisal of the caregiver and the caregiver is more concerned about a subsequent stroke than their ability to provide care.

In a study that sought to gain family caregivers' experiences while caring for a loved one with a stroke, researchers found several emerging themes including feelings of being imprisoned in their own lives, being drained by the tasks of caregiving, feelings of being uncertain about their future, and aloneness (Lu, Martensson, Zhao, & Johansson, 2019). Although the majority of the responses in this study were negative, there were also participants who did receive support however when family caregivers feel burdened and overwhelmed, the positive or meaningful experiences are overlooked (Lu, Martensson, Zhao, & Johansson, 2019). Self-efficacy in caregiving is the person's belief in themselves the fulfill the duties specific to their care recipient's needs (Hampton & Newcomb, 2018). Lack of confidence in one's ability to provide adequate care is paired with increased stress with the inverse proving true in this study of White women caregivers, and also with higher self-efficacy being associated with lower stress (Hampton & Newcomb, 2018). Furthermore, caregivers with greater confidence in their own self-care also had lower perceived stress levels, (Hampton & Newcomb, 2018).

In a study of caregivers of individuals recently discharged intensive care units, 21% of the informal caregivers reported experiencing post-traumatic stress disorder symptoms (Van den Born-Van Zaten, Donglemans, Dettling-Ihnenfeldt, Vink, & van der Schaaf, 2016). Post-traumatic stress disorder (PTSD) is disorder experienced following a dangerous, scary or shocking event leaving individuals with feelings of stress or fright when danger is no longer present (National Institute of Mental Health, n.d.). PTSD symptoms include frightening thoughts, flashbacks, bad dreams, sweating, and heart-racing (National Institute of Mental Health, n.d.). Independent factors associated with caregiver stress included having less social support, caregiver's income, functional status of the stroke survivor, less preparedness, income, gender, and insurance type (Byun, Riegel, Sommers, Nancy, & Evans, 2017).

Survivor of Stroke and Caregiver Dyad

The dyad is an integral part of rehabilitation, quality of care, for the care recipient as without it there would be a significant number of institutionalized care recipients. Depression, stress, and burden are reoccurring conclusions in the literature surrounding informal or family caregiving. In a study to examine partner effects on optimism, self-esteem, and perceived control on depression in stroke survivor dyads, evidence was provided on how each member of the dyad's self-esteem had an influence on the partner's depressive symptoms, indicating a mutual influence (Chung, Bakas, Plue, & Williams, 2016). This study furthermore resulted in the findings of lower levels of optimism in the caregiver lead to stroke survivors being more susceptible to symptoms of depression, however, the inverse, patient's optimism, was not associated to the depression of the caregiver (Chung, Bakas, Plue, & Williams, 2016).

In a study to determine the wellbeing of the caregiver might be a factor in explaining depressive symptoms in survivors of stroke by Grant, et al., (2013), 146 stroke-surivior/informal caregiver dyads were interviewed. The wellbeing of the caregiver is a mediator between impairments and problems suffered by the stroke survivor care recipient as well as depressive symptoms of the care recipient's symptoms of depression (Grant, et al., 2013). Also, Caucasian race, male gender, level of education, older aged caregivers were all associated with the survivor of stroke having fewer depressive symptoms (Grant, et al., 2013). Wan-Fei, et al., (2017) sought to examine the effects of depression on the quality of life in the survivor of stroke and caregiver relationships. Results indicated that with greater depressive symptoms in caregivers, there was a significant relation to poorer health in their care recipients (Wan-Fei, et al., 2017). Also, depression in the caregiver had an effect on the quality of life in both the survivor of stroke and the family caregiver (Wan-Fei, et al., 2017).

Caregivers of stroke survivors with aphasia were examined in regards to their perception of new roles and responsibilities resulting in a finding negative impact on the quality of life of the caregivers (Winkler, Bedford, Northcott, & Hilari, 2014). The extra duties and tasks acquired by the caregiver also had a negative impact on the dyadic relationship along with feelings of mental and physical exhaustion, feelings of loneliness, and resentfulness were identified (Winkler, Bedford, Northcott, & Hilari, 2014). This study also resulted in the findings of some positive outcomes including new levels of closeness, pride in achievements, and a new appreciation for life. (Winkler, Bedford, Northcott, & Hilari, 2014).

Summary and Conclusions

Following a stroke, the key role in the well-being of both the family caregiver and the survivor of stroke is the quality of the relationship (Bucki, Spitz, & Baumann, 2019). It is known, by the results of many research studies, of caregiver stress, burden, anxiety, and depression with the sudden undertaking of new and additional roles and responsibilities assumed post-stroke. Stroke survivors are also at risk for depression given the factors of the site of lesion, history of depression or emotional changes, severity of physical deficits, and the presence and/or severity communication deficits. Upon review of the literature, many studies have been performed on caregiver stress and burden along with post-stroke depression and contributing factors with these areas being well researched. Research is limited, however, regarding the caregiver/care recipient with post-stroke depression dyad. A gap was discovered in that there was no examination of the important determinants of the stroke/caregiver dyad's experiences (Wan-Fei, et al., 2017).

There is, therefore, a lack of awareness of the lived experiences of the family caregiver and the survivor of stroke with PSD as described by the caregiver and care recipient. This knowledge was discovered for this topic, during the review of the literature, leading to the necessity of this study. This literature review was conducted using many database searches for caregiver and care recipient with post-stroke depression dyad. The following chapter will contain how this phenomenological research study was conducted.

Chapter 3: Research Method

Introduction

The purpose of this study was to explore the lived experiences of stroke survivors with poststroke depression within the caregiver-care recipient dyad. To gather data, I conducted interviews with stroke survivors with poststroke depression and with family caregivers. In this chapter, I discuss the research rationale and design, the researcher's role, methodology, and, finally, issues of trustworthiness.

Research Design and Rationale

Qualitative researchers, as described by Ravitch and Carl (2016), seek an understanding of the way individuals view, experience, and determine the meaning of their experiences in relation to the study phenomenon. Qualitative research is conducted to obtain a complex and detailed understanding of the topic and because of the need to examine a group or phenomenon whose variables cannot be easily determined (Creswell, 2013). There are five qualitative methods of inquiry. These methods consist of narrative research, phenomenology, grounded theory, ethnography, and case study (Creswell, 2013). I chose phenomenology as the method of inquiry for this study because it was the most appropriate to gain an understanding of this subject matter. Phenomenology is defined as an inquiry strategy that allows the researcher to ascertain the crux of a described human experience as told by the participants (Creswell. 2009). According to Austin and Sutton (2015), the emphasis of phenomenology is understanding how the individual experiences a particular phenomenon and allows the researcher into the subjective experiences of the individuals.

Transcendental phenomenology focuses on the descriptive elements and experiences of participants and less on the researcher's interpretation (Crewsell, 2013). Researchers who use this design study individuals' lived experiences and their perceptions of the phenomena within their own consciousness (University of New England, 2020; Neubaur et al., 2019). I acquired the participant's personal accounts through semistructured interviews, participant observation, and personal accounts of the lived experience (see University of New England, 2020).

In this qualitative study, I chose transcendental phenomenology to explore the experiences of the family caregiver and care recipient with poststroke depression. Depression is a very common discussion in today's society with the increasing awareness of mental health, along with family caregiving also becoming more common, which can lend itself to research bias. Transcendental phenomenology was the best approach as the procedures entail the identification of the phenomenon, bracketing of the researcher's personal experiences, and data collection from individuals currently experiencing the phenomenon (Moustakas, 1994). To analyze the data, the researcher reduces the collected data to statements, then combines these statements into themes. A textural description of the participants' experiences is then developed along with a structural description of how they experienced the phenomenon using the situations, conditions, and context (Moustakas, 1994). The researcher combines the textural and structural descriptions to convey the complete essence of the experience itself (Moustakas, 1994). The objective of transcendental phenomenology is to obtain the experience of the participant prior to them being able to reflect, conceptualize, or categorize the experience (Neubauer et al., 2019).

For this qualitative study, my overarching research purpose was to understand the phenomenon of poststroke depression and the family caregiver based on their perceptions and experiences. The primary RQ developed for this study was, What are the experiences of the care recipient after stroke and the family caregiver as it relates to post-stroke depression and caregiver stress? The secondary RQs were as follows:

RQ1. How do caregivers and stroke survivors describe the factors that contribute to caregiver stress?

RQ2. How do caregivers and stroke survivors describe the factors that contribute to stroke survivors' depression?

RQ3. How do caregivers and stroke survivors cope with caregiver stress?

RQ4. How do stroke survivors cope with stroke survivors' depression?

RQ5. What is the experience with the caregiver and care recipient with reciprocity?

Appendix A illustrates the alignment of the research problem, RQs, and study purpose.

Role of the Researcher

As qualitative research is understood as research that is interpretative, my role was one that had an intense involvement with the selected participants (see Creswell, 2009). According to Austin and Sutton (2015), the researcher's role is to try to access the feelings and thoughts of the participants in the study, which involves asking for very personal insight. The researcher must also develop understanding and meaning that the participants attribute to their experiences (Austin & Sutton, 2015). The researcher must account for their own background, experiences, and personal history that may influence the analysis and interpretation of the study (Creswell, 2013b). Therefore, part of my role included identifying my values, biases, culture, history, and socioeconomic position that may have shape my derived interpretations of the study (Creswell, 2009). Before and during the process of research, the researcher must reflect on the collected responses to convey a proper understanding for the audience (Austin & Sutton, 2015). Additional researcher roles include obtaining access to potential participants; developing a relationship or rapport with participants that is ethical, professional, and personable; safeguarding participant information; and properly analyzing collected data for the study (Austin & Sutton, 2015).

As a qualitative researcher for this study, my role was to obtain data from each of the participants and analyze the data to produce concepts, patterns, and themes regarding the study phenomenon while ensuring that my personal biases and experiences could not influence reporting. My personal experience of working with stroke patients and their families as a medical speech-language pathologist, as well as my personal experiences of being a family caregiver, could have led to bias. As prescribed by the defined practices of transcendental phenomenological research, I used epoché, or bracketing, as described by Moustakas (1994), in which my personal experiences were set aside to glean a fresh perspective of the participants' experiences. Accessing the feelings and thoughts of the participants is not always easy in that it involves discussion of things that are personal (Austin & Sutton, 2015). I was able was to build a rapport with the participants and to create a safe environment for them to freely and honestly share their feelings and experiences.

Methodology

Participant Selection Logic

Selecting participants in qualitative research involves random selection to eliminate the potential of external variables as well as to ensure that the results can be generalized (Sargeant, 2012). I purposively selected the participants to gain access to individuals who would best elicit understanding of the phenomenon of poststroke depression and lived experience in the caregiver-care recipient dyad (see Creswell, 2009). Miles and Huberman (1994) also identified four aspects regarding site and participants, which include where the interview will take place, who will be interviewed, what the participants will be interviewed about or observed doing, and the events or process within the setting that evolve during the interview or observation (Miles & Huberman, 1994).

I recruited caregiver-care recipient dyads currently experiencing the phenomenon of family caregiving with a loved one with poststroke depression. These participants must be able to supply important perspectives and aspects related to this phenomenon (Sargeant, 2012). Qualitative research does not require the statistical calculation of a sample size as in quantitative research; the sample size is deemed sufficient when all elements important to the phenomenon are able to inform the researcher and audience (Sargeant, 2012). Data saturation is considered the point that no new concepts are identified even with additional interviews (Sargeant, 2012). There were six stroke survivor/caregiver dyads creating 12 participants in total. Each dyad was, at least, three months post-stroke and self-reported post-stroke depression diagnosis or self-reported emerging depressive symptoms. Post-stroke participants were able to adequately comprehend interview questions and respond to questions providing sufficient information regardless of syntax or grammar. Exclusion criteria include post-stroke individuals with severe expressive and receptive communication deficits including Werneke's Aphasia as described in Chapter 2. Participant age, race, and gender did not disqualify participants from this study.

Procedures for Recruitment, Participation, and Data Collection

Ravitch and Carl (2016) suggest that data collection methods in qualitative research should be emergent and dynamic, rigorous, intentional, and systematic, not fixed. The approach should create a condition for the researcher to fully understand and express the most contextualized picture of the experiences of the participants (Ravitch & Carl, 2016). The data collection process for this study involved the use of semi-directed one-to-one interview questions with prompts to generate the needed data. Individual interviews were conducted with each of the 12 participants. The interviews were audio and video recorded along with field notes to accompany the recorded interviews. Field notes complement the recorded data by capturing environmental contexts, nonverbal cues, and behaviors that could not be captured or missed on audio recordings (Austin & Sutton, 2015). Once the interview was complete, each participant was debriefed regarding interview questions asked along with reiteration of the purpose of the study, storage of private information, along with purpose of the study and potential outcomes. Participants were also provided with information regarding possible follow-up interviews if indicated.

I posted my research flyer on my social media pages with a post asking for referrals and to pass along the flyer for participants. Once contacted, I emailed a letter explaining my study, intended audience, and potential benefits of the results and requested referrals for possible participants. I also forwarded a statement detailing the process of the one-to-one interviews for each participant. Once the participants were selected, they were each provided with informed consent documents to ensure participants that their rights will be protected (Creswell, 2009).

Data Analysis Plan

Following data collection, processing the data took place immediately including details of time, dates, interaction highlights, and other pertinent factors and observations. (The Pell Institute, 2019). Data analysis also began during data collection as patterns and themes began to emerge with subsequent data being mentally categorized (The Pell Institute, 2019). Data reduction occurred to sort out and discard data that was not meaningful to this study. Keeping the RQ in mind, the raw data was organized as it related to the purpose of this study (The Pell Institute, 2019). This step also occurred during data collection and analysis. Content and thematic analysis took place as the process of the identification of themes and patterns that were meaningful were identified. During content analysis, the data was combed and coded to identify words, patterns and interpretation (The Pell Institute, 2019). Themes were developed that provided assistance with answering the RQ. Thematic groups, created from naturally emerging data, were created with a connection to the RQ. (The Pell Institute, 2019).

Once the data collection, processing, and reduction was complete and emerging patterns and themes were identified, the data was captured in a format which enabled me to the draw the conclusion (The Pell Institute, 2019). The final step in data analysis process was to draw and verify the conclusion. This process involved determining the meaning of the captured data, linking the found meanings to answer RQs and drawing inferences from the findings (The Pell Institute, 2019).

Issues of Trustworthiness

The affirmation that the findings are faithful to the experiences of the participants is referred to as trustworthiness or validity (Ravitch & Carl, 2016). Triangulation is a process by which researchers to ensure validity or trustworthiness using varied methods or sources that challenge and ratify a set of interpretations (Ravitch & Carl, 2016). More specifically, between- methods triangulation was used as data collection for this study with the use of in-depth interviews, field notes, and observations (Denzin, 2009). Ensuring the researcher obtains the appropriate kind of data to provide information that has depth and quality to confidently answer the posed RQs along with a rigorous quest of data collection was the goal of triangulation (Ravitch & Carl, 2016). Member checks were also used to ensure trustworthiness. Member checks or participant validation occurs when the researcher has the study participants verify the accuracy of the responses and statements made pertaining to them, ensuring that the researcher's interpretations are accurate (Ravitch & Carl, 2016).

Ethical Procedures

As researchers, it is expected that the rights of the participants used in our research studies are protected and that ethical consideration remains a consistent factor throughout the process. The American Psychological Association and Walden University maintain guidelines to inform and protect participants. As researchers, we have an ethical obligation to do good and to do no harm and provide humane treatment individuals and animals involved in our studies (Fisher, 2013). We are also charged with fidelity and responsibility, integrity, justice and respect for the rights and dignity of the people (Fisher, 2013). The university's Institutional Review Board safeguards participants and grants the researcher permission and approval to proceed with data collection based on set standards and participants safeguards.

Recorded personal and identifiable information were kept and continue to be kept confidential and password protected. Collected data was also safeguarded by storing on an external drive and kept in a personal safe, which will continue to be safeguarded for at least five years. As this research study focused on the experiences lived by individuals with post-stroke depression and their caregivers, there was the possibility that the recalled varied experiences may have induced psychological distress. Participants were allowed to discontinue the interview at any point; however, this did not occur. Fidelity was maintained with promise-keeping to ensure avoidance of any possibilities of conflicts of interest. Honest communication was provided to maintain the integrity and avoiding misrepresentation of this work.

Summary

The purpose of this chapter was to detail the proposed research method to answer the RQs for this study of post-stroke depression and the lived experience in the family caregiver and care recipient dyad. Transcendental phenomenology was the approach used to capture the experiences of the dyad participants. Participants shared their experiences of their daily lives along with their perceptions and feelings as it related to their dyadic experiences through semi-directed interview questions that were used to collect data. The goal of Chapter 4 is to report the results of the study and exhibit the described methodology of Chapter 3.

Chapter 4: Results

Introduction

The purpose of this qualitative study was to explore the lived experiences of family caregivers and stroke survivor with poststroke depression. I recruited a total of 12 participants: six family caregivers and six survivors of stroke, which equated to six dyads. Transcendental phenomenology was used to explore the lived experiences of family caregivers and stroke survivors with poststroke depression. Each interview was recorded, with the permission of the participants and the emailed receipt of the consent form. For member checking purposes, I provided participants with verbatim transcripts and allowed them to add more information concerning their experiences as the family caregiver or survivor of stroke with poststroke depression. The recorded data were transcribed using the transcription services of Rev, a professional transcription service. The transcribed data were then cross checked with the corresponding video recordings and my field notes for accuracy.

Setting

I initiated participant recruitment with the posting of my recruitment flyer on my social medial pages following Walden University Institutional Review Board approval. I posted my flyer on my personal page and in various social media groups geared towards stroke survivors and family caregivers. Family caregivers and their care recipient who was a survivor of stroke were eligible to participate in the study. Survivors of stroke had to be at least 6 months poststroke, have basic communication abilities, and have a diagnosis of poststroke depression or signs and symptoms of poststroke depression.

Participants also needed to be English speaking and 18 years of age or older. Exclusion criteria were (a) survivors of stroke with Wernicke’s aphasia, (b) survivors of stroke with limited comprehension and verbal expression, and (c) formal caregivers. I sent an email to potential participants that included a brief history of my journey and the rationale for selecting this topic of study, along with the potential benefits of the study and its implications for positive social change.

I also provided a brief description of the interview process and the platform that would be used to conduct the face-to-face interviews. The informed consent document was attached to the email for the participants to read and confirm their agreement. There were no conflicts of interest or organizational influences as I have no affiliation with any organization that could have had an influence on participants experiences. Participants independently made contact with me after viewing my recruitment flyer.

Demographics

The gender distribution of the study participants was one male family caregiver, five female family caregivers, three male survivors of stroke, and three female survivors of stroke. Family caregiver study participants ranged in age from 36 to 68, and survivor of stroke participants ranged in age from 50 to 78. Poststroke survivors ranged from 1 year to 10 years poststroke. All 12 participants were African American.

Data Collection

I conducted interviews using Zoom video conferencing platform because of its widely recognized familiarity and ease of access (Archibald et al., 2019). The Zoom platform has its own recording feature and is also password protected for privacy. Each participant was provided with a private access code and password link to join the interview. A digital audio recorder was used for back-up and was kept in a locked safe. Participants received a reminder email the day prior to their scheduled interview and a second reminder 15-30 minutes prior to the appointment time.

I collected basic demographic information at the start of the interview and explained the interviewing process. Participants were reminded that the interviews were being recorded and that all of their information would be kept confidential and that no names would be used in the discussion of the results. The interviews lasted from 30 minutes to 2 hours and 20 minutes depending on how much the participant chose to share.

After the interviews were complete, I informed each participant about how to contact me should they want to add additional information regarding their experiences as a family caregiver or a survivor of stroke. Each participant also gave permission for me to contact them with additional questions. Participants were emailed their verbatim transcripts to review for accuracy and provide additional information or further expound on their responses. Participants were also notified that their thank you gift would arrive at the completion of the study.

I saved all interview voice and video data on an external flash drive, a password-protected laptop, and a digital recorder. All devices that contain recordings are kept in a personal home safe to which I am the only person with access. Multiple recordings were captured as a backup or precaution in case of other recording equipment failure. All written communication between myself and the participants were made through the

Walden University email system and their personal or work email as provided to me for contact. I removed all identifying information to ensure privacy during data analysis. Each participant dyad was provided a number and letter (e.g., Participant 1a and 1b) for privacy.

Semistructured Interviews

I followed an interview protocol when conducting interviews with the family caregivers and the survivors of stroke (see Appendices B and C). Following the collection of the demographic information and some rapport building, I began the interview process. Additional probing questions were asked based on the response to the initial question. Participants were told that they reserved the right to not answer any question. Participants were free to express their lived experiences as family caregivers and as survivors of stroke with poststroke depression.

In keeping with the structure of transcendental phenomenology, I frequently addressed any personal bias with epoché prior to the interview and during data analysis. With regard to my concern about personal bias, I did find similarities to my personal experiences; however, I also found experiences that completely differed from my own. I was able to completely immerse myself into the process of interviewing the participants, thereby allowing participants to fully express themselves, which is why some of the interviews exceeded 1 hour.

Data Analysis

Once the interviews were complete, I sent the audio-recorded files to Rev.com for verbatim transcription. Transcripts copies were emailed to the participants for review along with the opportunity to offer any additional information they believed to be essential for me to capture the complete essence of their experiences as family caregivers and survivors of stroke with poststroke depression. No participants had any further information to add. I used a combination of inductive and deductive analysis whereby some themes were derived from the data collected and some were preconceived.

After familiarizing myself with the data collected, by reviewing the transcripts and taking notes as I combed through the data, I began to code. I derived labels for statements made to describe the content in order to move towards generating themes for those not preconceived and allowed the codes that fit within the preconceived themes to be placed respectively. Once my final list of themes was developed, I began to define each one. I made every attempt to create theme names that were easily understood and concise.

Evidence of Trustworthiness

I maintained data reliability by inspecting the transcripts for mistakes, allowing participants the chance to review and confirm the accuracy of the interview transcripts as well as add information regarding their experiences as a family caregiver or survivor of stroke with post-stroke depression as needed. I also provided an in-depth description of the data, applied input from my dissertation chair, and ensured the reporting all study results including those which did not align with my personal experience by the application of epoché to exclude my personal bias prior to each interview.

Results

The purpose of my study was to explore the lived experiences of the family caregiver and survivor of stroke care recipient with post-stroke depression. Although there is established knowledge of the family caregiver in general and post-stroke depression, literature was limited with regards to the lived experiences of the dyad (Wan-Fei, et al., 2017). The primary RQ was, What are the experiences of the care recipient after stroke and the family caregiver as it relates to post-stroke depression and caregiver stress? I will provide a description and supporting data for the themes resulting from the interviews.

Participants within each dyad were related as mother and child, siblings, spouse, and ex-spouse. Each participant shared that their relationship within the dyad were good relationships prior to the stroke. The following themes resulted from interviews with the family caregiver and their lived experiences.

Theme 1: Time and Commitment

Providing care for a family member is time consuming and requires a level of commitment consistent as a full-time job. Family caregivers find themselves juggling work, school, familial relationships, friendships, social life, and personal relationships. Participant 2a talks about a typical day and the time and commitment required:

> “a typical day busy because I’m working. Monday through Friday I’m working so feeding cooking breakfast, trying to work, changing her, trying to work, medicine time to work, it’s a lot. If my son or aunt doesn’t come past, it can be crazy. They know I work in a field dealing with money, so I have to concentrate

because it's easy to mess up. So, mama has to be put on hold so I can finish doing what I'm doing."

Participants 4a shared her difficulty with working and providing care for her mother. When asked to describe a typical day, she stated "well I work from home and I am in school so it's never enough time for her but I have other commitments because I take care of her and my job and I have to do school work but it has to be done so I do what I have to do trying to juggle it all." With a multitude of duties, personal and newly assumed, family caregivers find themselves struggling with the time and commitment involved in providing care for a loved one with post-stroke depression particularly with those family caregivers who have children, careers, and are in school. This next theme appears to be an emerging theme as lack of preparedness for being a *family caregiver is expressed by participants.*

Theme 2: Lack of Preparedness for Being a Family Caregiver

It may appear obvious, given the sudden onset of stroke, that family members are not prepared to become a caregiver of a loved one who was just recently independent. In this case, as reported in their experiences within this phenomenon, family members received minimal to no training for their role as a caregiver. This serves as a launching point of what initiates the negative perceptions of the experiences of being a family caregiver to a loved one who is a survivor of stroke with post-stroke depression. Related data was collected with the question of "How were you prepared for your duties of caregiving?" This question was incorporated to determine the amount of training received prior to the survivor of stroke leaving the hospital. Five out of six caregivers stated that they did not receive any training. Participant 2a stated that “everything happened all of a sudden, because we were in the process of getting the house together and then they [hospital personnel] was like ‘you’ve got to pick your mother up’ it was a mess”. Participant 2a went on to say “I wasn’t prepared for the emotional side; she would cry I didn’t know what to do so I just let her be.” “they didn’t prepare me for this” One participant, 6a, stated that “my experience as a nurse prepared me for caregiving so I was ready”. Participant 6a was also the participant who did receive training from the Speech Pathologist and the Physical Therapist.

It appears logical to infer that medical facilities are not providing adequate education to prepare families for the role of family caregiving which may impact the adequacy of care provided. Also, allied health professionals should take part in, or increase their part, in the information sharing to provide education and training to families for the preparation of providing care. The following theme was resultant from participants discussing how PSD impacted their experiences within their role of being a family caregiver.

Theme 3: Challenging Role Dealing With a Loved One’s Depression

Family caregivers were challenged when dealing with the recognition of the signs of depression in their care recipient. Although PSD is a neuropsychiatric occurrence that is common among stroke survivors, family caregivers were not made aware of the possibility of depression nor how to deal with symptoms as they arise. Participant 2a stated: “she [survivor of stroke] will have her days where she is not determined to do anything. She don’t’ want to be pushed, she just cries. It’s disappointing to me because she’s stronger than that, and I know that but then with the stroke, they have the emotional part that is not stable.” Participant 1a stated “I knew she was depressed because she couldn’t do certain things.” Participant 5a stated: he cries, he will stop eating and drinking. Participant 6a stated: he cried a lot, very sad that he had the stroke and he says he wouldn’t wish the stroke on anyone. I try to motivate him and provide family support and we have family dinners once a week. I’ve suggested that he join a stroke support group.

Based on the lived experiences of the family caregivers of survivors of stroke with post-stroke depression, it is reasonable to deduce that symptoms of depression are difficult to deal with coupled with the fact that there was a lack of awareness of what the survivor of stroke could experience in terms of depression post stroke. The lack of awareness leads to the inability to effectively cope and to provide adequate support for the survivor of stroke. The following theme describes the emotional toll that accompanies the role of being a family caregiver for a loved one who has survived a stroke and experiences post-stroke depression.

Theme 4: Overwhelming, Frustrating, and Burdensome Task

Feelings of being overwhelmed and frustrated were described as common elements among the family caregivers for a survivor of stroke with post-stroke depression interviewed for this study. The daily demands on the family caregiver along with maintaining their own personal responsibilities leads to the stressfulness of this phenomenon. Participant 2a stated: I don’t get any sleep. She calls out all times of night. It gets to the point where I just check out, I’m tired, I get tired like everybody else so they [other family members] need to pull their weight. Participant 3a states: It can be rough sometimes, I had to take off work for a month and a half, he couldn't do anything for himself and I would have to do his housework mainly cooking and cleaning. It was stressful seeing him struggle to try to say what he's trying to say, it bothers me a little bit. Participant 1a stated:

> I had to do everything because she could drive. I would go to work, leave come home check on her, fix lunch and go back to work. I had to get her dressed and bathed taking her to doctor's appointments and she was on some medications so just making sure she followed through with everything. It was stressful when I went back to work, financial stress because we only had one income. I think the only thing I was really overwhelmed about, just recognizing signs of a future stroke. I wanted to be around and make sure I didn't miss anything but I had to go to work. Patient 2a stated: "I don't like it [being a family caregiver] I don't want to do it but I don't have a choice.

The following theme describes the family caregiver participants as they dismiss their own needs to focus on the needs of their loved one with post-stroke depression.

Theme 5: Self-Neglect/Lack of Balance

Although the daily demands of a family caregiver are unique to dyad giving the severity of communicative and/or physical disability, family caregivers will be so heavily involved in the caring of their loved one with post-stroke depression that their own personal needs tend to be neglected. Participant 3a stated: "I became sick myself, that was when I was the most stressed and I was carrying it myself because I didn't want to tell my family because I was trying to look out for me, but at the same time I was thinking what's going to happen to me." Participant 1a stated: I ended up getting sick and she had to go stay with my parents for a while" "They [friends and family] came to help and would suggest that I go and focus on myself, I didn't need to go out anywhere, so I wanted to be close to home, close to her. Participant 2a shared: "I only get about four hours of sleep a night because she's always calling me, she's calling me now." She went on to state: "I'm here 27/7 [everyday all day] the only time I get out of the house is to go to the store."

Despite the fact that family caregivers of stroke survivors with post-stroke depression face daily overwhelming, stressful, and burdensome tasks, often when given the chance to focus on self to take care of personal needs, they repeatedly put their care recipients needs ahead of their own thereby neglecting their own mental and physical well-being. The next theme describes the family caregivers' feelings of isolation since taking this new role.

Theme 6: Isolation and Reduced Social Interaction

Loss of independence and freedom created feelings of being "a prisoner in your own home" and feelings of being trapped by the informal caregiver was found to be a common occurance in informal caregiving (Woodford, Farrand, Watkins, & Llewellyn, 2018). Participants often felt isolated given time required for care. Participant 1a stated "they [family] would come over and friends that were close to her. My outings were taking my son to baseball practice and going to church meetings. I didn't want to go so not a lot of social stuff going on" Participant 2a stated: in the beginning they [family] were over here faithfully but now, they see how much work it is to work and work with her, they don't come during the day. So, in the evenings, they [family] would come over for about four hours. My brother will be in and out. My sister, she'll be here. I mean, they'll be here but they'll be in and out. I go sit on the porch. The crazy thing about it is when they come, she's quiet. She don't call on nobody as much but when it's just me, it's just constant like [calling name repeatedly]. It's just like she always needs something". Many participants spoke on the absence of time with their friends for social engagements. Some participants felt that they needed to remain close by in case something happens or if their recipient of care needed them. Statistical evidence reveals 60-70% of family caregiver experience depression in which isolation is the culprit. (Family Caregiving Alliance National Center on Caregiving, 2020). The following theme speaks to the reported joys of being a family caregiver of a survivor of stroke with post-stroke depression.

Theme 7: The of Joy of Being a Family Caregiver Is Witnessing the Progress

Given the abrupt nature of becoming a family caregiver for a survivor of stroke, family caregiving has been perceived as suffering, an obligation and as a subjective choice (Zhang & Lee, 2017). As our participants have expressed many negative aspects of being a family caregiver to a stroke survivor with post-stroke depression, they were able to express the joy withing their lived experience. Participant 1a stated: That smile, I had missed that smile for too long but just seeing her smile everyday was just something I really never thought about missing until I couldn't see it. Once I got that back it brought me joy. I try to motivate her letting her know that it could have been worse. Participant

3a stated: When I see signs of improvement and when he’s doing things that he used to didn’t do or had stopped doing, and he’s doing again that would bring joy. To see the progress, he is making in speech and hearing, it made me feel good. Participant 4a stated: “being able to watch her progress brings joy.” Participant 2a shared: “It brings me joy just knowing that she’s being taken care of the way she wants to be and that she is here and not having to be in those facilities.”

Survivor of stroke participants were interviewed separately from their family caregiver. Residual deficits of the stroke survivors ranged from physical mobility, speech, receptive language, and cognitive impairments. The following five themes were derived from the responses of the survivor of stroke with post-stroke depression regarding their lived experiences. The survivors of stroke were asked to share their experiences using semi-structured questions. The first theme discusses the survivors of stroke feelings in regards to self-efficacy.

Theme 8: Lack of Self-Efficacy/Impatience From Family Caregiving/Overhelping

All survivor of stroke participants perceived a feeling of being rushed by their family caregiver (FCG). Participants felt as if their FCG did not understand that they could not move as fast as they did prior to the stroke, mentally and physically. Participants also expressed wanting to complete tasks themselves however the family caregiver would insert themselves to complete the task for the survivor of stroke when the survivor of stroke just needed more time. Participant 4b stated:

> We were at the store the other day, and we were ringing up. We went through the self-check-out, so I was putting my stuff up on the belt. So now she's going to put

it up on the belt. She's putting it through, putting it through. Of course, she can move it a whole lot faster than me. But now, I have a... Like I told you, I'm very intentional. Before I left home, I knew how I was going to do my payments and stuff, so once we get there ... Of course, her mind moves fast. Okay, the total is so and so and so, so I got to hurry up and take out my debit card and pay for it, type thing. And I'm like, "Okay, I need a second, because I already know how I want to pay for certain things and what I'm doing," so you know what I'm saying? Because she was rushing me, the more she rushed me... I was putting the payment in, then I kept pushing cancel, and then she's looking at me, "Now, I'll just pay for it. Do you want me to pay for it? Do you want me to pay for it? I'll just pay for it." And I couldn't even answer. So actually, [my sister] walked up, and she said, "She did ask you." I was like, "But you have to give me a second. I couldn't even answer, because you were going too fast. You ain't giving me a second to give you the feedback." And [my sister] was like, "Okay." [my sister] was like, "I get it," but she's never been in that. She don't know. She doesn't get that it takes me time. And I have to tell my husband a lot of the times, because he thinks I'm ignoring him. And I'm like, "You have to give me a second. It takes me a second to process, in order to give you the answer. So, I'm not ignoring you, give me a minute. I'm already flustered. "Because my mind was still on the making the payment, but she was ready to pay. She already was there to pay and I'm like, "I have the money," and so now I'm still thinking, "I have the money." I just knew what I wanted to do. There was certain money I wanted to use to pay for certain

> things. That kind of thing, because I have certain cards that I wanted to pay with. So, if you had just let me go through and pay with it, I would get it that way. But I had already had everything in my mind, what I was going to do when I left the house, and sometimes it is hard for me to pull back out of that [sadness]. So, it takes a second. I wanted to do it.

Participant 6b stated:

> She calls me to come downstairs, rushing me but it's like I said, it's not that I don't want to go downstairs, it's my brain tells me to move slow, because if I go fast, I can fall and hurt myself, because I could have trouble walking, and I still have pain in my leg and my arm.
>
> So, it's not like I'm regular, I have to take my time. [Speech Therapist] told me to take my time, so that's what I basically been doing. But my siblings get downstairs before I do. I have trouble walking, I walk with a cane, so I take my time, and try to get down there, if I feel like going downstairs. Most of the time, I feel like laying in the bed, but I just force myself to get up, because I know that bedrest is good, but getting up walking is even better.
>
> Participant 6b went on to say:
>
> One thing that I feel that I'm being rushed with, is just doing things. She call me for dinner, She call me nonstop, I'm like, "I'm coming, you got to give me a chance to get up". I keep telling Her that but she keep doing whatever, so it's like "whatever." You know? It's not that I don't Want to get up and come, she has to

> understand, I had a stroke, I'm trying to do my best to get down there, but can't, because I don't want to hurt myself.

In becoming one who has to be cared for, participants all shared their feelings with regards to feeling rushed and noticing the impatience which in turns results in feelings of dejection, sadness, or frustration due their new lack of self-efficacy along with feeling the frustration from the family caregiver. The family caregiver may overstep or overhelp the survivor of stroke by not allowing them time to complete a task in efforts to expedite the process thereby adding to the sadness experienced by the survivor of stroke.

Theme 9: Grieving: Thoughts of Former Self

The emotional trauma of having a stroke can trigger depression post-stroke with the survivor of stroke grieving their former self and life pre-stroke (Meyerson, 2020). In response to asking the participants to share their experiences of sadness post-stroke, patient 3b stated: "There are times that I'll be looking at TV right here and that's one thing I used to love to do and I lost it. I used to love it. But I love to watch the news, what's going on, on TV all the time and when I can't keep up with the news. I can keep up with the news pretty good and what they are saying, but I can't understand. I really want to understand and it makes me feel that way [sadness]" Participant 4b stated: "reflecting on my former self, no longer independent. I used to do everything myself, now I have to ask for help. Participant 5b stated: "usually when I feel I can't do something, because it's too hard, which is when I feel that way [sadness]. Participant 4b stated: "I want to feel successful and do it myself. I feel like I'm bothering them if I call and ask for help." Participant 6b shared: if somebody say something close to be being stupid not, I would just bust out in tears because I know I could do it before.

Cognitive-linguistic changes can also impact the survivor of stroke's ability complete what once was a simple routine task, which in turn creates a sense of loss leading to grief and sadness. A natural reaction to a loss is grief. Family caregivers and stroke survivors deal with loss and grief as part of their experience; however, each lacked the awareness that this occurrence is common and therefore were left without adequate coping mechanisms. The next theme emerged as survivor of stroke participants began to share experiences of not wanting to be alone or feeling left alone creating feelings of isolation.

Theme 10: Isolation

Participants often felt isolated from their family caregivers. Participant 2b stated: "I do not like feeling alone, when I'm in my room I feel alone I just cry, cry, cry too much. When I need my children and they aren't around it make me sad." Patient 4b stated: "I feel like she's tired of being a caregiver." I'm a talker. I'm a talker. Sometimes I guess I talk too much because they'll do about face when they see me coming. When she sees me coming, she's like, oh here she comes, and I'm like, you do feel like hearing me today? I don't know. Her [family caregiver] goes up and down. Sometimes if she's in a good mood she'll come in here with me. And then sometimes I have to look for her and then say, where are you going? Why don't you stay in here with me? and then she'll stay, that kind of thing. Sometimes she'll go upstairs into her room and stuff like that.

Based on the responses from many of the survivors of stroke with post-stroke depression, it is safe to surmise that many participants felt isolated or lonely. Many participants expressed feelings of being isolated from their friends and families, even when surrounded by family members and friends. Feelings of isolation can be felt not only when left alone, but also when being left out of a conversation or decision because others in the conversation may feel that the survivor of stroke may not understand. Individuals who are lonely are more probable to have symptoms of depression (Perissinotto, Cenzer, & Covinsky, 2012).

Theme 11: Lack of Coping Skills/Shut Down Response to Caregiver's Frustration

Frustration is a known part of the caregiving experience. Frustration of the family caregiver may lead to stress and an increased propensity to losing one's temper (Schempp, 2014). Survivor of stroke participants shared that they are aware when their family caregiver is becoming frustrated. The following responses are their reactions or responses to the caregiver. Participant 4b stated: "when I know [my daughter] is getting frustrated with my I just shut down because asking her is the last resort." Participant 2b stated: "I just cry when she [FCG] gets mad at me and I don't talk and I cry but to get me out I pray. I pray to God. Participant 5b stated: I just let the water flow [cry]. Those participants that did not feel that their caregiver ever appeared to be frustrated happened to be the cared for by a family caregiver who had some prior knowledge or preparation for the duties of family caregiving.

Theme 12: Difficulty Communicating

Communication problems are common following a stroke. The ability for an individual to express their needs and wants is referred to as expressive language. Receptive language is the ability to understand language, written and verbal. Survivor of stroke participants with communication defects secondary to the stroke shared the following: Participant 3b stated: I can keep up with the news pretty good and what they are saying, but I can't understand. I really want to understand. Participant 4b stated: I need somebody with me because sometimes when people are talking, like I said, the whole processing thing. Sometimes people say things so quick, and it's like, go right over my head. So, I'll be like, No, I can't do that independently. I need somebody to be with me when somebody's telling me something, to make sure I'm not missing it, that kind of thing. So that just makes me sad, of how I'm not independent. I can't do stuff I used to do. Not every survivor of stroke presents with a communication deficit, however when effective communication is impaired it creates a reduced quality of life leading to a lack of independence and negative feelings.

Conclusion

I presented information in this chapter that detailed participant recruitment procedures, organizational influence, data collection, storage of data, data analysis, evidence of trustworthiness and the results of the study. The data collected from the semi structured interviews revealed six emerging themes from the family caregiver interviews: (1) lack of preparedness for being a family caregiver, (2) challenging role dealing with depression, (3) overwhelming, frustrating, stressful. (4) self-neglect/lack of balance. (5)

isolation and reduced social interaction. (6) joy of family caregiving brings joy. There were five emerging themes from interviews with the survivor of stroke with post-stroke depression: (1) Lack of Self-Efficacy/Impatience from FCG/Overhelping, (2) Thoughts of Former Self/Grieving, (3) isolation (4) lack of coping skills/shutdown response, (5) difficulty communicating. Each theme resulted from the data collected during the interviews that resulted in the rich descriptions from the 12 participants of 6 family caregivers and 6 survivors of stroke with post-stroke depression. The interpretation of the findings will be presented in chapter 5. I will also report the limitations of the study, study implications and the impact on social change, recommendations based on the study results.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative study was to explore poststroke depression as it is experienced, perceived, and lived by the survivor of stroke and the family caregiver. Although there is an expansive amount of literature on family caregiver stress, burden, and burnout as well as poststroke depression (e.g., Tsai & Pai, 2016; Byun et al., 2017; Carek et al., 2010), the literature is limited on the lived experiences within the dyad of the family caregiver and survivor of stroke with poststroke depression thereby exposing a gap in the literature. The gap in the knowledge of poststroke depression with regard to the experiences lived with the family caregiver could create a challenge for medical and allied health services' ability to meet the needs of the dyad posthospitalization. This knowledge gap, with regard to the experiences within the dyad, also could create challenges for the family caregiver's mental health and wellness and the survivor of stroke's rehabilitative outcomes. Knowledge of the lived experiences and viewpoints of stroke survivors with poststroke depression and their family caregivers is critical for developing effective education strategies or methods that would help families and care recipients learn and understand stroke, family caregiving and poststroke depression.

A total of 11 themes emerged from the participant interviews. Six themes emerged from the family caregiver interviews and five from the stroke survivor interviews. Findings revealed that the tasks involved in family caregiving and attempts to find balance within the role are compounded by the minimal to no preparation of caregivers and their lack of awareness of the emotional aftermath of stroke for the survivor. Stroke survivors with poststroke depression in the study reported contending with myriad emotions and struggling with their physical and cognitive challenges all while realizing the added burden placed on their family caregiver which, in turn, may impact the relationship within the dyad. The way in which family caregivers and care recipients with poststroke depression experienced the phenomenon within their dyad differed from one another.

This chapter contains interpretation of the findings, discussion of the limitations of the study, recommendations for future research, and discussion of the implications of this study. In conducting the study, I sought to answer the following RQs:

RQ1. How do caregivers and stroke survivors describe the factors that contribute to caregiver stress?

RQ2. How do caregivers and stroke survivors describe the factors that contribute to stroke survivors' depression?

RQ3. How do caregivers and stroke survivors cope with caregiver stress?

RQ4. How do stroke survivors cope with stroke survivors' depression?

RQ5. What is the experience with the caregiver and care recipient with reciprocity?

Interpretation of the Findings

The following themes emerged from the analysis of the data from the family caregiver: (a) lack of preparedness for being a family caregiver; (b) challenging role of dealing with the depression; (c) overwhelming, frustrating, stressful; (d) self-neglect and lack of balance; (e) isolation reduced social interaction; and (f) joy of family caregiving is witnessing the progress. The following themes emerged from the analysis of the data from the survivor of stroke with post-stroke depression: (a) lack of self-efficacy impatience and overhelping from family caregiver, (b) grieving: thoughts of former self, (c) isolation, (d) lack of coping skills/shutdown response to family caregiver's frustration, and (e) difficulty communicating. I will interpret the findings using the literature review as the lens of the examination.

Theme 1: Time and Commitment

Time and commitment was a stress factor for family caregivers, particularly younger family caregivers with children, family, and careers. Three of the six family caregiver reported feeling bogged down with juggling their jobs, children, school, and providing care. In the United States, one in six Americans working part-time or full-time are family caregivers (Family Caregiver Alliance National Center on Caregiving, 2016). Those who are working at least 15 hours per week report that their role as a family caregiver negatively affected their work life (Family Caregiver Alliance, 2016). Female caregivers who work are more likely than men to take a job that is less demanding or completely give up working (Family Caregiving Alliance National Center on Caregiving, 2020). Family caregivers in this study who were over 50 found time and commitment less of a factor. Although all family caregiver participants in this study expressed some level of stress and burden, they all wanted the best care for the loved one.

Theme 2: Lack of Preparedness

A major finding of this qualitative study was the lack or readiness and preparedness for the role of becoming a family caregiver. This finding is an emerging theme as research is limited with regards to readiness to assume the role of family caregiving(Byun et al., 2017). Readiness would encompass education on the role of family caregiving, what to expect, how to build and use a support system, accessing community support, stroke education, PSD education, as well as timely notification of the discharge process and date to allow for home and support system set-up. Hampton and Newcomb (2018) found that lack of confidence in one’s ability to provide adequate care is paired with increased stress. Lack of preparedess can reduce the confidence of those who are considering moving into the role of family caregiving. According to Byun et al. (2017), independent factors associated with caregiver stress include having less social support, caregiver’s income, and less preparedness. Current studies corroborate the findings in my study. Strommen et al. (2018) concluded that family caregivers did not have sufficient education and training regarding how to care for their loved one and had to resort to trial and error as a learning tool. In another recent study, Pucciarelli et al. (2020) concluded that education provided to stroke survivors and family caregivers improved outcomes in the stroke survivors physical functioning, quality of life, and memory as well as improved outcomes in caregiver depression. Lack of preparedness is related to the first RQ, How do caregivers and stroke survivors describe factors that contribute to stress?

Theme 3: Challenging Role Dealing With a Loved One’s Depression

In this study, family caregivers shared their struggle with coping with the depression of their loved one and how this added stress and frustration to the caregiving process. PSD is defined as a neuropsychiatric occurrence that is common and is of great significance clinically in that it is a critical factor for rehabilitation, quality of life, and a source of family caregiver stress (Jyotirekha & Rajanikant, 2018). Family caregivers did not know how to respond or how to help their recipient of care manage their feelings. Many said they just walked away or left their loved one to deal with their feelings. Family caregivers in this study also expressed lack awareness that PSD could be a possible outcome for their loved one along with the lack of skills to help their recipient of care cope with the depressive symptoms.

Findings show that not understanding PSD and not having the skills to help the survivor of stroke with PSD cope are factors that contribute to family caregiver stress. Stress has the propensity to lead to physical and mental illness, and many of the family caregivers in this study suffered illnesses and self-reported sadness during their role of caregiving. Byun et al. (2017) found independent factors associated with caregiver stress included having less social support, caregiver's income, functional status of the stroke survivor, less preparedness, income, gender, and insurance type. These factors are consistant with the findings of my study. Informal caregivers providing care for stroke survivors reported anxiety, depression, and hypertension following the stroke event (King, et al., 2012). Also, the lack of knowledge of PSD leads to the lack of reporting of mental health symptoms or receipt of related care, which is consistant with King et al.'s (2012) finding that informal caregivers providing care for stroke survivors have health problems reported in areas such as anxiety, depression, and hypertension following the stroke event. With respect to family caregiver stress and my first RQ, lack of knowledge, information, and coping strategies regarding PSD are factors that contribute to family caregiver stress.

Theme 4: Overwhelming, Frustrating, and Burdensome Task

Family caregivers referenced feelings of being overwhelmed and frustrated at times creating stress. Participants expressed difficulty dealing with the daily demands of caregiving coupled with continuing to manage their own personal lives, careers, relationships, and schooling. Participants referenced lack of sleep as a major factor in feeling frustrated and having to take off from work for extended periods of time, assuming duties that were once split between the two parties. These findings are consistent throughout the literature as Woodford, Farrand, Watkins, and Llewellyn, (2018) reported feelings of being overwhelmed with the undertaking of new responsibilities previously handled by the survivor of stroke. The literature reflects that many family caregivers experienced PTSD associated with anticipation and experience of providing care (Van den Born-Van Zaten, Donglemans, Dettling-Ihnenfeldt, Vink, & van der Schaaf, 2016). The literature also shows family caregivers feelings of being drained by the tasks of caregiving and supports the feelings of burden and being overwhelmed and overlooking the meaningful experiences as reported by Lu, Martensson, Zhao, and Johansson, (2019). This theme relates to my RQ which asks how do caregivers and stroke survivors describe the factors that contribute to caregiver stress?

Theme 5: Self-Neglect/Lack of Balance

Lack of self-care and life balance was a consistently expressed theme by the participants in my study. Family caregivers stated that demands and concerns of providing care leave little time to think of their own personal needs. Family caregivers admitted to neglecting their own needs and becoming sick which in turn led to more worry and concern of their loved one's care.

The all-day everyday demands of caregiving are time and thought consuming which leave little room for family caregivers to balance their lives and care for self. Even when offering help, caregivers expressed not wanting to go too far from home because of wanting to be in close proximity to their recipient of care. Family caregivers who were confident in their own self-care had lower levels of perceived stress as reported by Hampton and Newcome, (2018). In a recent study by Stronmen et al. (2018), family caregivers reported lacking the time for self-care and renewal due to insufficient respite care. This theme lends itself to the RQs of how do family caregivers and stroke survivors describe factors that contribute to caregiver stress? This theme also contributes to the RQ of how do family caregiver and stroke survivors cope with caregiver stress?

Theme 6: Isolation/Reduced Social Interaction

Given the time, energy, and commitment involved in family caregiving, participants in my study expressed their lack of social interaction and feelings of isolation from friends, family, previous activities, and events. Family caregivers must take on additional duties that the survivor of stroke once managed, maintain their career and school as two participants were working on advanced degrees. Having to manage the additional duties and provide the care needed for their loved one left little to no time for socialization. These findings are consistent with the literature as Woodford, Ferrand, Watkins, and Llewellyn, (2018) found that feelings of being a prisoner in your own home and feeling of being trapped was a common occurrence in family caregiving. The lack of time with friends and social engagements.

Extra tasks and duties that are assumed by the family caregiver had a negative impact on the relationship withing the dyad. (Winkler, Bedford, Northcott, & Hilari, 2014). Family caregivers felt feelings of physical and mental exhaustions, along with loneliness and feeling resentful (Winkler, Bedford, Northcott, & Hilari, 2014). Statistical data reveals that 60-70% of family caregivers experience depression secondary isolation (Family Caregiving Alliance National Center on Caregiving, 2020). Although many participants expressed their understanding as to why they no longer socialized in their normal patterns, the findings of the literature are consistent with the findings of my study, all family caregiver participants experienced isolation or reduced social interaction. The challenges of recued social isolation faced by family caregivers lends itself to a factor that contributes to caregiver stress.

Theme 7: The Joy of Being a Family Caregiver Is Witnessing the Progress

During the interview process, family caregivers honestly expressed that this is something that they do not want to do. As previously stated, not only do family caregivers provide the physical care for their loved one, family caregivers also take on additional responsibilities, once handled by the survivor of stroke, along with managing their own personal responsibilities. This leaves the family caregiver with stress, frustration, burden, and feelings of being overwhelmed. They, however, were still able to find meaning and joy in the process. Family caregivers also expressed that they would rather provide the care than to let someone else do the job. The literature reflects positive outcomes including new levels of closeness, pride in achievements, and a new appreciation for life. (Winkler, Bedford, Northcott, & Hilari, 2014).

Family caregivers in this study found joy in witnessing the progress of their loved one and the joy of knowing that their loved one is being cared for without being in a facility. Zhang and Lee, (2019) found that cargivers saw the act of providing care as an opportunity that was meaningful, improved relationships within the dyad and created an appreciation for life. Zhang and Lee, (2019) also found caregiving helped to develop an improved relationship withing the dyad. These findings are consisten with the literature with respect to reciprocity.

Theme 8: Lack of Self-Efficacy/Impatience From Family Caregiving/Overhelping

An emerging theme in this study is the impatience and overhelping of the family caregiver. The act of impatience and overhelping from family caregivers led the survivor of stroke within the dyad experiencing less self-efficacy resulting in feelings of sadness. Survivors of stroke felt rushed by their family caregiver to complete tasks, often asking for patience, time, and independence to finish without assistance. When the family caregiver would step in to complete the task for the survivor of stroke, thereby overhelping, the survivor of stroke would be left with feelings of uselessness. Self-efficacy is one’s belief in their capability to perform and complete tasks (Torrisi, et al., 2018). The survivors of stroke in my study expressed feelings of being less independent and having less self-efficacy when the family caregiver stepped in and did not allow the survivor of stroke to complete the task. General self-efficacy was found to be a main factor of depressive symptoms post stroke within the first two years (Volz, Voelkle, &

Werheid, 2019; Volz, Voelkle, & Werheid, 2019). Voelkle and Werhied, (2019) also suggest that nurturing the belief in survivors of stroke ability to cope following the stroke may offset the exacerbation of symptoms of depression. The act of overhelping by family caregivers leads to feelings of reduced self-efficacy in survivors of stroke which, in turn, becomes a contributing factor to post-stroke depression.

Theme 9: Grieving: Thoughts of Former Self

It is natural to grieve the loss of a loved one after a death. There is however a loss incurred following a stroke when there are disabling effects creating a change to one's sense of normalcy. When former routines or abilities are lost, the feelings of grief can be just as significant as a physical death. Consistent with the literature, participants in this study expressed a sense of grief by grieving their former self. Survivors of stroke spoke often of what they used to be able to do prior to the stroke.

Participants spoke of driving, social activities, physical independence, cooking, and not needing help with activities of daily living as well as their former household roles and duties. Following a stroke, many patients experience a period of grief and loss of their former self. Stroke survivors have survived the stroke; however, they must deal with the unexpected event as well as the unexpected losses that come with having a stroke (Perna & Harik, 2020). Grief and loss negatively affect the survivor of stroke and impacts their mental and emotional health (Hughes & Cummings, 2020). The grief and loss experienced by the survivor of stroke can include loss of friendship, loss of role, as well as loss of physical, cognitive, or speech function (Hughes & Cummings, 2020). This theme is relative to factors that contribute to post-stroke depression.

Theme 10: Isolation

Stroke survivor participants expressed perceived isolation. The feelings of loneliness extended into feelings of sadness. Participants perceived feelings of being isolated occurs when family caregivers must tend to their personal needs, work, children, or when seeking some private time. Some participants also expressed perceived feelings of being isolated even when being surrounded by family and friends which could possibly be due to the survivor of stroke's inability to fully engage in the activity weather it is physical or cognitive involvement. Social isolation is an impact of disability and could be a factor in post-stroke depression.

Current literature is limited with regards to social isolation in survivors of stroke with post-stroke depression. Individuals dealing with functional limitations and those with limited family support are more likely to experience loneliness (Novetney, 2019). With respect to participants feelings of isolation even when around family and friends, Novetney, (2019) reports that loneliness is not just solitude or being by oneself, but also includes an individual's satisfaction with their connections. She goes on to report that loneliness can also bring forth raised stress levels, anxiety, and depression (Novetney, 2019). These findings suggest that isolation is a factor that may contribute to post-stroke depression.

Theme 11: Lack of Coping Skills/Shut Down Response to Caregiver's Frustration

Survivors of stroke found it difficult to cope when they recognized the frustration of their family caregiver, as reported during interviews for this study. Participants expressed their response to knowing their family caregivers were frustrated and did not want to be bothered by crying, shutting down and not talking, or praying. Recent literature revealed that a family caregiver's attempt to adapt to the losses and changes brought on by taking on a caring role led to their feelings of worry, social isolation, hopelessness thereby leading to emotions that are distressing including resentment, guilt, frustration, shame, anger, fear, and sadness (Woodford, Farrand, Watkins, & Llewellyn, 2018). Family caregivers were possibly unaware of the fact that their loved one was able to recognize their frustration which in turn resulted in the survivor of stroke's personal experience of distressing emotions due to observed emotional state of their family caregiver. It is safe to surmise that mental and emotional state of the family caregiver may alter the emotional state of their survivor of stroke, leading to stress, anxiety, and sadness. These aspects lend itself to factors that contribute to post-stroke depression as well as how survivors of stroke cope with caregiver stress.

Theme 12: Difficulty Communicating

Participants expressed their difficulty with communication. There were participants whose speech deficits were remediated with speech therapy and there were participants who continue to receive speech therapy services. Consistent with the literature, difficulty communicating is common post stroke and effective communication enhances one's level of independence (American Speech-Language and Hearing Association, 2019c). Difficulty with communication had an effect on the participant's independence and led to negative feelings as it made it difficult to for survivors of stroke to connect with others around them. Difficulty communicating can add to the frustration of the survivor of stroke and can be isolating placing them at a greater risk for depression

(Stroke Foundation, 2021). Finally, although participants who experience difficulty with speech and language received therapy services, some reported that family members were not taught how to effectively communicate with their loved ones leaving the survivor of stroke frustrated with not being understood or without successful communication of their wants and needs.

Limitations of the Study

The limitations of this study, post-stroke depression and the lived experience of the family caregiver and care recipient were caused by experiences within different lengths of service of being a family caregiver and survivor of stroke with PSD, the possible inequitable gender distribution, the varied disabilities resulting from the stroke experienced by the survivors, the ages of the family caregivers, the experience of the family caregivers, and potential of inaccurate self-reporting of the lived experiences from both parties within the dyads. Additionally, the findings of this study were based on a limited number of 12 participants totaling 6 survivors of stroke with post-stroke depression and family caregiver dyads in which the population may not truly represent this population. With regards to time spent being a family caregiver and survivor of stroke with post-stroke depression, there could have been a difference in the period of adjustment within the experience from 6 months to 2 years within this phenomenon. Lastly, previous experience in the allied health field which provides a greater baseline of knowledge and adds to the abilities of the caregiver provides for discrepant feelings and experiences.

My personal experiences as a family caregiver and as a speech-language pathologist could have influenced the results due to personal bias. The risk for bias was addressed by allowing the participants of this study to provide their personal accounts using specific open-ended questions that were semi-directed which produced rich descriptions from the interviews (Moustakas, 1994). Epoché was used as the guard from prejudgments as I actively refrained from drawing preconceived conclusions. I allowed the data revealed from the participant responses to provide descriptions of their experiences and to analyze accordingly.

Recommendations

Based on the findings of this study, it is recommended that hospital administrations implement a comprehensive stroke education programs for survivors of stroke and their family caregivers. The programs should be inclusive of a health psychologist stroke education, post-stroke depression along with tools to cope with post-stroke depression. The health psychologist would also help the family caregiver understand the role of family caregiving, develop a plan for care and support. Allied health training should also be provided including speech language pathology, occupational therapy and physical therapy. Speech-language pathology would focus on family caregiver training on how to effectively communicative with their loved one post stroke based on specific needs withing the scope of practice. Occupational therapy would focus on educating the family caregiver on how to assist the survivor of stroke and how to maximize functional independence with activities of daily living given the survivor’s limitations. Physical therapy would focus on proper body mechanics to assist the survivor of stroke and how to maximize functional independence. Counseling would provide wellness and coping tools for post-stroke depression and adapting to life post-stroke.

Nursing education is also recommended to help the family caregiver understand medication dispensing, and any possible medical warning signs and what to look for to ensure general health while providing care. Finally, case management is recommended to allow for adequate notification of discharge date to allow family caregivers sufficient preparation time.

Future Research

Several areas to target for future research are having more diverse participants and the possibility of coupling the research with quantitative research to glean a correlation between family caregiver stress and PSD or severity of PSD. Although this researcher still agrees with the use of qualitative research, a statistical component would provide increased strength and objectivity to the data realized with this qualitative research. Other areas for continued research that could compliment this study's findings, would be to target specific cultural populations, socioeconomic status, and a balanced gender distribution, in which a comparison of perspectives could be captured. between family caregivers and survivors of stroke. Lastly, a follow up qualitative study with a diverse participant group and larger sample sizes could increase the ability to generalize these results.

Implications

As we strive to improve individual and societal conditions, the implications of this study will have a definite positive social change for families and communities.

Family caregiving and post-stroke depression are not new experiences and are well researched, however the experiences of the dyad are just beginning to emerge. The positive social impact my study will have is the heightened awareness of the experiences and the knowledge that it brings with regards to factors that contribute to PSD and family caregiver stress. With the awareness of how stroke survivors with post-stroke depression and family caregivers experience the dyadic phenomenon and its bearing on general health and wellness of those involved, programs can be developed to help alleviate or prevent many of the negative outcomes of this experience. With stroke being the cause of disability and many survivors being discharged from facilities to the home and community leaving family to provide long-term care, understanding experiences of the dyad helps highlight the need for post-stroke depression and family caregiver dyad education programs as a necessary component of the healthcare process.

Conclusion

The purpose of this study was to explore the lived experiences of survivors of stroke with post-stroke depression and their family caregivers. This phenomenological study captured the experiences as perceived by the participants within their dyadic relationship. With 13.7 million new strokes globally each year, the family caregiver care recipient with post-stroke depression dyad is likely to grow (World Stroke Organization, 2021). The statistics are a clear indicator of the need for these and further findings on stroke survivors with post-stroke depression and the family caregiver dyad. Although there is extensive research on post-stroke depression and family caregiving as independent phenomena, literature regarding this dyadic relationship is just emerging.

Consistent with previous research family caregivers experience stress, burden, burnout, and depression. Factors contributing to family caregiver stress include isolation, lack of life balance, burdensome task of family caregiving, and its overwhelming nature. Other stress factors revealed from this study were lack of preparedness for the role, the time and commitment required to fulfill the duties, and the challenging role of dealing with the depression of the recipient of care with post-stroke depression. Coping with the stress proved to be a challenge for family caregivers of their loved ones with PSD within the dyad. Family caregivers did not possess the tools to aid the recipient of care in coping with PSD. Given the factors that lead to stress, and overall time and commitment leaves minimal time for self-care for those with limited familial support. Moreover, study findings revealed that family caregivers consistently indicate that they would rather deal with the stress and be the provider of care to ensure that their loved ones were getting the best care. Additionally, the mutual benefit of being a family caregiver, as reported by participants, is the found joy in witnessing the progress in their loved one with regards to reciprocity.

Study findings also revealed factors that contribute to post-stroke depression. These factors include lack of self-efficacy/overhelping from the family caregiver, grieving former self, isolation, lack of coping skills, and difficulty communicating. Difficulty coping with post-stroke depression proved difficult without awareness and education on the tools to combat the negative feelings for the survivor of stroke. The family caregiver also is often ill equipped to provide assistance to the care recipient when the symptoms of PSD emerge. Furthermore, family caregivers also lack the awareness of how their actions, responses, and stress can become a contributing factor to the recipient of care’s PSD. In conclusion, using the data collected from the 12 themes presented in this study to increase knowledge, awareness, and to develop and implement programs designed for the dyad of survivors of stroke with post-stroke depression and their family caregivers will potentially enhance this dyadic experience and thereby improve practice with those affected by stroke and PSD.

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Appendix A: Alignment of Research Problem, Questions, and Purpose

Research problem	Research question	Research purpose
Family caregiver stress	Family caregiver stress	How do caregivers and stroke survivors describe the factors that contribute to caregiver stress?
Poststroke depression	Poststroke depression	How do caregiver and stroke survivors describe the factors that contribute to the stroke survivors' depression?
Coping with caregiver stress	Coping with caregiver stress	How do caregivers and stroke survivors cope with caregiver stress?
Coping with poststroke depression	Coping with poststroke depression	How do stroke survivors cope with stroke survivors' depression?

Appendix B: Family Caregiver Interview Questions

1. Describe your relation with your loved on prior to the stroke.
2. What does it mean to you to be a family caregiver?
3. What are your feelings about providing care?
4. Describe a typical day with your loved one.
5. Describe the household duties that your loved one
6. Describe what gives you stress or tension during your caregiving.
7. How were you prepared for your duties of caregiving?
8. Describe how the training that you received help you for your role of caregiving.
9. Describe the caregiving duties that you were not prepared for.
10. What aspects of family caregiving leaves you feeling overwhelmed?
11. Describe how the communication deficits of your loved one impact you.
12. Describe your communicative interaction with your loved one.
13. What training to you receive on how to communicate with your loved one.
14. What aspects of family caregiving frustrates you?
15. Describe your loved one’s reactions to your frustration.
16. Do you recognize the sadness of your loved one?
17. How do you respond to the symptoms of depressions in you loved one?
18. Describe your coping skills.
19. How often do you get relief from you family/friends?
20. Describe your social life.
21. Describe the aspects of caregiving that brings you joy?

Appendix C: Survivor Interview Questions

1. Describe your relationship with your family caregiver prior to the stroke.
2. How often do you and your family caregiver talk?
3. Describe your interactions between you and your family caregiver.
4. Describe your outings in the community.
5. Describe the household duties that you help with.
6. Describe ways you feel you can be more independent.
7. Describe what you feel frustrates your family caregiver.
8. Describe how you respond when you feel your family caregiver is frustrated.
9. Describe the times when you feel rushed by your family caregiver to complete tasks.
10. Describe the times when you feel sad.
11. What causes your sadness?
12. How do your cope with your sadness?
13. Describe your feelings about how you communicate.
14. Do you feel that your family caregiver is patient with you?
15. Describe your social interaction with your friends and family.
16. What self-care activities to you do for yourself?
17. Describe your positive feelings of having a family caregiver.