

THE CATHOLIC UNIVERSITY OF AMERICA

The Relationship of Stroke Patients' Functional and Cognitive Status
And Caregivers' Resilience to Caregiver Burden

A DISSERTATION

Submitted to the Faculty of the

School of Nursing

Of The Catholic University of America

In Partial Fulfillment of the Requirements

For the Degree

Doctor of Philosophy

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Washington, D.C.

2015

The Relationship of Stroke Patients' Functional and Cognitive Status And Caregivers' Resilience to Caregiver Burden

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Currently it is estimated that 795,000 persons experience a stroke every year. Of that number up to one-third of survivors will be permanently disabled. It is neither financially feasible nor desirable to place these disabled stroke survivors in long-term care facilities to provide them with the needed assistance if they can be cared for at home. Frequently, the care of these patients is assumed by family members or friends. However, providing care has been shown to be burdensome for some caregivers of stroke patients (Johnson, 1998; Scholte op Reimer, deHaan, Pijnenborg, Limburg, & van den Bos, 1998a; Van Puymbroeck, Hinojosa, & Rittman, 2008).

The factors that contribute to development of caregiver burden have been studied by numerous researchers, but findings are inconclusive (Jeng-Ru, Hills, Kaplan, & Johnson, 1998; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Nelson, Smith, Martinson, Kind, & Luepker, 2008; Vincent, Desrosiers, Landreville, & Demers, 2009). The contribution of the stroke patients' functional and/or cognitive disabilities to the caregiver's burden level is not clear as a result of contradictory findings in the published research. Further, resilience has not been measured in stroke caregivers and evaluated as a possible mediating factor in burden's development. This study sought to clarify those interrelationships.

A descriptive correlational design was used in this study. Fifty-six stroke patient and caregiver dyads were evaluated at least two weeks after the stroke patient returned to the home setting after experiencing an acute stroke. All of the participants were adults who spoke English.

Stroke patients were evaluated functionally with the Barthel Index, and cognitively with the Mini-Mental State Exam by the investigator. Caregivers self-administered the Resilience Scale, the modified Zarit Burden Interview, and a demographic data collection tool.

Demographic data was evaluated with descriptive statistics and the hypotheses were tested using multiple regression. Regression analysis indicated that the functional status and cognitive status of the stroke patients were not significantly related to the burden level of their caregivers. However, the caregivers' personal resilience level was significantly related to caregiver burden [$F(4, 50) = 4.10, p = 0.048$]. Demographic data analysis revealed that there was also a significant relationship between the caregivers' perception that their own physical condition made it difficult to provide care and their burden level.

This study's findings contribute to the existing body of knowledge regarding caregiver burden in stroke patients. Identification of factors that contribute to or mediate the development of caregiver burden may aid nurses and other health care providers in identifying caregivers who are at risk for developing burden, and ultimately assist in maintaining stroke patients in their home setting long-term.

This dissertation by Margaret D. Nolan fulfills the dissertation requirements for the doctoral Degree in Nursing approved by Jean Toth, Ph.D., RN, as director, and by Teresa Walsh, Ph.D., RN, and Colleen Norton, Ph.D., RN as readers.

Jean Toth, Ph. D., RN, Director

Teresa Walsh, Ph. D., RN, Reader

Colleen Norton, Ph. D., RN, Reader

DEDICATION

To my children, Amanda and Jonathan, who have given up their time with me while I worked to
navigate the process of doctoral studies

and

To my mother and father, who inspired this study.

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ACKNOWLEDGEMENTS

I would like to express my gratitude to Dr. Jean Toth, my dissertation chairperson. I believe that her faith in me and her constant gentle push to complete this process is largely responsible for its accomplishment. Her talent with quantitative analysis is second to none. I am also grateful for the guidance of my committee members, Dr. Teresa Walsh, and Dr. Colleen Norton for giving their time, wisdom, and support to me during this process.

I am grateful to my friends and co-workers who have been fonts of encouragement for me: Tricia, Jean, Chad, Edilma, and Robert. You have lightened the load considerably.

Special thanks go to Dr. Nancy Crego for assisting me in statistical analysis of my data. Thanks also go to Dr. Irene Jillson, for reading my work and critiquing it in an encouraging, positive way. And finally, thanks and love to my son, Jonathan Lutton, who edited and formatted for me tirelessly as I sought to finish.

CHAPTER I

Introduction

Background

An estimated 795,000 persons experience a stroke each year. Of this number, 610,000 experience their initial stroke, while the remaining 185,000 experience a repeat episode of stroke (American Heart Association, 2009, p. 22). Cerebrovascular accident, commonly referred to as “stroke”, refers to an intracerebral hemorrhage or interruption of blood flow to the brain, resulting in transient or permanent neurological injury or death (Whitney-Rainbolt, 1993, p. 708). The resulting neurological injury manifests with changes in the functional or cognitive abilities of the surviving stroke patient. The rising number of older adults in the American population has contributed to the increasing number of persons experiencing stroke; however, medical advances have resulted in an increased rate of survival for stroke patients.

It is not financially feasible or desirable to place post-stroke patients with cognitive and functional disabilities in long-term care facilities to provide them with needed assistance if they can be cared for within a home environment. However, returning stroke patients to the home setting places a heavy burden upon their informal caregivers, who must assist them in many of their activities of daily living (ADLs). It is unknown whether the personal qualities of informal caregivers contribute to their success, or lack thereof, in this role. Resilience has been recognized as a factor that allows persons to rise above adversity and avoid negative outcomes, but the relationship between the negative outcome of caregiver burden and resilience has yet to be studied.

This chapter provides clarification as to why this study was necessary. Roy's adaptation model (1988) served as the theoretical framework for this study. The purpose, hypotheses and definitions of the variables involved are provided, with separate discussion of each of the concepts in turn.

Stroke

The American Heart Association (AHA) projected that a stroke is experienced every 40 seconds in the United States (2009, p. 72). Stroke ranks as the third leading cause of death in the United States, with 143,579 (or 1 of every 17) deaths resulting from stroke in 2005 (AHA, 2009, p. 72). Although the death rate as the result of stroke continues to fall due to improved medical therapies, the actual number of stroke deaths continues to be of significance as the result of the increased number of older adults in the American population. Elkins and Johnston (2003) project that despite the improvement in acute stroke treatment, stroke mortality will double by 2032 in the United States. Together, these projections indicate significant increases can be expected in the number of persons experiencing stroke in the future.

Stroke remains a leading cause of disability worldwide, due in part to the decreasing death rate. Providing care for those who are disabled as the result of stroke comes at a high cost. In 2009, the AHA estimated that direct and indirect cost of stroke in the United States would total \$68.9 billion (p. 172). Despite this fact, governmental support for stroke research has historically trailed other diseases. Federal funding to the National Institute of Health (NIH) for research in 2008 ranked stroke 70th out of 215 funded disease research areas (NIH, 2009). Relative to the amount of research funding provided, stroke research comprised less than 1% of the NIH budget (NIH, 2009).

The American Heart Association states that there are approximately 6.5 million stroke survivors coping with varying degrees of disability—defined as mild, moderate or severe—relative to the amount of impairment sustained (2009, p 31). AHA estimates that 15-30% of those who experience a stroke will become permanently disabled as the result of the incident (2009, p. 76). Based on the current incidence rate, this equates to a potential increase in the number of permanently disabled stroke patients by 238,000 each year.

Functional and Cognitive Status

There is no singular, predictable outcome of a stroke. Stroke results vary based upon the amount of damage to, and the specific area of the brain affected by the lack of blood flow. Damage to the brain from stroke potentially interferes with the person's ability to "function intellectually, express personality and mood, and interact with the environment" (McCance & Huether, 2002, p. 369). Stroke may result in minimal changes to a person's abilities, or cause such severe disability that the individual is completely dependent on others for all of their needs. Although all of the resulting deficits from stroke are cerebral in origin, stroke deficits may be classified as either cognitive or functional in nature. Evaluating a stroke patient's ability to perform basic activities of daily living provides a clear assessment of their functional status, while evaluating their mental faculties provides an assessment of their cognitive status. This study evaluated the relative contributions of the functional and cognitive status of stroke patients to the burden level of their primary caregivers.

Cognitive deficits from stroke may include an inability to remain awake, speak, comprehend the spoken or written word, and/or the loss of memory, judgment, reasoning, or concentration. Furthermore, cognitive disability may include changes in a person's perceptual

ability, including the inability to perceive the presence of the half of their body that has been affected by stroke. In this study, stroke patients' cognitive status was evaluated using Folstein, Folstein, and McHugh's Mini-Mental State Exam (1975).

Functional changes resulting from stroke may be limited to one side or one area of the body, rather than being global in nature. Functional deficits that result from stroke may include paralysis or paresis, visual changes, and losses or alterations to voluntary movement, bowel and/or bladder control, ambulation, or sensation (McCance & Huether, 2002, p 507-509). This study evaluated the functional status of stroke patients to determine whether the level of deficit sustained contributes to their caregiver's burden. Functional status was evaluated using the Barthel Index (Mahoney & Barthel, 1965).

Resilience

Garmezy was among the earliest researchers to focus on the concept of resilience. In an interview, Garmezy defined resilience as "manifest competence despite exposure to significant stressors" (Rolf, 1999, p. 7). This definition delineates resilience as a trait that one possesses, which enables them to function even in difficult circumstances. Dyer and McGuinness alternately describe resilience as a "process" rather than an inherent trait, but state that the presence of resilience is dependent upon factors which enabled its' development (1996, p. 277). As an extension of this, resilience has been shown in various studies to alternately be both a mediator in stressful situations and an outcome, achieved by exposure to stressful experiences (Kaplan, 1999). The interest in resilience stems from the fact that those persons judged to possess it are seen to unexpectedly experience fewer negative outcomes from difficult or challenging life situations than others.

Resilience has been studied to a great degree in pediatric and adolescent populations (Bradley, et al., 1994; Gest, Neemann, Hubbard, Masten, & Tellegen, 1993; Grossman, et.al, 1992; Spencer, Cole, DePree, Glymph, & Pierre, 1993). In fact, Garmezy's (1985) original studies of resilience evaluated school-aged children who were experiencing stressful situations. However, studies of resilience in adults are seen more frequently now.

Wagnild and Young (1990) conducted a qualitative study of older women and uncovered common themes—equanimity, self-reliance, existential aloneness, perseverance, and meaningfulness—which the authors determined to comprise resilience. Many of the women in their study discussed the importance of maintaining perspective and finding humor in their lives. In addition, studies of resilience across different age groups have noted that resilient persons are socially involved within a network of support (Butler et al., 2009; McLaren & Challis, 2009; O'Grady & Metz, 1987; Wagnild, 2003). Reflecting on this information, caregivers in this study who were identified as possessing resilience may have had the benefit of social support as well.

Wagnild and Young (1993) subsequently developed the Resilience Scale, which has been interpreted into multiple languages and used in various adult populations to measure resilience (Aroian & Norris, 2000; Christopher, 2000; Davis, 2000; Heilemann, Lee, & Kury, 2003; Leppert, Gunzelmann, Schumacher, Strauss, & Brahler, 2005; Nygren, Randstrom, Lejonklou, & Lundman, 2004). Wagnild and Young's findings from the study of older women provided the basis for two of this study's hypotheses. Resilience, as measured by the Resilience Scale, was evaluated as a factor in the development of caregiver burden in this study (Wagnild & Young, 1993).

Caregiving

As a result of Medicare cutbacks and the nationwide adoption of a managed-care orientation for the provision of medical benefits, the care of disabled persons has shifted to the home caregiver. Most commonly, in the case of the stroke victim, the care provider is likely to be either a spouse or a family member. In 2009, the National Alliance for Caregiving (NAC) found that approximately 28.5% of all American households provide some degree of caregiving services to a family member or friend. This means that more than 66 million informal caregivers provided care during that year for patients with disabilities and chronic conditions, including stroke. The investment provided by home caregiving was estimated to be worth \$306 billion per year in 2004 (Arno, 2006), which reflects an increase of \$110 billion over the cost seven years prior (Arno, Levine, & Memmott, 1999). This emphasizes the increasing importance of informal caregivers to the maintenance and care of patients with disabilities.

In general, caregiving research has focused on the negative outcomes of providing long-term care, such as stressors, depression, or a change in caregiver well-being (Bakas, & Champion, 1999; Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998; DuCharme, Levesque, Zarit, LaChance, & Giroux, 2007; Fraser, 1999; Kim & Schulz, 2008). Further, much of the existing burden research undertaken has centered on the caregivers of patients with altered cognition due to dementia or Alzheimer's disease (Clay, Roth, Wadley, & Haley, 2008; Hong, & Kim, 2008; Roth, Ackerman, Okonkwo, & Burgio, 2008; Sanders, Ott, Kelber, & Noonan, 2008; Schulz, et al., 2008; von Kanel, et al., 2008). However, altered cognitive function in stroke patients is not necessarily of the same nature or magnitude as that of other demented patients, and may elicit a different type of caregiver response than is seen in other caregiving situations.

Alzheimer's disease (AD) is a slowly developing condition in which the patient experiences increasing levels of forgetfulness, confusion, disorientation, general neurological deterioration, and mood swings over a lengthy period of time. AD patients develop functional motor impairment over time, but usually only after their disease is well-established: approximately eight or more years after the development of cognitive deterioration (Boss, 2002, p. 465). This provides the caregiver with time to cope with the slowly developing alterations. Stroke patients more commonly experience an immediate onset of functional and/or cognitive impairment at the time of their stroke. Furthermore, many stroke patients experience recurrent strokes, with each subsequent episode causing further functional and cognitive deterioration (AHA, 2009). As stroke patients may evidence immediate alterations to both their functional and cognitive abilities at the time of their stroke, there is not time for preparation or adjustment for most caregivers. It is evident that stroke patient caregiving provides a different level of stress, and will therefore elicit a different caregiving response than is seen in AD caregiving.

Caregiver Burden

One of the most commonly evaluated phenomena in caregiving studies is that of caregiver burden (Almbert, Grafstrom, & Winblad, 1997; Bedard et al., 2001; Jones, 1996; Scholte opReimer, deHaan, Pijnenborg, Limburg, & van den Bos, 1998, Zarit, Reever, & Bach-Peterson, 1980). As with caregiving research, the majority of caregiver burden studies have focused on the caregivers of Alzheimer's patients, in which the primary factor affecting the caregiver is the altered cognition and behavior of the care recipient. Much of caregiver burden research has focused on characteristics of the patient that result in the caregiver's experience of burden (Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998b; Watson,

Modeste, Catolico, & Crouch, 1998). The measurement of burden gives an indication of how laborious the care is that the caregiver provides.

It is known that providing care on a day-to-day basis exacts a price from the caregiver's physical and mental health (Bugge, Alexander, & Hagen, 1999; Morimoto, Schreiner, & Asano, 2003). The question that arises is whether the level of burden experienced is greater in caregivers of stroke patients exhibiting functional and/or cognitive disability. This may be clarified by studying caregivers whose stroke patients suffer either functional impairment alone, cognitive impairment alone, or who exhibit both impairments concurrently.

Hypotheses relating to the functional and cognitive status' effect on burden are based on the findings of Zarit, Reever, and Bach-Peterson (1980). The Burden Scale was developed to measure burden in the caregivers of patients with both functional and cognitive impairment. Although lower amounts of caregiver burden were observed in their original sample than expected, all of the patients, who were moderately to severely cognitively impaired, were able to perform their own activities of daily living without much assistance. Zarit et al.'s (1980) study of burden in caregivers of Alzheimer's patients showed that caregiver burden was decreased when relatives visited the AD patient frequently. Although social support has been shown to be of less significance than Zarit et al.'s study indicated, it is believed that it will be a silent, contributing factor seen in the situation of resilient caregiving (McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Miller, Townsend, Carpenter, & Montgomery, 2001; Visser-Meily, Post, van de Port, Heugten, & van den Bos, 2008).

In summation, despite the plethora of articles on caregivers, there are inconclusive findings regarding specific factors that influence the outcome of caregiver burden relative to the care of

stroke patients. Few authors discuss predictors of informal stroke caregiving outcomes, and no published articles were found to discuss the effects of the stroke caregiver's personal resilience on the level of burden they experience.

Statement of the Problem

Review of current research reveals that the interrelationship among the variables of stroke patients' functional and cognitive status, caregivers' personal resilience, and caregiver burden has not been established.

Theoretical Framework

The Roy Adaptation Model (1988) serves as the theoretical framework for this study. Roy's model was chosen as the framework for this study because it specifically evaluates the adaptation of individuals or groups. Roy's model focuses on the concept of human adaptation, and is derived from the scientific theories of general systems and adaptation-level theory. Philosophically, the model incorporates the principles of humanism and veritivity, a term coined by Roy, which she defines as "a principle of human nature that affirms a common purposefulness of human existence" (1999, p. 32). The scientific underpinnings of the Roy Adaptation Model were utilized in this study as well.

Subsystems

Roy views the individual as an "adaptive system" (1999, p. 18). She describes each adaptive system as a composition of internal processes—including the regulator, cognator, innovator, and stabilizer subsystems. The regulator subsystem is composed of the physiologic

mechanisms that allow the person to adapt or cope with the changing environment while the cognator subsystem is comprised of the psychological, intellectual, and emotional mechanisms that contribute to adaptation. Both the regulator and cognator processes have subsystems, whose contributions to adaptation are outside of the limits of this study. Innovator and stabilizer subsystems address the adaptation of persons within a group dynamic—evaluating change, growth, and group stability and maintenance (Roy, 1999, p. 31-32).

Although the stroke patient has experienced adaptation as well, this study specifically evaluated the adaptation of caregivers. Both Roy's and this study acknowledge that the caregiver does not exist in a void, separate from groups such as familial groups and social groups. However, the focus of this study considered the personal adaptation of the caregiver alone, with the only considered group being that of the caregiver and care recipient dyad. This study evaluated the caregiver's overall adaptation by measuring the level of caregiver burden experienced.

Stimuli

Roy views persons as being “co-extensive with their physical and social environments”, and her model evaluates the adaptation of individuals in light of the contributing factors from their environment (1997, p. 42). The environment to which the person is adapting is further defined as “the conditions, circumstances, and influences surrounding and affecting the development and behavior of persons and groups” (Roy, 1999, p. 19). Hence individuals are in a state of continuous interaction with their environment. Roy further categorizes environmental input as focal, residual or contextual stimuli.

Roy defines a focal stimulus as “the internal or external stimulus most immediately

confronting the human system” (1999, p. 31). In the case of stroke caregivers, the caregiving demands presented by the stroke patients’ altered functional and cognitive abilities form the focal stimuli under examination. The patients’ altered function and cognition are external stimuli to the caregiver.

Roy defines contextual stimuli as “all other stimuli present in the situation that contribute to the effect of the focal stimulus” (1999, p. 31). Contextual stimuli are stimuli that affect how a person deals with the focal stimuli under examination. The caregiver’s level of personal resilience is the primary contextual stimulus evaluated in this study. As previously mentioned, resilience has been evaluated in the past as both a mediator and an outcome. Although resilience can be considered a psychological contributor to the caregiver’s adaptation, it cannot provide a complete evaluation of the caregiver’s cognator subsystem. Therefore, in this study, the trait of resilience will be evaluated as a contextual stimulus.

Other contextual stimuli that may affect the ultimate outcome of caregiver burden will be collected with a demographics form. These include specifics to each individual caregiver including the contribution of assistance with caregiving by either skilled or non-skilled others, amount of respite from caregiving and coexisting caregiver health problems.

Residual stimuli are those stimuli whose ultimate effects may be unknown. The age of the caregiver, collected as demographic data is a residual stimulus. Roy acknowledges the dynamic interaction of the focal, contextual and residual stimuli involved. Therefore it is realized that these stimuli may fluctuate, based on the current situation (Roy & Andrews, 1999). This theory, therefore, lends itself easily to the situation of stroke caregiving, where the focal stimuli may change from one day to the next. However, ultimately the above named stimuli jointly

contribute to the person's adaptation level. Roy further identifies modes and levels of adaptation, which are beyond the scope of the present study.

From a systems theory perspective, behavior is the output or end result of the adaptive process. In addition, the resulting behavior or response may provide feedback for modifying the adaptation process (Roy, 1999). The caregiver's level of burden is evaluated as the output of the adaptive process in this study. The proposed conceptual-theoretical-empirical structure is presented in Figure 1.

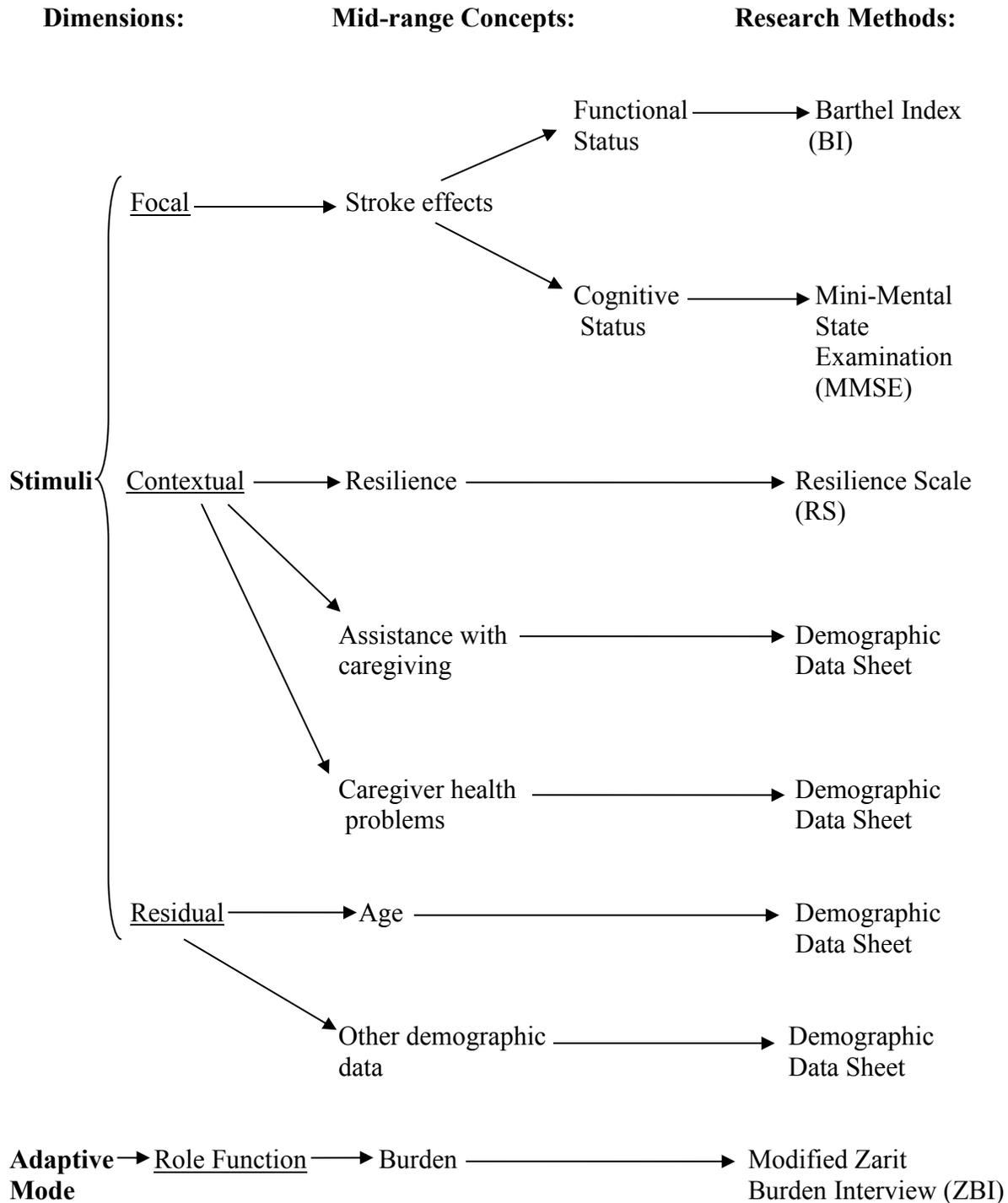


Figure 1. *Conceptual-theoretical-empirical structure*

Research Questions

The following research questions were evaluated by this study:

1. What is the relationship between the functional abilities of stroke patients and the level of burden experienced by their caregivers?
2. What is the relationship between the cognitive function of stroke patients and the level of burden experienced by their caregivers?
3. What is the relationship between caregivers' resilience and their level of caregiver burden?
4. How much of the variance in caregiver burden is explained by stroke patients' functional status, stroke patients' cognitive status, and caregivers' resilience?

Statement of the Purpose

The purpose of this study was to investigate the relationship of stroke patients' functional and cognitive status, and caregivers' resilience to caregiver burden.

Definition of Terms

Stroke

Theoretical definition. A stroke is theoretically defined as “a neurological deficit that has a sudden onset, lasts more than 24 hours, and results from CVD (cerebrovascular disease)” (Hudak, Gallo, & Morton, 1998, p. 687).

Operational definition. This study defined stroke as a pre-existing condition of the care recipient, as diagnosed by their physician or nurse practitioner during a previous evaluation or

hospitalization and validated by either a magnetic resonance imaging (MRI) or a computerized tomography (CT) examination.

Functional Status

Theoretical definition. Venes defines functional ability as “the ability to perform activities of daily living, including bathing, dressing, and other independent living skills, such as shopping and housework” (2009, p. 5). Activities of daily living include the ability to be mobile, dress, feed, keep oneself clean and perform toileting functions.

Operational definition. Functional status was defined in this study as the score obtained on the Barthel Index (Appendix A) by Mahoney & Barthel (1965).

Cognitive Status

Theoretical definition. Cognition is defined as “thinking skills, including language use, calculation, perception, memory, awareness, reasoning, judgment, learning, intellect, social skills, and imagination” (Venes, 2009, p. 481).

Operational definition. Cognitive status was defined in this study as the score obtained on the Mini Mental State Examination (Appendix B), by Folstein, Folstein, & McHugh (1975).

Resilience

Theoretical definition. Resilience is theoretically defined, in its’ purest sense, as “the action or act of rebounding or springing back” (Brown, 1993, p. 2562). Resilience has been theoretically defined by researchers Wagnild and Young as “emotional stamina...used to describe persons who display courage and adaptability in the wake of life’s misfortunes” (1990, p. 254).

Operational definition. Caregiver resilience was defined in this study as the score

obtained on Wagnild and Young's (1993) Resilience Scale (RS) developed for use with older adults (Appendix C).

Caregiver

Theoretical definition. Theoretically, a caregiver is a person who provides care to someone who is either completely or partially dependent (Venes, 2009, p. 373). Examples of providing care include providing assistance with activities of daily living such as dressing, eating, bathing, toileting, and ambulating, or assisting the patient with their instrumental activities of daily living such as assisting with their medications or shopping.

Operational definition. A caregiver was defined in this study as an adult who was providing financially-uncompensated care for a person who had experienced a stroke.

Caregiver Burden

Theoretical definition. Caregiver burden is the subjective belief that one does not possess the required resources to sufficiently meet the demands that are placed upon them by the caregiving role (O'Rourke, & Tuokko, 2003).

Operational definition. Caregiver burden was defined in this study as the score achieved by the caregiver on the Zarit Burden Interview (ZBI) (Zarit, Reever, & Bach-Peterson, 1980), as modified by Bedard, et al. (2001) (Appendix D).

Research Hypotheses

The following hypotheses provided the structure and focus of this study, measuring the relationship between the independent variables of stroke patients' cognitive status, stroke patients' functional status, and caregivers' resilience level and the dependent variable of

caregiver burden.

- H1: There will be an inverse relationship between the functional status of the stroke patients and caregiver burden.
- H2: There will be an inverse relationship between the cognitive status of the stroke patient and caregiver burden.
- H3: There will be an inverse relationship between caregivers' resilience and caregiver burden.
- H4: A significant amount of variance in caregiver burden will be explained by the combination of stroke patients' functional status, stroke patients' cognitive status, and caregivers' resilience.

Significance of the Study

This study's research significance is that it has the potential to broaden the understanding of factors that contribute to caregiver burden as well as the effect of resilience in the stroke caregiving situation. This study sought to determine if relationships existed among stroke patients' functional and cognitive level, caregivers' resilience level, and caregiver burden. The identification of factors which contribute to or minimize caregiver burden has implications, not only for nursing, but also for health professions as a whole.

One of the goals of nursing is to assist patients in achieving the highest level of function possible. In view of the long-term recovery or adaptation process in stroke patients, it is not feasible for this process to be accomplished on a continuing in-patient basis. As most informal caregivers are friends or family of those receiving care, the caregiver has an emotionally-vested

interest to support the care recipient through the process of recovery or adaptation to his or her new reality of daily living. Therefore, supporting caregivers in the caregiving process optimizes the potential recovery of stroke patients. This ultimately helps to keep stroke patients in the home environment for their non-acute care.

However, caregiving has been shown to have consequences (Fredman & Daly, 1997; Riedel, Fredman & Langenberg, 1998). In identifying the contributory factors to caregiver burden, this study may assist in the early identification of those caregivers at highest risk for experiencing burden and needing nursing intervention. Knowledge of burden's contributing factors allows health care providers to intervene at an early stage with burdened caregivers, potentially preventing health alterations in caregivers and a possible breakdown in the caregiving process.

Assumptions

The assumptions of this study included the following:

1. Caring for a stroke patient can cause burden in their caregiver.
2. Responses given by caregivers and care recipients will be truthful.

Summary

The effect of stroke patients' functional and cognitive deficits on their informal caregivers' burden level is not fully established. It is known that caregiving is often characterized as burdensome but the effect of resilience in the caregiving situation has not been studied. This chapter laid the foundation for the study of these factors' interrelationships.

CHAPTER II

Review of the Literature

The purpose of this study was to investigate the relationship of stroke patients' functional and cognitive status, and caregivers' resilience to caregiver burden. The acute care phase of stroke and the etiology of stroke were beyond the scope of this study. Therefore, this review of the literature addresses pertinent issues related to the post-stroke experience, and caregiving of the stroke patient. The review of literature is organized as follows: (a) stroke, (b) resilience, (c) caregiving, (d) caregiver burden, and (e) summary of the existing literature.

Stroke

Incidence and Prevalence

The American Heart Association estimates that an individual in the United States experiences a cerebrovascular accident (CVA) or "stroke" every 40 seconds (AHA, 2009, p. 72). This is a testament to the large number of Americans for whom stroke is a personal reality. As of 2009, there were an estimated 6.5 million stroke survivors in the United States (AHA, 2009). These statistics refer to those who experience a symptomatic stroke each year, but it has been estimated that up to 11 million persons annually experience their first "silent" stroke, in which the patient is asymptomatic (Leary & Saver, 2003).

Of the 795,000 strokes experienced each year, 87% (692,000) are of ischemic etiology, while the remaining 13% (103,000) are of hemorrhagic origin (AHA, 2009). Fortunately, ischemic stroke evidences a lower mortality rate than hemorrhagic stroke. Approximately 45% of persons over 65 years of age experiencing hemorrhagic stroke will die within a month, as

compared to 8% of persons with ischemic stroke (El-Saed, et al., 2006). Studies of mortality in younger stroke patients reveal that from 45 to 65 years of age, 8-12% of ischemic stroke patients, and 37-38% of hemorrhagic stroke patients die within the first month post stroke (Rosamond, et al., 1999). This means that between 55% and 92% of those over 65 years of age and 62% and 92% of those from 45 to 65 years of age survive post-stroke, with varying levels of alteration in cognitive and/or physical abilities, leaving the stroke victim and his or her caregiver(s) with long-term consequences. Given the “aging” of American society, the number of stroke survivors is expected to significantly increase in the coming decades, despite advances in treatment and prevention of acute CVA.

Demographics

Frey, Jahnke, and Bulfinch (1998) evaluated the demographics of stroke at a large neurological institute with 1,716 patients seen over a seven-year period of time. As a result of the study’s setting, the sample showed a preponderance of Caucasian, Hispanic and Native American patients. In keeping with the population of the area, few African American or Asian subjects were seen; therefore their data were insufficient to merit evaluation for those populations. Frey et al. found that the mean age for the onset of stroke was highest in Caucasians, followed by Hispanics, and that Native Americans stroked at a younger age than all others. Each of the different ethnic groups had the same risk factors, but at significantly different levels. The only exception to this was a history of hypercholesterolemia, in which all groups were equal.

Stroke has been shown to disproportionately affect people of different ethnicities and people of color (Stansbury, Huanguang, Williams, Vogel, & Duncan, 2005). Given the fact that

minority groups in this country have higher rates of stroke than the white population, Elkind (2003) suggested that stroke prevalence may have been underestimated by as much as 50% in past years. Elkind's claim is given credence by studies of stroke prevalence, which were conducted by the National Heart, Lung, and Blood Institute (2006). During the 14-year period of time from 1987-2001, the National Heart, Lung, and Blood Institute (NHLBI) reported that black men under the age of 55 experienced stroke or transient ischemic attack at a rate of over four times the rate of white men of the same age. The trend was similar for black women, who had strokes at three times the rate of white women. During the next decade of life, the rate for both black men and women dropped from quadruple to double the rate of stroke in white persons. After age 65, the rate of stroke in black men and women dropped to approximately one and one half times that of white persons of the same age group (NHLBI, 2006, p. 20).

Stroke prevalence studies reveal there are also differences in the rate of strokes between men and women, and that these differences are comparable in other countries as well. Appleros, Stegmayr, and Terent (2009) conducted a review of the literature from 19 countries to determine sex-differences in the epidemiology of stroke. They found that the average age of stroke onset was 68.6 years for men and 72.9 years in women. Furthermore, they found that the incidence of stroke is 33% higher in men than in women, but that women experienced more severe strokes, and had a 25% higher death rate than men. Reeves, et al. (2008) note however, that women over the age of 85 experience stroke at triple the rate of men. Despite the death rate of women after stroke, Gresham, et al., (1998) in their evaluation of long term stroke survivors found that nine out of ten women who survived stroke for an average of 27.4 years still had excellent functional status.

Stroke Outcomes

Given the significant number of persons who have died as the result of a CVA in years past, emphasis has been placed on the early identification of and intervention with acute stroke patients. Toward that goal, the American Stroke Association—formed in 1997—launched initiatives to disseminate information about stroke to the public (Fedder, 2008). Subsequently, the Center for Disease Control and Prevention (CDC) developed a system of state-based registries for tracking the treatment of acute stroke, establishing the Paul Coverdell National Acute Stroke Registry in 2001. Participation in this federally-funded registry is voluntary, and 11 states currently participate. The mission of the registry has been to limit stroke sequelae by improving care during the acute phase of stroke treatment (CDC, 2009, para.2).

Unfortunately, focus on the acute phase of stroke does not address the needs or experiences of the patient after the stroke has occurred: the chronic phase of stroke disability. There is currently no mandatory national databank established that tracks or characterizes the disabilities of the millions of persons who are stroke survivors; therefore the true percentage of stroke patients—who have purely functional deficit or purely cognitive deficit, or a combination of both—remains unknown.

Each survived episode of stroke has the potential to manifest with the impairment of functional status, cognitive status, or both. The magnitude of these potential alterations can be overwhelming for both the individual and the caregiver. Functional and cognitive status alterations may also be interwoven in a stroke, as the brain must be able to interpret what is being asked of it before the body can respond to any given situation. Despite that, in order to plan for treatment and care, an attempt is made to define functional and cognitive abilities as

distinctively different from one another.

Impaired functional status, as the result of stroke, indicates that the patient may lose all or part of his/her ability to carry out basic physical function tasks. These functional tasks may include: the ability to feed and clothe oneself, control bowel and bladder function, speak, read and/or write, or the ability to control limb movement (McCance & Heuther, 2002, p 507-9; Venes, 2009, p 2222-3). Loss of these functional abilities potentially necessitates complete care by another person for survival.

Impaired cognitive status indicates potential alterations to the individual's sensory perception, thinking abilities, memory, personality, and emotional status (Venes, 2009, p. 481). The result of loss of one's cognitive abilities not only necessitates complete care by another, but can also result in the loss of the stroke patient's unique identity and personality. These stroke-related disabilities can be all-encompassing; any or all of the person's former abilities may be absent after he or she experiences a stroke. Furthermore, since persons who survive stroke commonly experience subsequent strokes, it is important to note that their abilities can potentially deteriorate with each occurrence.

The American Heart Association estimates that 15-30% of persons who experience a stroke will evidence some permanent form of disability: either physical impairment, cognitive impairment or both (2001, p. 15). Moreover, Asplund, Stegmayr, and Peltonen (1998) project that approximately 20% of stroke patients will continue to require institutional care three months after their stroke, due to the severity of their disabilities. In contrast to the statistics of the United States, however, Hafsteinsdottir and Grypdonck's (1997) review of research studies in the United Kingdom reflect that about two-thirds of stroke patients die within a month and that

approximately two-thirds of the survivors evidence a permanent disability.

Kelly-Hayes, et al. (2003) evaluated ischemic stroke survivors of the Framingham study six months post-stroke and found significant disabilities. Among those disabilities experienced were hemiparesis (50% of the sample), aphasia (19%), inability to walk without assistance (30%), and ADL dependency (26%). Furthermore, the disabilities seen in this study were so significant that 26% of the ischemic stroke survivors studied still required institutionalized care six months post-stroke, significantly exceeding the earlier projections of Asplund, Stegmayr, and Peltonen (1998).

Co-morbidities associated with stroke outcomes

In a study of post-stroke functional and cognitive status and co-morbidity differences by ethnicity, Haan and Weldon (1996) found significant differences between non-Hispanic white, and English-speaking and Spanish-speaking Hispanics. Both English-speaking and Spanish-speaking Hispanics experienced more functional disability in basic activities of daily living (ADL) and instrumental activities of daily living (IADL) than non-Hispanic whites. Further, among the subjects whose education was less than 8th grade level, Spanish-speaking Hispanics displayed significantly lower scores on the Mini-Mental State Exam than the other groups. This result was not seen in those whose education was greater than 8th grade level. Finally, those post-stroke Hispanic patients, who also had two or more co-morbidities, evidenced significantly higher levels of functional disability in both ADLs and IADLs than matched non-Hispanic whites with similar co-morbidities.

In their study of types of stroke and its outcomes, Frey et al, (1998) found lacunar infarcts to be significantly more prevalent in the Native American population; hemorrhagic infarcts were

significantly more common in Hispanics; and cardioembolic strokes were more commonly seen in Caucasians. The majority of strokes, however, are atherothrombotic in nature, and there was no difference seen between ethnic groups in the occurrence of this type of stroke. The evaluated outcome for stroke with all groups combined found that those who suffered lacunar stroke had the greatest chance of recovery, followed by those with cardioembolic or atherothrombotic stroke. The least favorable outcome for all patients was seen in those with hemorrhagic stroke. The authors defined a “favorable” outcome as a discharge to either a home environment or a rehabilitation facility, as opposed to an “unfavorable” outcome of discharge to a nursing home or death (Frey et al, 1998). Although data relating to stroke etiology are gained in this study, little data are provided detailing the functional or cognitive status of patients with a “favorable” outcome.

The presence of preexisting comorbidities has been shown to negatively affect the functional outcome of stroke patients. In a large multicenter study, Weimar, Ziegler, Konig, and Diener (2002) found that diabetes, older age, and fever within three days of stroke were predictive of long-term functional dependency or death after stroke. Further, history of a prior stroke, as well as arm weakness 48 hours post-stroke, and cognitive deficit on arrival at the hospital were found to be predictive of not recovering functional independence. Female gender, however, was associated with functional recovery. Their finding—that a history of stroke is significantly related to not recovering functional independence—is of further concern when reflecting upon the study of Leary and Saver (2003), who estimated that approximately 11 million persons annually experience a first stroke which is asymptomatic.

In a subsequent study, Bushnell, Lee, Duncan, Newby, and Goldstein (2008) evaluated

105 women to study the effect of co-morbidities on functional recovery post-stroke. Similarly, they found that higher scores on a co-morbidity index were associated with lower functional abilities three months after the stroke. Diabetes and coronary heart disease were evaluated independently of the comorbidity index and determined to be correlated with lower functional ability as well, validating the findings of Weimar, Ziegler, Konig, and Diener (2002).

Family history has been evaluated to discern if there is a relationship between having a family history of stroke and stroke patient outcomes in first-stroke patients. Hertzberg, Weiss, Stern, and Frankel (2006) found that a family history of stroke correlated positively with a younger age at the time of an initial stroke, increased stroke severity, diabetes, and hypertension, but negatively with a history of coronary heart disease and congestive heart failure. However, in those participants younger than 65 years of age, positive family history of stroke was associated with having less functional disability at the time of discharge, and being discharged directly to home. There was no correlation seen between positive family history of stroke and mortality. Alternately, Lisabeth, Smith, Brown, Uchino, and Morgenstern (2005) found no difference in the prevalence of risk factors for stroke between those with a positive family history of stroke and those without history. Contrary to the findings of Hertzberg, Weiss, Stern, and Frankel (2006), a positive family history of stroke was associated with less functional recovery in the study by Lisabeth, Smith, Brown, Uchino and Morgenstern (2005).

Studies have also found relationships between cognitive status and functional ability level. Bassett and Folstein (1991) evaluated community dwelling adult patients in an attempt to find the relationship between psychiatric diagnosis and level of cognition. They found that cognitive status was most predictive of functional ability in their study population. Similarly,

Ford, Haley, Thrower, West and Harrell (1996) found that cognitive status—as measured by the Mini-Mental State Exam—was predictive of functional abilities in their study population of white and African American demented patients.

These interrelationships have also been demonstrated in stroke patients. Kelly-Hayes, Jette, Wolf, D'Agostino, and Odell (1992) evaluated functional level in elderly persons and found that functional level was significantly predicted by cognitive level and a past history of stroke. Finally, Hinkle (2006) studied a population of patients post-stroke with functional deficits, and found that initial functional level, age and cognitive status predicted a significant amount of the variance in the recovery of function at 3 months post-stroke.

Measurement of post-Stroke Functional Disability

Of the 25 tools identified by the US Agency for Health Care Policy and Research for assessment of stroke function, one of the most commonly used is the Barthel Index (Mahoney & Barthel, 1965). The tool was originally designed to evaluate patients at regular intervals with chronic musculoskeletal or neuromuscular disorders, in order to assess their potential for independence in self-care. The Barthel Index (BI) is considered ideal for evaluation of post-stroke patients, and it is the tool against which many functional ability scales are evaluated (Green, Forster, & Young, 2001; Hsueh, Lin, Jeng, & Hsieh, 2002; Kwon, Hartzema, Duncan, & Lai, 2004; Schuling, de Haan, Limburg, & Groenier, 1993). The BI is a proven, reliable tool for assessing stroke patients (Loewen, & Anderson, 1988; Cohen, & Marino, 2000).

The original Barthel Index (Mahoney & Barthel, 1965) was comprised of ten questions designed to evaluate the patient's ability to perform tasks reflecting normal activities of daily living. Each question was scored with a zero, if the patient was unable to perform the task at all.

If the patient was either independent, or could perform the activity with assistance, scores of 5, 10, or 15 were assigned, depending on the question. The total maximum score for the tool was 100 points, with higher scores indicating more independence in functional abilities, and lower scores reflecting less functional ability.

In the years since the introduction of the original BI, there have been three other commonly used versions of the BI modified by other researchers, each of which is still referred to as the Barthel Index. These include: (1) the modified ten-item version of the Barthel Index (Collin, Wade, Davies, & Horne, 1988) with possible total scores from 0 to 20; (2) the five-item Barthel Index (Hobart & Thompson, 2001), with a total possible score of 20; and (3) a twenty-item expanded version of the Barthel Index with a possible total of 100 points (Shah, Vanclay, & Cooper, 1989). As each of these tools is referred to as the Barthel Index, it is often unclear as to which of the tools is being used in any given study.

There are also several other versions of the BI which have been neither widely-used nor well-documented. This further compounds the difficulty in comparing studies using the BI. In their evaluation of the use of the Barthel Index in stroke trials, Quinn, Langhorne, and Stott (2011) have recommended that the original version of the BI (Mahoney, & Barthel, 1965) be adopted as the standard to be used in future stroke studies. This would bring clarity to comparisons of the results of these studies.

The primary limitation of the BI cited in studies is that it demonstrates so-called “floor and ceiling” effects. That is to say that the tool is not sensitive enough to discriminate between levels of functional difference at very low levels of function (floor effect) and very high levels of function (ceiling effect) (Dromerick, Edwards, & Diringer, 2003; Quinn, Langhorne, & Stott,

2011). However, in past studies, the Barthel's responsiveness in detecting meaningful change in level of function has been shown to be similar to other measures of physical function (Hsueh, Lee, & Hsieh 2001).

Measurement of Post-Stroke Cognitive Disability

One of the most widely used tools for assessing cognitive status is the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975). The tool was initially developed to provide clinicians with an easy, concise examination of the cognitive status of patients with various disorders. The authors of the tool state that it is not designed to assess psychiatric disorders—such as mood disorders or altered thought processes—but to assess changes in cognition alone. The tool was initially tested on the inpatients of a neuro-geriatric ward, who suffered from delirium and dementia due to various disorders, and a comparison group of age-matched community-dwelling older adults. The study validated the MMSE by comparing it with the Weschler Adult Intelligence Scale (WAIS). One of the reasons for development of the MMSE was to provide a more easily administered, rapid tool for evaluating cognition as compared to the WAIS. The MMSE tool was shown to be a reliable, valid measure of cognition that was easily utilized by physicians and nurses.

The MMSE tool consists of 11 questions which require either a verbal response—e.g., orientation, doing serial calculations, or demonstrating short term memory—or a response by performing a task—e.g. naming an object shown, writing a sentence or drawing a polygon. The total possible score on the tool is 30, with 21 points dependent upon the verbal responses, and the remaining nine points dependent on performance-based responses. Higher scores on the MMSE indicate higher cognitive abilities. As this tool was originally tested on older, adult patients with

cognitive changes, it is a logical choice for use in evaluating patients post-stroke.

As indicated in a previous discussion of post-stroke patient status by Haan and Weldon (1996), the MMSE has been shown to demonstrate scoring differences in patients with varying levels of education, as well as persons of different ethnicities. Additionally, the age of the patient being evaluated has also been shown to affect the MMSE score. Crum, Anthony, Bassett, and Folstein (1993) evaluated a large population of adults, varying in age from young adulthood to older adults, and demonstrated that age as well as educational level affected scoring on the MMSE.

Finally, gender has been shown to affect the MMSE score in a healthy population. In reevaluating previous study results by Measso, et al., (1993), Grigoletto, Zappala, Anderson, and Lebowitz (1999) found that the MMSE scores of young healthy females were higher than those of same-aged males, but significantly lower for older females than same-aged males. Hence, females' MMSE scores were more affected by age than males' scores in their study sample.

Rare studies have taken issue with use of the MMSE in evaluating stroke patients. In an attempt to evaluate the validity of the MMSE, Nys et al. (2005) evaluated 34 hospitalized acute stroke patients with a matched set of healthy controls. They found no relationship between age, educational level, and prior level of cognition and the MMSE score; moreover, they found it to be insensitive to significant neurological impairment. Despite the findings of Nys, et al. (2005), the MMSE continues to be one of the most commonly utilized tools to evaluate stroke patients' cognitive level.

Resilience

Background

Norman Garmezy is considered to be the founder of modern resilience research. His pioneering studies, published in the early 1970's, focused on children who came from highly stressed backgrounds, yet who displayed the ability to adapt, and even succeed in their life experiences. In an interview with Rolf, Garmezy described resilience as a collection of protective factors that is comprised of both "psychological elements and biological predispositions" (1999, p. 13). However, as the focus of his studies implied, the demonstration of resilience is dependent on having experienced a stressful situation or condition in the past.

Rutter (1985) also described resilience as the result of possessing certain protective factors, but further as existing on a continuum, and as the polar opposite of vulnerability. He later described resilience as a buffering factor against stress (1987). Jacelon (1997) similarly described resilience as a trait manifested by one's ability to overcome adversity and return to normal coping ability. Finally, Kadner (1989) listed ego strength, resourcefulness, and social intimacy as coexisting requisites of resilient persons.

Resilience is a multifaceted concept, characterized by each researcher in slightly different manner, yet with some overlap with other researchers. For example, resilience has been studied as an inherent quality or trait possessed by those who unexpectedly resist negative stressors, despite overwhelming difficulties (Garmezy, 1974). From this perspective, resilience is viewed as a mediating factor. This characterization of resilience was used in this study. Alternately, resilience has been studied as an outcome criterion or as a process unto itself (Glantz & Sloboda, 1999; Kaplan, 1999).

Resilience is also a construct that incorporates psychological, biological, and social factors. Personality, temperament, intelligence, and social competence are all believed to be components of resilience. Studies have even suggested that physical attractiveness (as part of the global concept of social competence) is associated with resilience (Heinzer, 1995). As a result, some researchers have suggested abandoning the overarching concept of resilience in favor of studying more discrete phenomena: components of resilience that more easily lend to direct measurement (Kaplan, 1999; Tarter & Vanyukov, 1999).

In their review of the existing research, Glantz and Sloboda found that resilience has also manifested differently in research studies:

There does not appear to be any credible evidence that there is a single quality or circumstance, and certainly not a single universal factor of resilience that is beneficial in most if not all circumstances. In fact, at least in some cases, it seems that the qualities and circumstances which contribute to a positive outcome in one situation may be irrelevant or even counterproductive in another. (1999, p. 115)

Despite this, research into the trait identified as resilience continues, and belief in the concept as a contributory factor to positive outcomes persists.

Most of the current studies of resilience focus on determining protective factors or processes in specific populations, based upon Rutter's concept. Studies have been conducted to evaluate resilience in those with chronic disease, and in immigrant or minority populations (Christopher, 2000; Davis, 2000; Siegel, & Meyer, 1999; Taylor, 2000). However, the overwhelming majority of resilience studies are still predominantly conducted with adolescent or pediatric populations.

Dyer and McGuinness (1996) published their conceptual analysis of resilience, in which they defined resilience as a “dynamic process” that requires specific competencies to have developed in a person’s individual, interpersonal and familial life. Dyer and McGuinness likened these competencies to the protective factors suggested in Garmezy’s (1985) research. Dyer and McGuinness identified the critical attributes of resilience as: the ability to rebound from adversity and continue on, a sense of self that is in proper perspective, personal determination, and a positive attitude towards others. As with other authors, they stipulated that developing resilience was dependent on having experienced adversity in the past, but added that it also depends on having interaction at some point in the past with a caring individual. Although they have published further studies based upon their concept analysis, their studies have focused on the pediatric population, including studies on foreign-born adopted children (McGuinness, McGuinness, & Dyer, 2000). Therefore, the applicability of their results to a study of adult resilience is limited, as it has not been validated in an adult population.

Polk (1997) published a concept synthesis of resilience to develop a nursing mid-range theory on the topic. Based on a synthesis of 26 articles primarily from the field of child and adolescent psychology, she defined four categories of characteristics of the resilient individual. The four categories are: dispositional pattern, philosophical pattern, relational pattern, and situational pattern. Comparison of the four patterns identified with the numbers of children/adolescent studies vs. adult based studies displayed somewhat of a dichotomy in categorization. Disproportionately, the adult studies demonstrated qualities of resilience that were categorized in the philosophical pattern, while significantly more children/adolescent studies described qualities categorized as dispositional pattern. One of the underlying

assumptions of the synthesis was that resilience could be similarly characterized in persons of all ages. However, it seems that although there may be some areas of overlap, persons in different phases of life may indeed manifest resilience differently.

Polk (2000) subsequently published her own resilience scale, incorporating the previously published concept synthesis. Indeed, the sample in which Polk's theory was eventually tested was an adolescent population (2000), bringing into question its applicability in a study of older adults. Polk's theory characterizes resilience, but it is likely that it captures the essence of resilience most clearly in the pediatric and adolescent population. Hence, although her study provides nursing with a model of resilience and a tool for measuring adolescent and pediatric resilience, it is of limited use to this study.

Wagnild and Young (1990) qualitatively studied and described the characteristics of 24 well-adjusted older women (mean age 78) who were active participants in a senior citizens center. Each of the participants was asked questions regarding how they have coped with difficulty in the past. They were asked to relate a significant loss in their lives, how they responded at the time, and how they managed both at that difficult time and in the difficult times since that experience. The older women that were interviewed mentioned sources of strength that allowed them to cope, including: faith, a sense of humor, determination, having family and friends to support them, and having hobbies such as gardening, and music.

Adams (1998) conducted a qualitative study of ten persons 85 years of age and older to identify components of resilience in their lives. As studies of childhood and adolescent resilience often find, the elders reported stable relationships in childhood and adulthood to be foundational to their resilience. Adams also identified spirituality, socialization, staying

physically and mentally active, and maintaining a healthy diet as some of the common factors that contributed to resilience in his study participants. Adams also found his participants displayed the personal characteristics of perseverance, stamina, a sense of purpose, and courage. The elders related that they believed worrying served no purpose, and they focused on things that were within their control rather than things that were not. Similarities are seen in some of Adams' findings when compared to those of Wagnild and Young.

A similar study by Felten (2000) qualitatively examined women over 85 years of age. Felten's study defined resilience as "the response of rebound and improvement in function after devastating illness" (2000, p. 102). Her study found that the older women, despite being frail, maintained strong social connections, and believed in caring for themselves as well as others. All of the participants had past experiences with hardship, although of varying types. Felten identified determination and social support as contributing factors to resilience as in Wagnild and Young's study. However, Felten found that unlike the women in Wagnild and Young's study, her participants related that they actively planned their resilience, noting that it was not coincidental (2000).

Resilience Measurement

Wagnild and Young (1993) subsequently developed the Resilience Scale to quantitatively measure resilience in adults. In evaluating their tool, Wagnild and Young surveyed 810 community-dwelling elders with a mean age of 71 years, validating it with existing tools to measure life satisfaction, morale and subjective well-being, depression, and physical health. The relationships between age, gender, income, education and resilience were non-significant. However, resilience was significantly related to positive coping methods such as high morale,

satisfaction with life, and maintaining good health. Depression was significantly negatively related to resilience. Wagnild and Young also compared this study to findings of adult resilience in five previously conducted unpublished studies that each individually validated the tool. The tool has subsequently been translated into other languages for use in other cultures (Aroian, and Norris, 2000; Aroian, Schappler-Morris, Neary, Spitzer, and Tran, 1997). As all stroke caregivers evaluated in this study were adults, and often older adults, Wagnild and Young's Resilience Scale was chosen to evaluate caregivers in this study.

Few studies have examined resilience in caregiving. Mannion (1996) qualitatively evaluated spouse caregivers of the mentally disabled and described them as possessing family resilience, personal resilience, and consumer resilience based on their adaptation. Gaugler, Kane and Newcomer (2007) evaluated dementia caregivers, evaluating resilience as the amount of perceived burden experienced with high caregiving demands. However, resilience was not actually measured. McNurlen (1996) evaluated protective factors contributing to resilience in the parent-caregivers of resilient children. But, to date, no quantitative studies have been found that both evaluate and directly measure resilience in stroke caregivers.

Caregiving

Demographics of caregiving

In 1997, Robinson projected that approximately 2.1 million persons would be family caregivers by 2001. Robinson predicted that a large number of family caregivers would continue to work during their caregiving, and that 32% of family caregivers would be categorized as poor or near-poor. Twelve years later, in 2009, The National Alliance for Caregiving (NAC)

published an updated national study of the prevalence of American caregiving. According to their report, approximately 65.7 million U.S. households were providing caregiving services in which informal (not financially compensated) caregivers were utilized for provision of care. Of this number, approximately 43.5 million involved provision of care for someone who was 50 years of age or older (NAC, 2009). Myriad caregiving circumstances exist, with care recipients being cared for by a parent, a friend, an adult child, an adult child's spouse, a partner, or a spouse. Each of these situations brings different stresses to the caregiving relationship.

The NAC's 2009 study found that those caregivers who were providing the highest level of care were more likely to be female, and at least 65 years of age, as compared to those who provided less involved care. Those high-level caregivers were more likely to be retired and the spouse of the care recipient, as well. Thirty-one percent (31%) of high-level caregivers reported personal physical or mental health problems as a result of their caregiving, and yet a higher number (53%) reported they experienced emotional stress from their caregiving endeavors. Those caregivers listed significantly higher levels of physical strain than other caregivers and 21% stated that their caregiving posed a financial hardship for them as well (2009, p. 23-24). The NAC study noted that high-level care providers are more likely to list dementia or stroke as the main reason for the required intensity of their caregiving (2009, p.14). Of interest is that African American caregivers in this study reported a higher incidence of stroke than other ethnic groups as the reason for their level of caregiving, with 12% being stroke survivors, as opposed to the 7% high-level caregivers of stroke patients by other ethnic groups. This finding is not surprising given that African Americans have a significantly higher rate of hypertension and stroke than other ethnicities (AHA, 2009, p. 72).

The National Heart, Lung and Blood Institute's Framingham Heart Study estimated from 50-70% of CVA patients experience or regain functional independence after stroke recovery (as cited by AHA, 2001, p. 15). But the term functional independence does not convey the subjective level of disability that a patient may have and still be termed independent. Conversely, as previously cited (Asplund, Stegmayr, & Peltonen, 1998), it was estimated that at least 20% of stroke patients would require institutionalization for care three months post-stroke. These statistics seemed to imply that a small number of stroke patients would require long-term skilled care. However, when nursing home patient data were examined by Sahyoun, Pratt, Lentzer, Dey and Robinson (2001) they found that the percentage of patients admitted to nursing homes with the overarching diagnosis of cardiovascular disease (including stroke) has remained constant over time, and that functional decline and cognitive impairment are among the most common reasons for placement.

Sahyoun et al. (2001) found that the functional level of the average nursing home resident had decreased, and the average number of activities of daily living (ADLs) with which the nursing home resident required help had risen to 4.4 ADLs (out of a total of six possible), from 3.8 ADLs over the previous 15 years. This indicates that the patients admitted for extended care were more disabled than in years past, and by reflection, that patients in home caregiving were also more disabled than in past years. Further, Sahyoun et al. (2001) found that nursing home residents are discharged in half the time of 12 years prior, with the average time for care dropping from 89 days to 45 days.

The trend to discharge patients to spousal caregivers as early as possible has been substantiated in research as well. In evaluating results of the 1985 National Nursing Home

Survey, Freedman (1993) discovered that male nursing home residents who had a living wife were discharged to home approximately four months earlier than those who did not. In fact, having a wife was also found to be associated with an overall increased rate of discharge from the nursing home (Freedman, 1993). However, the study did not find a difference in discharge times for men having a living child versus those who did not.

Caregiving Demands

The experience of caregiving presents both rewards and costs to the caregiver, but coping is a significant component of all caregiving situations. Studies focusing on the transition from hospital care to home care have shown that providing support and education is helpful to the caregiver, but few caregivers feel prepared for the initial demands of home caregiving (Weaver, Perloff, & Waters, 1998; Arts, Francke, & Hutten, 2000). Picot's study of African American caregivers (1995) investigated the methods of coping used in the caregiving role, and discovered that perceived (personal) cost, perceived (personal) reward, and quality of social support were better predictors of the method of coping used than caregiving demands, income, or relationships in that population.

Bakas and Champion (1999) compared two analyses of stroke caregivers in which they found that adult child caregivers for functionally and cognitively impaired stroke patients experienced more negative caregiving outcomes in their lives than caregiving spouses. Specifically, Bakas and Champion found that those adult child caregivers who perceived little benefit from their caregiving, and experienced emotional distress from the process were more likely to experience a high level of negative caregiving outcomes, as manifested by negative changes in their personal well-being, health, and social interactions.

The sense of loss of self to the role of caregiving is a common theme. Grant and Davis' (1997) qualitative study discovered that stroke caregivers experienced a sense of "self loss" when establishing themselves in the caregiving process. This loss of self was manifested in four subcategories of personal loss that reflected overwhelming changes to the caregiver's life. Similarly, Secrest (2000) described the process of change in the relationship between stroke patient and caregiver as part of the caregiving process. Her phenomenological study uncovered themes of caregiver fragility, vigilance, the sense of loss, and responsibility that develops in the caregiving process over time.

Obviously, patients with cognitive alterations require more attention and care than do patients without cognitive impairment. The National Alliance for Caregiving survey (NAC, 1997) reported that caregivers who were providing care for greater than 40 hours per week related that the primary reason was dementia and/or stroke of the care recipient. This group of caregivers was more commonly at least 65 years of age, retired, and caring for a spouse (whose average age was 77), as compared to caregivers providing fewer hours of care. A study by Stewart, Doble, Hart, Langille, and MacPherson (1998) found that 85% of stroke caregivers found the continual vigilance required and behavioral and emotional reactions of cognitively impaired patients to be a major concern in their caregiving.

In their study of 204 elderly caregiver/disabled care-recipient dyads, Yates, Tennstedt and Chang (1999) found that the number of hours of care provided was significantly, but indirectly, related to the development of depression in the caregiver. When evaluated in light of the NAC study, it suggests that those caregivers who are providing care for high-needs stroke patients, especially those who are cognitively impaired, are at high risk for development of

caregiver depression. Yates, Tennstedt, and Chang also found that emotional support and the presence of a quality relationship with the care recipient were effective mediators in preventing caregiver depression.

Social support has been hypothesized as a potential mediator in negative caregiving outcomes. Men and women caregivers are noted to use different aspects of social support, with men more likely to use formal care than women, and indeed to go through a different cognitive and emotional process in making the decision for institutionalization of their loved one (Coe & Neufeld, 1999). Miller and Guo (2000) found that Caucasian, male, spousal caregivers were more likely than all other groups to receive emotional support in their caregiving (especially from their children) and also to receive practical technical assistance from formal organizations. However, Li and Seltzer (1997) found daughter caregivers received more social support than wife caregivers.

Alternately, multiple studies acknowledge that formal social support is not an effective mediating factor for home caregivers. Richardson, Warburton, Wolfe and Rudd (1996) studied the effects of a support service in which stroke patients and their family caregivers were given caregiving advice, information, and emotional support in the early post-stroke period. No significant differences were seen in those receiving the provided support as compared to a control group who received information from the hospital in preparation for discharge. Similar results were seen by Forster and Young (1996), who hypothesized that use of a nurse support team would improve psychosocial outcomes, improving social integration and perception of health in stroke patients, and encouraging adjustment for both the patients and their caregivers. The use of nurse support teams, who provided counseling and emotional support, produced no

significant differences from a control group that did not receive support nurse visits.

Respite from caregiving has been viewed as a strategy for relieving some of the burden of caregiving, preventing negative caregiving consequences. Strang and Haughey (1999) qualitatively studied the process of caregiver respite in ten dementia caregiving families. They uncovered three phases of the respite process: recognition of the need for respite, giving self-permission for respite, and realizing the availability of respite resources. Caregivers found adult day-care type programs did not provide respite, but instead time to accomplish tasks such as shopping or housework, and hence little relief, if any. Conversely, longer respite times were associated with times of institutionalization of the care recipient, when the caregivers were assured of the safety and care of their demented loved one.

Based on previous studies that indicated a higher prevalence of depression in stroke caregivers, Dennis, O'Rourke, Lewis, Sharpe, and Warlow (1998) evaluated 222 stroke patients and the emotional outcome of their caregivers, six months after discharge. They found that 55% of the caregivers suffered depression or anxiety six months after assuming caregiving responsibilities, and caregivers of those who had a subsequent stroke were more depressed than caregivers of first-stroke patients. Additionally, stroke severity was positively correlated with caregiver depression level as well. In their review of the classic literature of stroke caregivers, Han and Haley (1999) acknowledged the finding that depression rates are high among stroke caregivers, as evidenced in multiple studies. Wright, Hickey, Buckwalter, Hendrix and Kelechi (1999) echoed this finding in their evaluation of physical and emotional health in spousal caregivers of newly-diagnosed stroke and Alzheimer's disease (AD) patients. Wright et al. found that spousal caregivers of stroke patients experienced a lower rate of depression than AD

caregivers initially, but in the subsequent year, the number of Caucasian, depressed stroke caregivers climbed from 11% to 18%. At the same time, African American stroke caregivers experienced a higher level of depression at time of diagnosis, but fewer were experiencing depression at the six-month period of caregiving.

Qui and Li (2008) evaluated 92 Chinese stroke caregivers to determine factors associated with caregiver depression, which was found in 44.6% of their stroke caregiver sample. They found that caregiver depression was predicted by the stroke patient's functional status and the particular coping strategies employed by the caregiver. Furthermore, depression was also significantly correlated with patients' cognitive status, family income, and length of hospital stay during stroke (indicating severity). This reaffirms the finding of the link between stroke severity and depression as cited by Dennis, et al. (1998). Caregiver gender and age, however, were not found to be associated with depression in Qui and Li's study.

Li, Seltzer, and Greenberg (1997) compared daughter and wife caregivers and found that daughter caregivers' social participation was negatively related to the level of depression experienced, while personal health status was related to the caregiving wives' depression. In both daughter and wife caregiver groups, behavior problems of the care recipient were related to caregiver depression.

Schreiner, Morimoto, Arai, and Zarit (2006) evaluated a mixed sample of 128 family caregivers of stroke and chronic obstructive pulmonary disease (COPD) patients to see if the Zarit Burden Interview could provide a numerical indicator that would identify caregivers at risk for depression. Caregivers were assessed with the Burden Interview, Geriatric Depression Scale, and the Centre for Epidemiologic Studies Depression Scale (CESD). A higher number of the

stroke caregivers in this study were male, who reflected higher burden and depression scores than did the COPD caregivers. Statistical analysis revealed that the Zarit Burden Interview alone could be used as an indicator of depression risk for stroke caregivers, at a score of 25 out of a possible total score of 48 (with higher scores indicating higher burden).

A recent study evaluated caregivers of stroke survivors qualitatively. El Masry, Mullan, and Hackett (2013) evaluated ten stroke survivors and their caregivers in an attempt to evaluate the psychosocial aspects of stroke caregiving. The participants had been in caregiving situations anywhere from three months to three years, and the caregiving required that the stroke survivor need assistance with one activity of daily living. The authors found five themes in the dyads. The participants reflected changes in: relationships within the dyad, outside social relationships and emotional challenges due to caregiving, the cognitive abilities and personality of the stroke patients as the result of the stroke, and caregiver employment and resultant financial strain. Finally the “outcomes” of caregiving—which the authors admitted were primarily negative—were cited, but the findings did reflect positive change in the personal perspective and priorities for the caregivers. A large limitation of this study was the high variability seen in the amount of caregiving being provided. Caregiver eligibility for this study required that the stroke patient require assistance with one activity of daily living (ADL) or more, but the authors listed instrumental activities of daily living among the ADLs as a qualifying activity. Hence, one caregiver could have been assisting a stroke patient with toileting and feeding, while another caregiver could only have been assisting with weekly grocery shopping. In a limited sample of ten dyads of significantly differing caregiving demands, it is difficult to see how the results are generalizable despite this being a qualitative study.

Caregiver Burden

Etiology of Caregiver Burden

One of the most commonly studied outcomes of caregiving is the concept of caregiver burden. Caregiver burden has been examined at length in the literature, with much of the burden research focusing on caregivers of Alzheimer's Dementia (AD) patients. However, although burden has been extensively studied, its' meaning and appropriate methods of measurement are still debated, as acknowledged by Johnson (1998).

Phillips, et al. (1995) evaluated 209 patients with varying levels of cognitive function and their family caregivers in an attempt to discover if the situational context of caregiving and the interactions between caregiver and recipient were determinants of the quality of caregiving provided. The authors initially found that caregiver burden contributed to provision of poor quality care, but as other components were factored into the analysis, the predictive power of burden was significantly decreased. Ultimately, caregiving's interactional components of other stressors and the degree to which the caregiver could reconcile with the difference in the care recipient (from prior to post-stroke) were discovered to be predictive of the quality of care provided.

Similarly, Jones (1996) attempted to discern the differences between the effects of subjective and objective components of caregiver burden in her three-year study of caregivers of mentally ill persons. Although the author was not successful in clearly differentiating between the components of burden, she found that negative interactions between the caregiver and the recipient were the primary sources of caregiving burden. This reinforces the findings of Phillips et al.'s (1995) study.

Watson, Modeste, Catolico, and Crouch's (1998) study reaffirmed that high level needs in the care recipient are implicated in burden. The authors conducted a study on caregivers of 52 patients (with several classifications of diseases) who had been discharged from a rehabilitation facility within the past two years. Caregiver burden was found to be associated with communication deficit, locomotion deficit, and transfer deficit of the care recipient, all of which are commonly seen in the stroke patient. Additionally, care recipients' self-care deficit was predictive of caregiver burden.

Conversely, other studies find no correlation between care-recipient needs and burden. Wallhagen's study (1992) of 60 elderly caregivers reported that caregivers were more significantly impacted by the personal (subjective) demands of caregiving than the task (objective) demands. In like fashion, Fink (1995) found that the amount of help required by an elder did not contribute to strain, but that the caregiver's perception of burden was predictive of role strain.

Almberg, Grafstrom, and Winblad (1997), in their study of caregivers of demented elderly family members, found caregiver perception of limited social life, and lack of a positive appraisal of caregiving to be associated with high levels of caregiver burden and burnout. Subsequently, Almberg, Jansson, Grafstrom and Winblad (1998) evaluated the difference in burden between male and female caregivers of demented persons versus non-caregivers of non-demented persons. The authors reported that female caregivers of demented persons experienced higher levels of strain than either male caregivers or non-caregivers.

African American caregivers present an exceptional case in caregiving outcomes. African American caregivers have been shown to experience less caregiver burden than other

caregivers, perhaps as the result of high levels of social support within the African American community (Allen-Kelsey, 1998). In a study with a similar population, Fulton Picot, Youngblut, and Zeller (1997) found caregiving demands to be positively associated with perceived rewards, with a follow up study reflecting a correlation between higher levels of perceived rewards and lower levels of caregiver burden and depression. Grant, Weaver, Elliott, Bartolucci, and Giger (2004) also found Caucasian caregivers to be at 3.7 times greater risk of caregiver depression than African Americans.

Burden in Stroke Caregiving

Tiegs et al. (2006) evaluated stroke caregivers to determine gender differences in caregiving. In evaluating 175 caregivers of veterans post-stroke, the authors found male caregivers to report lower scores for depression and burden than did women. Female caregivers experienced more impact on their personal lives and subsequently higher levels of burden than did the male caregivers but reported being more satisfied with the patient. However, after controlling for burden level, caregiver depression was not predicted by the caregiver's gender.

In a similar study of 87 post-stroke veterans and their caregivers, Van Puymbroeck, Hinojosa, and Rittman (2008) found that burden was predicted by the number of hours of daily caregiving required, and stroke patient comorbidities. The authors found that the sense of coherence score was predictive of both burden and depression. Ethnicity was also predictive of depression, as Caucasian caregivers were more likely to report depression than Puerto Rican, Hispanic, and African American caregivers. This finding echoes the results of Allen-Kelsey's (1998) study, which reported low burden levels in African American caregivers. In Van Puymbroeck, Hinojosa, and Rittman's (2008) study, however, female caregivers of stroke

patients reported less depression and burden than did the male caregivers, in opposition to the findings of Tiegs, et al. (2006).

In studying rural stroke caregivers in the role for at least six months, Johnson (1998) found that although caregiving manifested positive outcomes, burden was an inherent part of the caregiving role, directly related to lifestyle changes imposed by caregiving. This implies that burden is an unavoidable consequence of caregiving that can only be viewed positively in light of the beneficial outcomes associated with the role. Not all studies find positive consequences from caregiving, however.

A study by Vincent, Desrosiers, Landreville, and Demers (2009) attempted to differentiate the predictors of burden in caregivers of stroke survivors who were discharged from an acute care hospital as opposed to an inpatient rehabilitation unit. In patients discharged from an acute care facility, they found that caregiver burden was predicted by the stroke patient's verbal comprehension and the ability to ambulate; however, in patients discharged from inpatient rehabilitation units, leg mobility, neurological status, and hours of care being provided were predictors of caregiver burden. Overall, however, along with the previously mentioned patient characteristics, higher burden was seen in older female caregivers, who were retired. A major drawback to Vincent et al.'s study (2009) is that it measured variables thought to contribute to burden while not using a singular acknowledged burden measurement tool. Furthermore, caregivers of stroke patients with significant cognitive deficits were not included in the study, limiting the generalizability of the findings.

Scholte op Reimer, deHaan, Pijnenborg, Limburg, and van den Bos (1998a) conducted a study on 166 stroke caregivers six months post-stroke. In their research they found that

caregivers experienced burden due to the consequences of caregiving in their personal lives, as reflected in worry, the burden of responsibility for the care recipient, and being the source for all of the care provided. Morimoto, Schreiner, and Asano's study (2003) echoed these findings. Scholte op Reimer, et al. (1998a) found that higher levels of burden were predicted by the patients' cognitive impairment and physical disability as well. A later study by Scholte op Reimer, et al. (1998b) which was conducted on 115 stroke family caregivers three years post-stroke reaffirmed the same findings but found burden to be more significantly related to the caregivers' emotional distress than to any caregiving the caregiver may provide.

The contribution to caregiver burden by altered functional status and/or cognitive status of the stroke patient is commonly evaluated in studies of stroke caregiving; however, there has been no consensus as to its' contribution to caregiver burden. A study by Kao and McHugh (2004) evaluated 147 stroke caregivers of elderly Taiwanese stroke survivors to determine the factors which most correlated with the development of caregiver burden. They found that male caregivers reported significantly less burden than female caregivers. However the factors contributing to burden were different between genders. Female caregivers' burden was significantly predicted by the functional status of the stroke patient, as measured by the inability to perform ADLs, while male caregivers' burden was significantly predicted by cognitive function, frequency of falls of the patient, as well as ADL function. Also of interest was that caregiver burden was predictive of institutionalization of the older stroke patient for both male and female caregivers, with male caregivers being twice as likely to institutionalize the stroke patient as female caregivers.

Choi-Kwon, Kim, Kwon, and Kim (2005) evaluated 147 stroke patient/caregiver dyads in South Korea over a three year period of time to evaluate the factors that contributed to the development of caregiver burden. Hemorrhagic stroke patients and patients with other serious co-morbidities were excluded from participation in this study. Caregiver factors associated with the development of caregiver burden in this sample included anxiety and depression, unemployment, relationship to stroke patient, and gender. Stroke patient characteristics associated with the development of burden were patient depression, unemployment, functional disability, cognitive disability and having a co-morbidity of diabetes. The study further delineated the findings that aphasia, dysphagia, and dysarthria were significant contributing factors to burden. The authors noted that long-term care facilities for institutionalizing stroke patients were not available in South Korea, raising concern regarding caregiver burden (Choi-Kwon, Kim, Kwon, & Kim, 2005, p. 1043).

In attempting to differentiate contributors to burden in two distinct populations, Muraki et al. (2008) conducted a comparative study in Japan of four groups of patients. The four groups were composed of caregivers for: persons with dementia, normal elderly patients without stroke or dementia, and stroke patients with and without dementia. When compared to the control group of elderly patients without stroke or dementia, all other groups had higher levels of caregiver burden. Of interest, however, was the finding that—when comparing patients with dementia (both with and without stroke)—the burden scores were similar, inferring that functional disability did not increase the burden level in caregivers of an already demented patient.

A study conducted in Jordan by Kamel, Bond, and Froelicher (2012) evaluated the contributing factors to caregiver depression and burden in 116 stroke patient/caregiver dyads. There was a wide range in the stroke patients' age, most of whom were women. The average age of their caregivers was 40 years old. The stroke patients were significantly functionally impaired, necessitating approximately 4.25 hours daily of providing assistance with ADLs on average (p. 149). Caregiver depression was predicted by: the use of outside health assistance agencies, caregiver burden and the caregiver's health. Caregiver burden was predicted by caregiver depression and the stroke patient's functional level. Cognitive level was not significantly related to burden in the multivariate analysis, and time in caregiving did not contribute to either depression or burden.

A study of 104 veteran stroke patients and their caregivers sought to determine the relationship between sense of coherence, depression, and burden (Chumbler, Rittman, Van Puymbroeck, Vogel, & Qnin, 2004). Sense of coherence indicates the caregivers' perception of their ability to appropriately adapt and cope with a stressful situation. Burden was significantly associated with depression in the caregivers, which was also associated with a lower sense of coherence. The only patient factor that approached significance in predicting a negative outcome was functional status. In like fashion, Visser-Meily, Post, Schepers, and Lindeman (2005) evaluated 187 Dutch stroke caregiving dyads to determine contributors to burden and quality of life. At one year, 87% of caregivers reported low quality of life attributable to numerous factors of which use of passive coping strategies was the most significant predictor. The only stroke patient factor predictive of caregiver burden was functional disability (ADL dependency).

Nelson, Smith, Martinson, Kind, and Luepker (2008) evaluated 281 stroke caregivers at 4

and 12 months post-stroke to see if declining health of the stroke patient would predict changes in their caregiver's burden and health. Subjective caregiving burden was found to be increased by the declining neurological status of the patient over time, specifically with caregivers of patients who were older and, had a lower level of education. Subjective burden was not increased, however, by decreasing levels of physical function over time. Higher levels of objective burden were also predicted by the patients' declining neurological status, as well as the original severity of the stroke (as determined by hospital records). Again, declining functional status of the patient was not predictive of objective burden level. Caregiver health was not predicted by patient neurologic status, functional status or deterioration over time.

Jeng-Ru, Hills, Kaplan, and Johnson (1998) evaluated 51 Taiwanese stroke caregivers to determine the relationship between caregiver burden, functional and cognitive level, social support and caregiving attitudes. All of the patients were at least 60 years of age, and they could not have aphasia or preexisting mental illness to participate in the study. All caregivers in their study were members of the stroke patients' families. Caregivers ranged widely in age, with an average age of 47 years old. Although the researchers found a correlation between impaired functional status, impaired cognitive status, and the amount of time spent in caregiving activities, there was not a significant correlation found with caregiver burden. Caregivers with higher levels of education reported more social support and less burden than others.

McCullagh, Brigstocke, Donaldson and Kalra (2005) studied 232 stroke patients and their caregivers to discover what factors contributed to quality of life and caregiver burden. Caregivers were provided training to assist them in providing care to the stroke patients, and a support network of both family support and social services. The dyads were subsequently

evaluated at three months and 12 months post-stroke. Caregivers were evaluated for perceived quality of life and burden. Although caregiver burden was found to correlate with the patient's disability level, and anxiety and depression of both stroke patients and caregivers, regression analysis demonstrated that patient and caregiver anxiety were the only predictive factors for caregiver burden at three months. By 12 months post-stroke, burden was decreased overall, but the level of caregiver depression, less use of social services, stroke patients' anxiety and depression, and severity of disability were predictive of institutionalization of the stroke patient.

Burden Measurement

One of the challenges in evaluating studies of caregiver burden is that the term "burden" is often used as an overarching term to define the negative consequences of caregiving. Therefore, researchers evaluate caregiver strain, depression, social isolation, sense of competence, and/or the caregiver's appraisal of the caregiving experience, labelling all of the resulting findings as caregiver burden. Given the wide variety of approaches to measuring burden, it is likely that the studies utilizing these methods are measuring components of caregiver burden rather than the phenomenon itself.

Visser-Meily, Post, Riphagen, and Lindeman (2004) examined the tools commonly used to evaluate stroke caregiver outcomes, and they found that there are 45 tools currently being used to evaluate caregiving outcomes, including 16 tools that reportedly quantify caregiver burden. Seven of the tools were used only once to evaluate stroke caregiver burden, and the remaining nine burden scales varied widely in what was actually measured. The most commonly used scale was the Caregiver Strain Index (CSI) (Robinson, 1983). However, the CSI only measures the subjective components of burden, which correlates to caregiver mood, without considering

objective burden (Blake & Lincoln, 2000). Other tools' scores include the assessment of myriad factors as proposed components of burden, measuring satisfaction in the caregiving role, stress level, adaptation to the caregiving role, health and well-being, emotional involvement with the stroke patient, the amount of time involved in caregiving, and esteem.

This study utilized the 12-item Zarit Burden Interview (ZBI) as adapted by Bedard et al. (2001). The ZBI was originally developed by Zarit, Reever, and Bach-Peterson in 1980 as a 29-item tool, and then later adapted by the authors to a 20-item tool. The original tool was designed to quantify caregiver burden in the primary caregivers of cognitively impaired persons. The ZBI is now commonly used to evaluate caregiver burden in stroke caregiving of both cognitively impaired and cognitively intact stroke survivors. The tool evaluates two components of caregiver burden: personal strain, and role strain. Personal strain questions make up nine of the questions of the ZBI, and the remaining three questions address the caregiver's perception of role strain. For each of the twelve questions in the ZBI, the caregiver responds with how often they feel when caregiving for the care recipient. Five possible answers range from "never" to "nearly always" for each question, with a resulting score for each from zero to four for each answer. The score is totaled to provide an overall score for burden. In this way, more of the essence of what makes the care "burdensome" to the caregiver is identified, and insight into how burdensome the specific indicator (question) is for the caregiver is obtained. The tool does not ask about specific tasks of the caregiving role, focusing rather on how the caregiver perceives the situation.

Summary

This review discussed the issues relative to the caregiving experience for caregivers of stroke patients. Altered functional status and cognitive status have been shown to contribute to negative caregiver outcomes, and alternately, to have no effect on the caregiver. Resilience has been studied extensively, primarily in children and adolescents, as a factor significant for promotion of adequate coping with change, but has not been studied in the adult stroke caregiver population. Caregiver burden has been shown to be greater in the functionally impaired, while other studies show that caregivers of the cognitively impaired experience more burden. Finally, some studies find no relationship between functional status or cognitive status and caregiver burden. Older, spousal caregivers have been shown to display the highest levels of burden, and conversely, lower levels of caregiver burden than younger caregivers.

Given the fact that there are over seven million stroke survivors in the U.S. as of 2014, and that this number is likely to increase as a result of the aging population, the ability of family members and others to care for stroke survivors is a significant public health and nursing issue. The lack of clarity in the existing data in the relationship of stroke patients' functional status, cognitive status, and caregivers' resilience to caregiver burden warrants further research to yield data that can bring clarity to this interrelationship.

CHAPTER III

Methodology

The purpose of this study was to investigate the relationship of stroke patients' functional status, cognitive status, and caregivers' resilience to caregiver burden. This chapter discusses the study design, research questions and hypotheses that were evaluated. Description of the setting, subjects and protection of human subjects, instrumentation, procedure, and data analysis method are presented. The instruments that were involved are (a) the Barthel Index (Appendix A), (b) the Mini-Mental State Examination (Appendix B), (c) the Resilience Scale (Appendix C), (d) the modified Zarit Burden Inventory (Appendix D), and (e) a demographic data collection form (Appendix E).

Design

A descriptive correlational design was used to examine the relationships between the proposed contributing factors of stroke patients' functional and cognitive status, caregivers' resilience and the outcome of caregiver burden. Burns and Grove (1997) stated that "the purpose of a descriptive correlational design is to examine the relationships that exist in a situation," so as to facilitate identification of factor interrelationships (p. 259). This study did not attempt to prove causation; however, the relative contributions of each of the factors evaluated were calculated in an attempt to discern the cumulative effect of the factors on caregiver burden and which factor had the greatest impact on caregiver burden.

Research Questions

The research questions addressed in this study were as follows:

1. What is the relationship between the functional abilities of stroke patients and the level of burden experienced by their caregivers?
2. What is the relationship between the cognitive function of stroke patients and the level of burden experienced by their caregivers?
3. What is the relationship between caregivers' resilience and their level of caregiver burden?
4. How much of the variance in caregiver burden is explained by stroke patients' functional status, stroke patients' cognitive status, and caregivers' resilience?

Research Hypotheses

The following hypotheses were tested in this study to evaluate the relationship of the independent variables of (a) stroke patients' functional status, (b) stroke patients' cognitive status, and (c) caregivers' resilience level, and the dependent variable of caregiver burden.

- H1: There will be an inverse relationship between the functional status of the stroke patients and caregiver burden.
- H2: There will be an inverse relationship between the cognitive status of the stroke patient and caregiver burden.
- H3: There will be an inverse relationship between caregivers' resilience and caregiver burden.

H4: A significant amount of variance in caregiver burden will be explained by the combination of stroke patients' functional status, stroke patients' cognitive status, and caregivers' resilience.

Setting

This study was conducted in a large metropolitan area in the mid-Atlantic region of the United States. The surrounding area intersects three states that are home to a large population, which is both racially and culturally diverse. Study participants were sought through several hospitals in the area. Data collection was conducted in the individual homes of the caregivers and care recipients. The site for this study was a natural, uncontrolled setting, as is appropriate for a descriptive correlational study.

Sample

Sample Size

This study evaluated 56 stroke patient/caregiver dyads. The sample size was based on Cohen's formula for power analysis of a multiple regression correlation with three independent variables, which was designed to achieve a power of 0.80, with an alpha of 0.05, and a large to moderate effect size of 0.15 (Cohen, 1988, p. 452; Munro, 1997, p. 248). The sample was purposive in nature,—and self-selecting—as stroke patients and their caregivers had the ability to choose to participate or not.

Inclusion Criteria

Study participants were referred from one large hospital which had been designated as a

referral center for stroke patients. For inclusion in this study, the following eight criteria were met. First, the stroke patients' caregivers could not be financially compensated for caregiving, thus defining them as “informal” caregivers. Next, included caregivers and stroke patients were at least 18 years of age. In addition, the stroke patients included in this study were living in a home setting as opposed to another type of facility, and they had been diagnosed as having experienced a stroke by their health care provider during a previous hospitalization. Sixth and seventh, the stroke patient and the caregiver had to understand the English language.

Lastly, for inclusion in the study, the minimum length of time required that must have elapsed prior to data collection was two weeks from the return to the home setting after the patient had experienced a stroke. It was anticipated that this minimum amount of time was required for a caregiving situation to become established, and for caregivers to adjust to the new demands upon their life and time. A maximum length of time since stroke occurrence was not specified as an inclusion factor.

Stroke patients with coexisting dementia prior to the stroke or mental illness that resulted in acute mental health inpatient therapy within two months prior to data collection were excluded from this sample. Further, stroke patients who were unable to perform their activities of daily living prior to the stroke were excluded from the sample. This exclusion allowed the researcher to more clearly evaluate the caregivers' burden that results directly from the stroke. It was expected, however, that stroke patients would have co-existing diseases—especially hypertension, cardiovascular disease, or diabetes.

Procedure

The researcher obtained prior approval for this study by the Committee for the Protection of Human Subjects at The Catholic University of America. Subsequently, Institutional Review Board (IRB) approval was sought from two participating institutions prior to subject recruitment. The chief medical officers of neurology at one or more local teaching hospitals, which had been designated as Stroke Centers, were approached by the researcher to discuss support of this study.

Each of the involved neurologists had a team of residents, interns, and nurses, which comprised the Stroke team for their hospital, and treated all stroke patients in the facility. The researcher provided letters of introduction (Appendix H) to the Stroke team physicians of each participating hospital for distribution to stroke patients and their caregivers. This letter provided basic information about the study, and the researcher's contact information. When the patients and their caregivers indicated an interest in study participation, their contact information was provided to the researcher, with their verbal permission, by a member of the Stroke team. Alternately, the potential participants could contact the researcher independently via the contact information contained in the letter of introduction. All stroke patients, who were not discharged to a nursing home, were referred to this study by a Stroke team member of the cooperating hospitals. If a stroke patient was already participating in another study, they were able to be referred once they completed that study.

When speaking with potential participants, the researcher briefly explained the study and then screened the potential participants, based on the aforementioned inclusion criteria. Participants were advised that the researcher was a doctoral candidate at The Catholic University of America, and not employed by the hospital where they received their care. At that time,

arrangements were made to meet the subjects for data collection after discharge.

The researcher obtained a signed informed consent (Appendix F & G) from both the stroke patient and their caregiver prior to data collection. If the stroke patient was unable to sign their name, their consent was affirmed verbally, with both the caregiver and the researcher signing to attest to the stroke patient's consent. Alternately, if the stroke patient was unable to indicate their consent to participate in any way, the caregiver was allowed to sign the stroke patient's consent form, if they were the patient's medical power of attorney.

After the participating subjects signed the appropriate informed consent documents, data collection began. After the data were collected, subjects were informed that they have the right to discontinue their participation in the study at any time. They were also informed that, if mandated by court order, an outside party could examine their records. Study participants were obtained from the Stroke Center until 56 subject dyads were obtained.

Instrumentation

Five instruments were used to gather data in this study. The stroke patient was administered (a) the Barthel Index (Mahoney & Barthel, 1965), and (b) the Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975) by the researcher, while the caregiver self-administered (c) the Resilience Scale (Wagnild & Young, 1993), (d) the Zarit Burden Interview (Zarit, Reeves, & Bach-Peterson, 1980) as modified by Bedard, et al. (2001), and (e) the demographics data collection instrument. These instruments are discussed in sequence below.

The Barthel Index

The Barthel Index (BI) (Mahoney & Barthel, 1965) is a ten item tool that is acknowledged

to be among the best of tools available to evaluate a patient's ability to perform basic activities of daily living, such as self-feeding, dressing, grooming, and bathing (Appendix A). Initially designed as an indicator of independence for patients with neuromuscular or musculoskeletal disorders, it has gained widespread acceptance as an indicator of patients' level of ability/disability in performing basic necessary life tasks (Kelly-Hayes, 2004). The ten abilities that are evaluated by the BI are (a) feeding self, (b) moving from a wheelchair to bed and return, (c) personal grooming, (d) getting on and off the toilet, (e) bathing self, (f) walking or ability to propel a wheelchair on a level surface, (g) ascending and descending stairs, (h) bowel control, and (i) bladder control. For each of the aforementioned skills, the person is evaluated as being either (a) unable to perform a task, (b) able to perform with assistance, or (c) functionally independent. In all cases, an inability to perform the skill is assigned a score of zero.

Each item is scored differently, and in some cases, a score of zero is assigned even if the person can perform the skill but requires assistance. The authors provide an in-depth key to scoring the tool, which assists in the consistency of scoring. A higher score on the BI implies a higher level of function. The maximum score achievable is 100, indicating that the person does not require a personal assistant for these specific skills. Mahoney and Barthel (1965) note that achieving a perfect score on the BI does not imply that the person is able to live independent of others, however, because it does not measure the instrumental activities of daily living, which include abilities to shop, prepare food, handle finances and manage taking their own medications, among other tasks.

The BI has demonstrated validity, correlating with the Katz Index, the PULSES Profile, and the Frenchay Activities Index (Granger, Albrecht, & Hamilton, 1979; Gresham, Phillips, &

Labi, 1980; Schuling, de Haan, Limburg, & Groenier, 1993). It has also displayed test-retest reliability of 0.93 among multiple raters of varying levels of training (Collin, Wade, Davies, & Horne, 1988), and reliability when used as a telephone interview collection tool (Korner-Bitensky, & Wood-Dauphinee, 1995). Testing of inter-rater reliability of the Barthel Index was conducted along with the Mini-Mental State Examination, which is discussed below.

The Mini-Mental State Examination

The Mini-Mental State Examination (MMSE) is an 11-item tool (Appendix B) that measures cognitive status. It establishes a person's baseline level of cognitive function in the domains of orientation, registration, attention and calculation, recall, and language (Folstein, Folstein, & McHugh, 1975). Each question has a specific number of possible points assigned to it, with a maximum possible total score of 30. A higher score achieved on the MMSE indicates a higher level of cognitive function. Instructions for use of the tool and its' scoring are printed directly on the exam. The tool is well established and has been used in multiple settings (Crum, Anthony, Bassett, & Folstein, 1993, Zwecker et al., 2002).

Concurrent validity has been evaluated by comparing the MMSE to the Wechsler Adult Intelligence Scale, in which the correlations ranged from 0.660 - 0.776 (Folstein, Folstein, & McHugh, 1975). Subsequent testing of the MMSE in evaluating cognitively impaired patients with Alzheimer's disease patients showed that the tool is sensitive—discriminating between study participants of different ages and educational levels (0.897 – 0.919) (Tombaugh, Hubley, McDowell, & Kristjansson, 1996). Further, the same study revealed that the MMSE displayed reliability ($\alpha = 0.81$) and construct validity of 0.78 (Tombaugh et al, 1996).

Inter-Rater Reliability

Prior to initiating data collection, the researcher conducted a pilot study involving administration of the Mini-Mental State Exam and the Barthel Index. The purpose of this pilot study was to establish reliability data for usage of the two tools. These two tools were concurrently administered by a Neurology Clinical Nurse Specialist, who was skilled in their use, and the researcher, to ten stroke patients in an inpatient setting. Instructions for the use of these tools were provided by the “Definition and Discussion of Scoring” sheet for the Barthel Index (Appendix A) and the instructions for administering the Mini-Mental State Exam (Appendix B) that accompanied the tool. Scores were compared, and inter-rater reliability in administration was computed. Complete agreement between the scores of the Neurology Clinical Nurse Specialist and the researcher was found in the scores of both tools for all ten patients.

The Resilience Scale

The Resilience Scale (RS), created by Wagnild and Young (1993), is a 25-item tool that was developed to study community dwelling older-adults (Appendix C). Each of the 25 items is scored on a 7-point Likert scale, with possible scores from 1 (disagree) to 7 (agree) provided by the study participant. Blank answers to a question in this tool were to be given a score of zero. This allows for a possible sum score for the RS that range from 0 to 175. Higher total scores are indicative of higher levels of resilience.

Wagnild and Young (1993) further define two separate constructs that are found within the Resilience Scale. Factor I is titled Personal Competence, which is evaluated by 17 of the 25 questions of the scale. Factor II is titled Acceptance of Self and Life, which is determined by the

score on the remaining 8 questions on the scale. Together these two components contribute to resilience, as defined by the authors.

Wagnild and Young's published study (1993) showed an internal consistency coefficient of 0.89. Construct validity was established by correlating the Resilience Scale with constructs determined to be foundational to the definition of resilience: self-esteem, life satisfaction, morale, and health (were positively correlated with resilience), while depression, stress, and perceived stress were negatively correlated. The authors of the tool presented data for five previous studies—with participants of varying age groups—in which the alpha coefficients ranged from 0.76 to 0.91. Additionally, individual components of the RS tool were shown to correlate well with other established tools including the Life Satisfaction Index, the Philadelphia Geriatric Center Morale Scale, the Beck Depression Inventory, and a Physical Health self-report tool (Wagnild & Young, 1993).

The Caregiver Burden Interview

The 12-item modified Zarit Burden Interview (ZBI) was used in this study (Appendix D). Originally developed by Zarit, Reever, and Bach-Peterson (1980) as a 29-item self-report tool for evaluation of burden in home based caregivers, the authors further defined two sub-constructs of caregiver burden, which were evaluated by their tool: personal strain and role strain. More recently, Bedard, Molloy, Squire, Dubois, Lever, and O'Donnell (2001) modified the ZBI to the 12-item tool. A 4-item tool, intended for the initial screening of caregivers, is also available.

Analysis of Bedard et al.'s 12-item tool showed correlations ranging from 0.92-0.97 against the original tool, when tested with a sample of 413 home-caregivers of Alzheimer's disease patients. In addition, the tool was validated against the original tool, and five additional

indices known to relate to burden. In each case, the short (12-item) version of the ZBI was shown to predict caregiver burden as well as the original tool. Subsequent studies of the modified tool demonstrated alphas of 0.88-0.94 (Hassinger, 1986; O'Rourke & Wenaus, 1998) and validity of 0.73 (O'Rourke & Tuokko, 2003).

The 12-item version of the ZBI is scored with each of the 12 questions having five possible answers: "never" (0), "rarely" (1), "sometimes" (2), "quite frequently" (3), and "nearly always" (4). A total burden score is achieved by adding the actual numbers from each answer. Bedard, et al. (2001) stated, based on their findings, that a score over 16 on the 12-item tool is indicative of high levels of caregiver burden. The authors added, however, that their data could not be assumed to be normative. Although this tool was designed for assessing burden in caregivers of Alzheimer's disease (AD) patients, as was the original ZBI, it was expected to adequately capture the essence of burden in caregivers of persons with both functional and cognitive impairment, as many AD patients eventually require assistance with basic functional tasks as well.

Demographics Tool

A 24-question demographic data collection tool (Appendix E) was provided to the caregivers to complete in this study. Information collected included the relationship of the caregiver to the stroke patient, length of time in caregiving, amount of assistance received in caregiving, and opportunity for respite time. The tool asked if other dependents were living with the caregiver and if the caregiver was simultaneously employed outside the home. Finally, the tool asked about the health of both the caregiver and the care recipient and the medications they take. The purpose of this tool was to assist in the final analysis of contributing factors to

caregiver burden, and to identify possible confounding variables.

Protection of Human Subjects

This study was initially reviewed at the School of Nursing, and subsequently at the Committee for the Protection of Human Subjects at The Catholic University of America prior to data collection. Further, approval by the IRB of the participating hospital(s) was obtained prior to subject referral.

Stroke patients and their caregivers were advised that the researcher was a doctoral student and not employed by their physician team. All participants in this study signed an informed consent (Appendices F & G) that described the potential benefits and risks to participating in this study, as well as information about their rights relative to the research study regarding confidentiality, maintenance of anonymity, and their ability to withdraw from the study at any time. Further, the consent provided information regarding the purpose of the study, and resources that could be contacted, if necessary, including mental health professional assistance.

After data collection, a code number was attached to the data, and the data was separated from the names of the participants. Participant names were not kept in the proximity of the data. Coded data and consent forms were kept in a secure facility, accessible only by the researcher. The list of participants' names and the data's code numbers were destroyed following completion of data analyses. Other records will be maintained for approximately five years, and then destroyed.

Data Analysis

Demographic data was analyzed using descriptive statistics. Correlation between the variables was calculated. Hierarchical regression analysis was used to test the four hypotheses. Each of the hypotheses was tested at the alpha = 0.05 significance level. Length of time in caregiving (in months) was entered into the regression equation first, in order to control its' effect on the independent variables. Subsequent entry of the three independent variables into the regression equation was in the following hierarchical manner: functional status score (BI) was entered into the regression equation first, followed by cognitive status score (MMSE), then followed by resilience score (RS). Regression analysis used the formula:

$$Y = b_0 + b_1X_1 + b_2X_2 + b_3X_3 + e$$

Where: Y = caregiver burden score (ZBI)

 X₁ = stroke patient score for functional status (BI)

 X₂ = stroke patient score for cognitive status (MMSE)

 X₃ = caregiver resilience score (RS)

 e = error

Limitations

As the sample for this study was self-selecting and purposive, it is realized that the generalizability of the findings will be limited.

Summary

This chapter described the methodology that was utilized in this study. Included in this discussion were the following components: (a) design of the study, (b) research questions, (c) hypotheses, (d) study setting, (e) sample, (f) procedure, (g) instrumentation, (h) internal and external validity, (i) protection of human subjects, (j) data analysis, and (k) study limitations

CHAPTER IV

Findings

The purpose of this study was to evaluate the relationship of stroke patients' functional and cognitive status and stroke caregivers' personal resilience to caregiver burden. Caregiver burden was the dependent variable under study, with the stroke patients' functional and cognitive status, and the caregiver's personal resilience being evaluated as the contributing independent variables. This chapter describes the recruitment of subjects for the study, composition of and characteristics of the final sample and the findings derived from the data collected.

Subject Recruitment

The inclusion criteria for this study follow: (a) primary caregivers could not be financially compensated for caregiving, (b) caregivers and stroke patients must be at least 18 years of age, (c) stroke patients must be living in, and receiving caregiving in a home setting, (d) patients must have been formally diagnosed as having experienced a stroke, (e) both the stroke patient and the caregiver must speak and understand the English language, and (f) at least two weeks must have elapsed between discharge from the hospital and the time of the interview.

Exclusion criteria for the stroke patient/care recipient included: (a) dementia prior to stroke, (b) inpatient mental health treatment within two months prior to stroke, or (c) inability of the stroke patient to perform their activities of daily living prior to stroke. All recruited subjects and caregivers met the inclusionary criteria as specified, and met none of the exclusionary criteria.

Institutional Review Board (IRB) approval was obtained through two local hospital stroke centers, but only one of the hospitals ultimately contributed subjects to the study. The neurology nurse educator identified potential study subjects and obtained approval from patients and family members for the investigator to discuss the study with them. If the caregiver and/or patient agreed to speak with the investigator, a brief introduction to the study was given, and consent to participate was obtained. Contact information was obtained, to enable the investigator to contact them at least 2 weeks after discharge to their home. If stroke patients or families were not available to be interviewed, a letter of invitation to participate in the study was left at the bedside by the nurse educator. No subjects were effectively recruited by use of the stroke study invitation letter.

Subjects were recruited and subsequently data were collected over approximately 20 months. During that time, a total of 78 stroke patient/caregiver dyads were recruited. Of that number, 22 dyads were lost to the study which resulted in the final participation of 56 dyads (71.8% of those recruited). Evaluation of the 22 dyads lost to the study included: (a) 9 patients (11.5% of those recruited) who were unable to be reached at the number or address provided, (b) 5 dyads (6.4%) in which the caregiver was no longer willing to participate, (c) 5 dyads (6.4%) in which the stroke patient was admitted to long-term care, (d) 2 stroke patients (2.6%) died after discharge from the hospital but before participating in the study, and (e) 1 dyad (1.3%) in which the patient's family employed a full time (24 hours per day) patient home caregiving team, which disqualified them from study participation.

Two stroke patients included in the sample were determined to have experienced a Transient Ischemic Attack (TIA) that led to their hospitalization. However, as both had histories

of a documented stroke within the past, they were included in the study. These two patients had been diagnosed as having a stroke at 24 months and 31 months prior to their interview. One patient's time from stroke until interview was not documented as the actual time of stroke was unknown. The patient's family acknowledged several years of a parent's increasing dementia which they believed to be due to her age, but finally was informed it was related to several past strokes.

Sample Description

Fifty six stroke patient and caregiver dyads comprised the final subject group. Much of the sample descriptive data were garnered from the Demographic Data Sheet (See Appendix E). Demographic data collected included information regarding: (a) age of stroke patient, (b) age of caregiver, (c) marital status of the caregiver, (d) relationship of stroke patient and caregiver, (e) time since patient's stroke, (f) amount of assistance provided to caregiver by others, (g) co-morbidities of both the stroke patient and caregiver, (h) presence or absence of children in the household, and other data. Data not collected in the overall sample include: (a) ethnicity, (b) history of previous stroke, (c) effects of previous stroke.

Demographic Data Sheet

The Demographic Data Sheet was designed to gather facts about the caregiving dyad, but more specifically the caregiver. Questions were designed to gather data about (a) general demographics, (b) the potential needs of the stroke patient, and the (c) demands upon and resources of the caregivers. Caregiver and stroke patient's genders were identified at the time of the interview.

General demographic information included relationship between patient and caregiver, marital status, and years of marriage. Potential needs of the stroke patient included questions related to the health of the patient pre-stroke and post-stroke, as well as presence of dementia or physical disability prior to stroke. Caregiver demands and resources included (a) patient attendance at rehabilitation services, (b) patient attendance at group activities, (c) assistance by others, paid and nonpaid, (d) church membership, (e) presence of children up to age 18 in the home, (f) opportunities for respite, and (g) health of both caregiver and stroke patient.

Health issues of the stroke patient were reported by the caregiver. In order to obtain the best indication of health or health challenges, caregivers were asked to identify their own health issues and any medications they were taking. The same questions were asked relative to the stroke patient. As non-professional caregivers may not know why they or the patients were taking specific medications, health issues were categorized by systems based on a combination of their reported health problems in conjunction with the medications they were taking. Health categories identified for purposes of this study included: (a) musculoskeletal or connective tissue disorders, (b) cardiovascular disorders, (c) pulmonary disorders, (d) renal or gastrointestinal disorders, (e) psychiatric or neurologic disorders, (f) endocrine disorders, (g) other disorders not listed, and (h) more than one category of disorder identified.

Demographics of Stroke Patients

Most of the stroke patients in this study were female, comprising 57.1% of the sample. Stroke patients' ages ranged from 32 to 92 years with a mean of 60.2 years, and the most frequent age of stroke being 65 years of age. The majority of the patients in the sample (51.8%)

were receiving care/assistance by someone other than a spouse. Table 1 provides further data regarding the stroke patients in this study.

In all cases, the stroke patient had more co-morbidities than did the caregiver. Although 57% of the sample was not currently attending rehabilitation sessions, 32.1% were attending 2 or more sessions per week. Patients who were not attending rehabilitation therapy were either finished with formal rehabilitation or else were (in multiple cases) awaiting approval of an outside funding source to begin therapy. Only one of the stroke patients (1.8%) was reported to attend an outside support group activity.

Table 1.

Characteristics of Stroke Patients

Variable	Value	Frequency ^a	Percent of Subjects ^b
Age in years	32-39	3	5.4
	40-49	12	21.4
	50-59	12	21.4
	60-69	14	25.0
	70-79	11	19.6
	80-89	3	5.4
	90-92	1	1.8
Comorbidities ^c	0	2	3.6
	1	10	17.8
	2	19	33.9
	3	10	17.8
	4	9	16.1
	5	3	5.4
	6	3	5.4
Barthel score ^d	35-50	7	12.5
	51-75	7	12.5
	76-100	42	75.0
MMSE score ^d	5-10	2	3.6
	11-15	5	8.9
	16-20	2	3.6
	21-25	19	33.9
	26-30	28	50.0

^aN=56. ^bTotal for all variables=100%. ^cTotal number identified by caregiver. ^dTotal score.

Caregivers provided the information for stroke patients' physical and mental health issues. Most of the patients were reported to have no physical disabilities (83.9%) prior to the stroke, but those with physical disability were affirmed to be able to perform their activities of daily living previously. All but two stroke patients (94.6%) were reported to have no mental illness, with depression offered as the diagnosis of those with mental illness. However, 76.8% of the stroke patients had identified health issues other than stroke, and 44 of those with other health concerns (78.6%) were found to have more than one category of health concerns. This will be discussed in more depth later in this chapter.

Overall, stroke patients in this study were high functioning both physically and cognitively. The average Barthel Index for these patients was 84.7 on a scale of 0-100 (S.D. =19.57, range 35-100), with a mode of 100 (39.3% of patients) for functional status. Stroke patients also showed a moderate level of cognitive abilities, with a mean score of 24.3 on a scale of 0-30 (S.D. =5.94, range 5-30) and mode of 30 (19% of patients) on the Mini-Mental State Exam.

The time between the stroke and the interview varied widely. Two cases of delayed entry into the stroke study were discussed earlier. In none of the interviews of stroke patient/caregiver dyads, were the interviews held in less time than one month after their stroke, in excess of the two week minimum time specified protocol for this study.

Demographics of Caregivers

Caregivers' ages ranged from 20 to 84 years with a mean age of 53.9 years and a mode of 65 years of age. While none of the stroke patient/caregiver dyads were males caring for males, 18 (32.2%) involved male caregivers providing care to female patients. The largest dyad group

was composed of 24 (42.8%) female caregivers caring for male patients. Lastly, female caregivers provided care for female stroke patients in 25% of the sample. A synopsis of selected characteristics of caregivers in this study is provided in Table 2.

Most of the caregivers studied were females (67.9%), who were not married to the stroke patient (51.8%). The 48.2% of caregivers who were married to stroke patients had been married an average of 31.3 years, with marriages ranging in time from 10-57 years and a mode of 42 years. Half of the caregivers in this study (50%) were working outside the home as well as caregiving. Further data regarding the employment type, status, and hours of time per week were not gathered.

In this sample, 12 (21.4%) of the caregivers also had responsibility for children under 18 years of age. Age data for the children were grouped into categories of (a) preschool age (0-5 years), (b) early school age (6-10 years), (c) middle to high school age (11-15 years), (d) older teens (16-18 years), and (e) children in more than one category. Three of the caregivers (25% of those with children) responded that they had children in more than one age group, but the most common age group for children of caregivers in this study was from 11-15 years of age.

Only two of the caregivers in this study (3.6%) had a paid skilled assistant, with a range from 8-40 hours per week. Answers were given for the type of care provided by the assistant. These were clustered into 5 categories: (1) personal hygiene (give bath, change linens), (2) feeding, (3) giving medications, (4) companionship only, (5) physical activity (take on a walk), or (6) more than one of the above activities. One caregiver reported that the assistant only provided help with personal hygiene, while the other reported that more than one of the categories of assistance was provided.

Table 2.

Characteristics of Caregivers

Variable	Value	Frequency ^a	Percent of subjects ^b
Age in years	20-29	5	8.9
	30-39	5	8.9
	40-49	11	19.6
	50-59	10	17.9
	60-69	15	26.8
	70-79	5	8.9
	80-84	3	5.4
	Did not disclose	2	3.6
Relationship to patient	Spouse or ex-spouse	27	48.2
	Child	15	26.8
	Parent	6	10.7
	Friend	2	3.6
	Fiancée	2	3.6
	Other family member	4	7.1
Health problems ^c	No	23	41.1
	Yes	33	58.9
Children in home by age	(0-5)	2	3.5
	(6-10)	1	1.8
	(11-15)	5	8.9
	(16-18)	1	1.8
	More than one age group	3	5.4
	No children at home	44	78.6

^aN= 56. ^bTotal percentages for all variables =100%. ^cSelf-identified by caregiver.

Despite the minimal number of caregivers having hired assistance, 20 caregivers (35.7%) stated they received assistance from a non-paid helper, most of whom (30%) were related to them. Reported number of days per week assisted ranged from 1-7 days, with a bimodal finding of 1 day per week (10.7%) and 7 days a week (10.7%). The average for days of non-paid assistance was 3.7 days. Hours of non-paid assistance per week were widely-ranged, from 2-70 hours per week, with only 15 of the 20 caregivers providing answers to the question. However, the mode was 8 hours per week and the mean being 21.3 hours of unpaid assistance per week (S.D.= 21.4). Twenty caregivers (35.7%) reported also having household help. It was not asked if the household help was hired or unpaid. The number of days per month for household help also varied widely, from 1-30 days (mean = 8.6 days per month, mode =2).

A little over two thirds of the caregivers (69.6%) reported belonging to a church. Slightly fewer responded to the query if caregiving interfered with their ability to attend church services, but 58.9% responded that it did not interfere. Caregivers were also asked if their caregiving responsibilities interfered with their ability to do things that were important to them in their daily lives. The majority of these caregivers (80.4%) replied that it did not interfere with things that were important to them. When asked what types of activities they were unable to do related to their caregiving, a slightly larger number (23%) provided answers of what they were inhibited from doing. Caregivers reported social outings, personal care outings (going to the doctor, having hair done), work or work related activities and a combination of these. The most commonly reported limitation (8.9%) was the inability to do personal care outings, with a mode of 5 reports.

Caregivers were asked if their own physical condition made it difficult for them to provide care. The majority (89.3%) indicated that their health did not impair their ability to give care. Of the six caregivers who responded that their health provided caregiving challenges, three (5.4%) reported orthopedic or connective tissue disorders, one (1.8%) a cardiovascular disorder, one (1.8%) reported a non-categorized disorder, and the last (1.8%) reported having more than one disorder. However, 58.9% of caregivers reported having health issues on a separate question, and when medications were evaluated, 66.1% of the caregivers were found to have health issues.

Thus, caregivers consistently under-reported the health problems of the patients and themselves in this study, as they viewed health problems differently than do health care professionals. For this reason, caregivers were asked to identify health problems, but information was also collected re: their current medications, for purposes of identifying other health “issues” not listed by the patient. Caregivers’ list of current medications revealed numerous conditions for which they (or the stroke patient) were being treated. When asked why those conditions were not listed, a common reply was that it isn’t a health problem because it was being taken care of by their medications.

As medications can be given for different types of conditions, and one condition can require multiple medications, the decision was made to categorize the medications as to body system and count the number of affected body systems as evidenced by medications list in addition to the caregivers’ lists. The body systems were listed as: (1) musculoskeletal and connective tissue disorders, (2) cardiovascular, (3) pulmonary, (4) renal or gastrointestinal, (5) psychiatric or neurologic, (6) endocrine, (7) other disorders, and (8) more than one category listed.

Caregivers were asked if they had the opportunity for respite time away from the stroke patient. One caregiver (1.8%) did not answer this question. However, 22 caregivers (39.3%) answered in the positive indicating they had the opportunity for respite time.

Caregivers assessed their personal resilience level with a 25-item tool. Each item consisted of a statement to which the caregiver assigned a number from a Likert scale, indicating their level of agreement with the statement. Possible scores included (1) “Strongly Disagree” through (7) “Strongly Agree”, with no qualifying statements between those values. The total possible score for the tool ranged from 25-175. Reported caregiver resilience scores were high with a mean score of 150.8 (S.D. 20.725), and ranged from 47-175, with a mode of 161 out of a possible 175 points.

Caregivers answered 12 questions that addressed possible sources of caregiving burden. Possible answers included: (a) Never, (b) Rarely, (c) Sometimes, (d) Quite Frequently, and (e) Nearly Always. An answer of “Never” received zero points on the burden scale, while an answer of “Nearly Always” received 4 points for burden with possible total burden scores ranging from 0 (indicating no burden) to 48 (indicating extreme burden). The average burden score was 11.8 (S.D. 8.301), with a median of 10 and mode of 8.

Instruments Used in the Study

Four instruments were utilized in this study: (a) the Barthel Index (Appendix A), (b) the Mini-Mental State Exam (Appendix B), (c) the Resilience Scale (Appendix C), and (d) the Zarit Burden Interview (Appendix D). The Demographic Data Sheet (Appendix E) was used to gather specific demographic information about the caregiving dyads in the study. The Barthel Index

(BI) and the Mini-Mental State Exam (MMSE) were administered to the stroke patient by the investigator, while the Resilience Scale, the Zarit Burden Interview, and the Demographic Data Sheet were filled out by the caregiver. However, if the caregiver asked, the investigator would verbally ask the questions for each of these remaining caregiver tools and record the answer given.

In order to evaluate inter-rater reliability of the MMSE and the BI, a pilot study was done prior to beginning the study. Ten inpatient stroke patients, were randomly chosen for this study. A neurology clinical nurse specialist (CNS) and the investigator independently evaluated both the functional and cognitive status of the patients with the BI and the MMSE. Results showed 100% agreement in scores for the BI and the MMSE between the CNS and the investigator.

The Barthel Index

The Barthel Index is a 10 question tool to measure functional ability, first published by Mahoney and Barthel in 1965. This tool is ideally used for stroke patients, as it was originally developed for evaluating abilities in performing activities of daily living in patients with musculoskeletal and neuromuscular disorders (Mahoney & Barthel, 1965). The tool evaluates patients' mobility, continence, and abilities for self-care. The ten items are scored differently, but in all cases, the patient is scored as either "independent", "needs help", or "unable to perform". In scoring each item, if a patient is unable to perform the activity, they are given a score of zero. Each item has a score that is zero or in multiples of 5 for needing help with performance and multiples of 5 (up to maximum of 15) for being independent in performing the skill for a possible total score of 100 on the Barthel Index. Further discussion of scoring specifics for the Barthel Index is attached to the tool (See Appendix A). A total score on the BI of 100

indicates that the patient is able to perform all activities of daily living without assistance, hence is physically independent.

The analysis of the Barthel Index is presented in Table 3. Cronbach's alpha for the BI in this study was .89, indicating a high level of internal consistency. Patient scores ranged from 35-100. Patients' average score for the BI was 84.7 (S.D. = 19.57) which indicated a high level of functional abilities. In this sample, 73.2% of stroke patients scored an 85 or greater on the BI. Given the mean score of 84.7, this reflects the presence of some extremely low scores of the remaining 26.8% of patients in the study. The corrected item/total correlations, which ranged from a value of .334 and .337 (questions on bladder and bowel continence) to .811 (ability to ascend and descend stairs) indicate that all of the items in the tool were adequately correlated with the total score achieved on the Barthel Index.

Table 3.

Analysis of The Barthel Index^a

Item	Range	Mean ^b	S.D.	Item/Total ^c
Feeding	0-10	8.48	2.320	.645
Moving	0-15	13.39	3.301	.788
Grooming	0-5	4.02	2.004	.736
Toileting	0-10	8.93	2.070	.744
Bathing	0-5	3.84	2.130	.754
Walking	0-15	12.23	4.565	.770
Stairs	0-10	8.30	3.202	.811
Dressing	0-10	8.04	2.464	.610
Bowel	0-10	8.84	2.334	.337
Bladder	0-10	8.66	2.429	.334
Total score	0-100	84.73	19.573	

^aCronbach's alpha =.89. ^bActual mean. ^cCorrected item/total correlation.

Mini-Mental State Exam

The Mini-Mental State Exam is an 11-item tool that is commonly used to assess cognitive function in adults. Originally designed for assessment of psychiatric patients, Folstein, Folstein, and McHugh noted that the exam is only used to assess cognition, and does not identify altered thinking nor mood components of psychiatric patients (1975, p. 189). This made the MMSE ideal for the purpose of evaluating purely cognitive function without other interfering variables

in this study. This test was administered to the stroke patient by the researcher. It was an untimed test, but took less than 10 minutes to administer in all cases.

The 11 items assessed in this tool included: (a) and (b) orientation to time and place, (c) registration (hearing three words and then repeating the words back again), (d) attention and calculation (serial subtraction), (e) memory (recall of three words previously mentioned), (f) ability to identify two objects by name, (g) repeat a spoken phrase, (h) follow a three part command, (i) read, comprehend and carry out a written direction, (j) write a sentence, and (k) draw interlocking pentagons. Each individual answer in the tool receives a score of either a zero for an incorrect answer or inability to perform the requested task or answer the question, or a score of one for a correct answer. MMSE total scores range from zero to 30, with a higher score indicating higher cognitive level. Analysis of the MMSE is provided in Table 4. Cronbach's alpha in this study was .78 which indicated an acceptable level of internal consistency. The average score achieved by patients on the MMSE was 24.3 (S.D.= .80, range 5-30) indicating a moderate to high level of cognitive function in this group of patients. The most common score on the MMSE was 30 (19.6%) which indicated a large number of the participating stroke patients were completely cognitively intact. The corrected item/total correlations—which ranged from a value of 0.223 to 0.834—indicated that all of the items in the tool were adequately correlated with the total score achieved on the Mini-Mental State Exam.

Table 4.

Analysis of the Mini-Mental State Exam^a

<u>Item Name</u>	<u>Range</u>	<u>Mean^b</u>	<u>S.D.</u>	<u>Item/Total^c</u>
Oriented to time	0-5	3.93	1.628	.834
Orientation to place	0-5	4.45	1.159	.672
Registration	0-3	2.88	.507	.609
Calculation	0-5	3.09	1.890	.548
Recall 3 words	0-3	2.00	1.206	.479
Name 2 objects	0-2	1.96	.187	.223
Repeat phrase	0-1	.88	.337	.390
Follow command	0-3	2.71	.594	.323
Read and do	0-1	.89	.312	.463
Write sentence	0-1	.86	.353	.473
Draw pentagrams	0-1	.61	.493	.541
<u>Total score</u>	<u>0-30</u>	<u>24.27</u>	<u>5.986</u>	

^aCronbach's alpha=.78 ^bActual mean. ^cCorrected item/total correlation.

The items with the highest percentages of correct answers were question 6, (98%) which asked the patient to identify a pen and a watch, and question 3 (96%) in which the patient was asked to repeat three words said by the researcher. The questions with the fewest number of correct answers were question 10, with 61% of patients able to perform the drawing correctly,

and question 4 (61.8%) in which the patient was asked to do serial subtraction from 100 by 7 repeatedly.

The Resilience Scale

The Resilience Scale (RS) is a 25 item tool by Wagnild and Young (1987) that assesses personal resilience. This tool was self-administered by the caregiver for analysis of their resilience level. Possible scores for each question ranged from 1-7, with a maximum possible total score of 175 for the tool. Each item of the tool is in the form of a statement, to which the caregiver chose an answer on a Likert scale ranging from (1) strongly disagree to a (7) strongly agree. There are no descriptions beyond those, but numbers alone. The tool directs the subject to circle the number that represents the way they feel regarding the statement, and further directs the subject to circle a (4) if they have no strong feelings in response to the question (i.e. are “neutral” on the question). The higher a score on the Resilience Scale, the higher the person’s resilience is judged to be. The mean resilience score for caregivers in this study was 150.98 (S.D. 20.372) with a range from 47-175. This indicates that this sample of caregivers was highly resilient.

The Cronbach’s alpha for the entire RS tool was .94 in this study, indicating a high level of internal consistency. The corrected item to total correlations ranged from .451 to .843 for the 25 question tool, indicating that the scores for each answer were highly correlated with the total score achieved on the tool. Analysis of the Resilience Scale is seen in Table 5.

Table 5.

Analysis of the Resilience Scale^a

Item Name	Range	Mean ^b	S.D.	Item/Total ^c
Q1. Make plans	1-7	6.04	1.008	.624
Q2. Manage somehow	1-7	6.27	1.000	.673
Q3. Depend on myself	1-7	6.29	1.140	.558
Q4. Interest is important	1-7	6.29	1.091	.667
Q5. On my own	1-7	6.41	1.318	.551
Q6. Proud accomplishments	1-7	6.32	1.029	.652
Q7. Take in stride	1-7	5.59	1.535	.536
Q8. Friends with myself	1-7	6.20	1.285	.763
Q9. Can handle by self	1-7	5.64	1.299	.685
Q10. Determined	1-7	6.39	1.039	.665
Q11. Wonder the point	1-7	4.89	2.333	.383
Q12. One day at a time	1-7	5.64	1.589	.472
Q13. Difficult times	1-7	6.07	1.248	.702
Q14. Self-discipline	1-7	5.91	1.225	.659
Q15. Keep interested	1-7	6.13	1.046	.683
Q16. Laugh	1-7	6.21	1.232	.724
Q17. Belief hard times	1-7	6.09	1.339	.827
Q18. Rely on	1-7	6.46	.894	.600
Q19. Look at situation	1-7	6.29	.909	.617
Q20. Make myself do	1-7	5.70	1.334	.451
Q21. Life meaning	1-7	6.41	1.172	.843
Q22. Do not dwell	1-7	5.73	1.368	.542
Q23. Find my way out	1-7	6.13	.974	.689
Q24. Enough energy	1-7	5.75	1.297	.551
Q25. Ok if don't like	1-7	6.14	1.381	.611
Total score possible	25-175	150.98	20.372	

^aCronbach's alpha=.94 ^bActual means. ^cCorrected item/total correlation.

The Zarit Burden Interview

There have been several versions of the Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980) since it was originally published as a 29-item tool. This study utilized the modified 12-item version of the ZBI as developed by Bedard et al. (2001, p. 652). Analysis of this tool is seen in Table 6.

Each of the questions of the modified ZBI asks a direct question re: how the caregiver feels relative to caring for (in this case) the stroke patient. There are five possible answers for each question which are: (a) Never, (b) Rarely, (c) Sometimes, (d) Quite Frequently, and (e) Nearly Always. Each of the five possible answers is scored from a zero for the answer “Never”, up to 4 points for “Nearly Always”, with a possible score of 0-48 for the entire tool. The lower the total score on the ZBI, the less burden the caregiver is experiencing. Each question has a blank area where the caregiver is to insert the name of the person for whom they are providing care. Overall, in this sample, caregiver burden, as measured by the modified Zarit Burden Index was low with an average of 11.89 (S.D.=8.283), and a range from 0-30 for total burden score.

Table 6.

Analysis of the modified Zarit Burden Interview^a

<u>Item Name</u>	<u>Range</u>	<u>Mean^b</u>	<u>S.D.</u>	<u>Item/Total^c</u>
Q1. Time for myself	0-4	1.50	.953	.677
Q2. Stressed responsibilities	0-4	1.50	1.062	.703
Q3. Angry	0-4	.88	.916	.634
Q4. Relationships	0-4	.70	.872	.557
Q5. Strained	0-4	.77	.972	.763
Q6. Health suffered	0-4	.54	.830	.675
Q7. No privacy	0-4	.75	1.083	.578
Q8. Social life	0-4	.79	1.004	.585
Q9. Lost control	0-4	.64	1.103	.675
Q10. Uncertain	0-4	1.23	1.175	.683
Q11. Doing more	0-4	1.34	1.083	.328
Q12. Do better job	0-4	1.27	1.168	.421
Total Score	0-48	11.89	8.283	

^aChronbach's alpha=.89. ^bActual means. ^cCorrected item/total correlation

Summary of Instruments

There were four recognized instruments used in this study. The instruments were: The Barthel Index, The Mini-Mental State Exam, The Resilience Scale, and the modified Zarit

Burden Interview. All were well established, commonly used instruments. In addition, a Demographic Data Sheet was utilized. Summary data are listed in Table 7.

Table 7.

Summary of Instrument Data

<u>Tool name</u>	<u>Cronbach's alpha</u>	<u>Mean/possible^a</u>	<u>Range of item/total correlations</u>
Barthel Index	.891	84.7/100	.334-.811
Mini Mental State Exam	.782	24.3/30	.223-.834
The Resilience Scale	.940	150.9/175	.451-.843
The modified Zarit			
Burden Interview	.891	11.9/48	.328-.763

^aOverall mean score compared with total possible score.

Hypothesis Testing

Research Questions

The following questions were to be answered in this study:

1. What is the relationship between the functional abilities of stroke patients and the level of burden experienced by their caregivers?
2. What is the relationship between the cognitive function of stroke patients and the level of burden experienced by their caregivers?
3. What is the relationship between caregivers' resilience and their level of caregiver burden?

4. How much of the variance in caregiver burden is explained by stroke patients' functional status, stroke patients' cognitive status, and caregivers' resilience?

Study Hypotheses

In order to answer the research questions, the following hypotheses were proposed:

- H1: There will be an inverse relationship between the functional status of the stroke patient and caregiver burden.
- H2: There will be an inverse relationship between the cognitive status of the stroke patient and caregiver burden.
- H3: There will be an inverse relationship between caregivers' resilience and caregiver burden.
- H4: A significant amount of variance in caregiver burden will be explained by the combination of stroke patients' functional status, stroke patients' cognitive status, and caregivers' resilience.

To put in a concise manner, Hypotheses 1,2, and 3 state that it was expected that higher levels of stroke patients' functional ability, mental ability, and caregivers' resilience would be associated with lower levels of caregiver burden, while lower levels of functional ability, mental ability and caregivers' resilience would be associated with higher levels of burden. Hypothesis 4 stated that the stroke patient's functional level and cognitive level, and the caregivers' resilience level would together explain the level of burden the caregiver experienced.

Hypotheses Testing Results

Table 8 presents the results of the zero-order correlation matrix for the dependent variable, Zarit Burden Interview score (ZBI), the controlling demographics variable (time between CVA

and interview), and the three independent variables: Barthel Index (BI) score, Mini-Mental State Exam (MMSE) score, and Resilience Scale (RS) score. The expected outcome (paralleling the hypotheses) was that functional level (BI), the cognitive level (MMSE) and resilience level (RS) would all be negatively related to burden level (ZBI). This was the case between functional level and burden, and resilience level and burden. However, cognitive level was not negatively related to burden. Although MMSE score was positively related to burden score (unexpectedly), the level of correlation was not significant. The zero order correlation matrix shows that the only significant correlation between the independent variables and the dependent variable was between resilience level (RS) and the burden level (ZBI) at the 0.05 level ($r(54) = -.259, p = .028$). A negative correlation was also found between the demographic controlling variable (time between CVA and interview) and functional level (BI) ($r(54) = -.293, p = .015$) in the zero order correlation matrix. However, time was controlled for in the regression model.

Hypothesis testing was based on the regression model summary, with hypothesis 4 being verified by the ANOVA significance. Before the regression analysis was completed, the three requirements of normality, linearity, and homoscedasticity were examined. The zero order correlation matrix provided evidence that there was no multicollinearity, but it was tested for with more specific calculations in the regression analysis. The P-P plots of each of the variables validate the normality, linearity and lack of homoscedasticity in the study variables. The following charts display the P-P plots of the variables: (a) Chart 1: Barthel Index, (b) Chart 2: Mini-Mental State Exam, (c) Chart 3: Resilience Scale, and (d) Chart 4: Zarit Burden Interview.

Table 8.

Zero-Order Correlation between Control, Independent Variables and Dependent Variable ^a.

Correlations^b

		Zarit Burden Index total score (DV, Burden)	Demog: time between CVA and interview in months (controlled variable)	Barthel Index total score (IV, Functional Status)	MMSE total score (IV, Cognitive Status)	Resilience Scale total score (IV, Caregiver Resilience)
Zarit Burden Index total score	Correlation	1.000	.218	-.211	.155	-.259
	Sig.		.055	.061	.129	.028
Demog: time between CVA and interview in months	Correlation		1.000	-.293	.012	.094
	Sig.			.015	.467	.247
Barthel Index total score	Correlation			1.000	.081	.025
	Sig.				.278	.427
MMSE total score	Correlation				1.000	-.067
	Sig.					.313
Resilience Scale total score	Correlation					1.000
	Sig.					

^a IV's = Barthel Index score, Mini Mental State Exam score, Resilience score; DV = Zarit Burden score; Control = Demographic variable: time between CVA and interview in months. ^b N=55.

Chart 1.

Normal P-P Plot of Barthel Index Scores

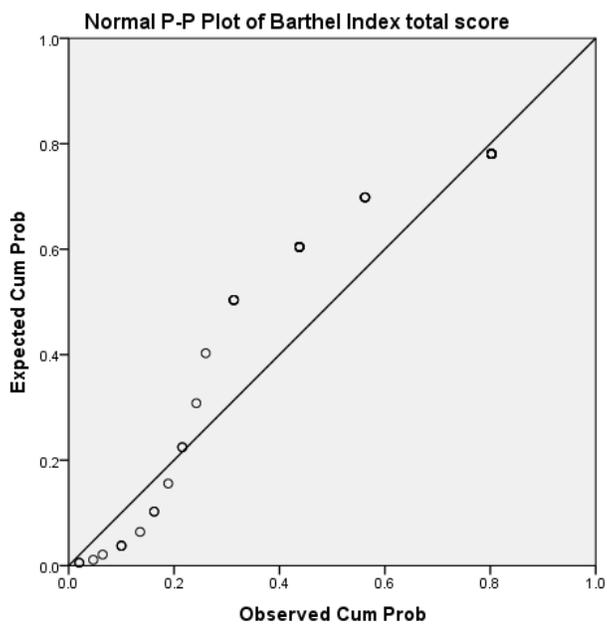


Chart 2.

Normal P-P Plot of Mini-Mental State Exam Scores

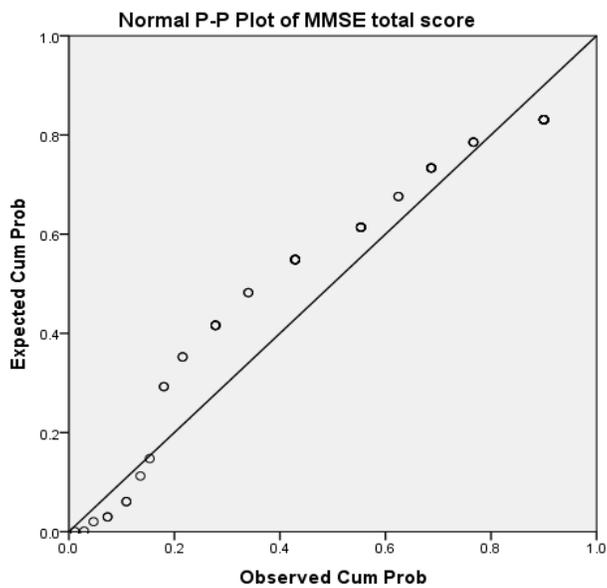


Chart 3.

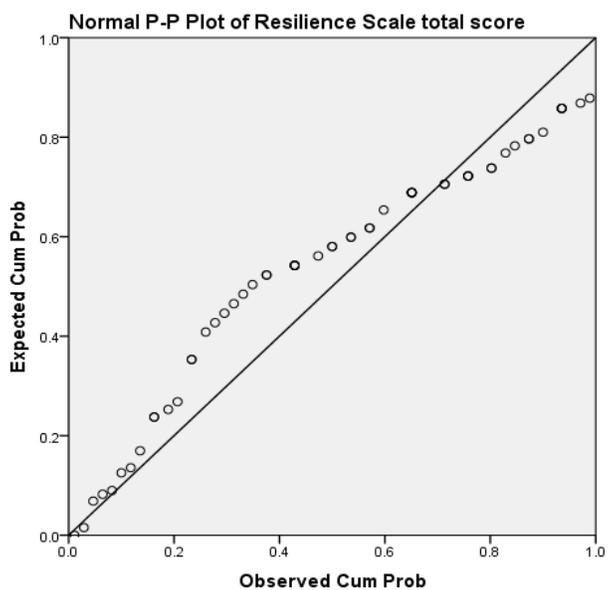
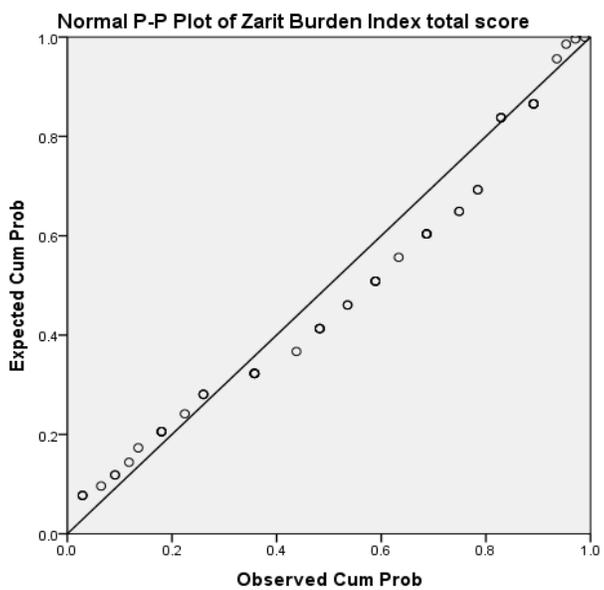
Normal P-P Plot of Resilience Scale Scores

Chart 4.

Normal P-P Plot of Zarit Burden Index Scale Scores

Regression analysis controlled only for the length of time in caregiving, as it was expected that a longer period of time in caregiving would allow for adaptation, and a possible change in the level of burden (dependent variable) experienced by the caregiver. The regression was conducted in a hierarchical model with control for time between the stroke and the interview by entering it into the regression first. The regression's independent variables were entered in the following manner: (1) time between stroke and interview, (2) Barthel Index score for functional status, (3) Mini Mental State Exam score for mental status, and (4) Resilience Scale score for caregiver resilience level. The regression model summary is presented in Table 9. Multicollinearity was demonstrated to not be of concern in this study, as the tolerance statistics ranged from .901 to 1.000 and VIF ranged from 1.000 to 1.110 in the four models of the regression analysis.

Table 9.

Regression Model Summary of IVs on DV^a with Control for Time Between Stroke and Interview

Step	Variable Entered	R ²	R2 Change	df of F ^b	F Change	p ^c
1	Time	.048	.048	1, 53	2.65	.110
2	Barthel	.071	.024	2, 52	1.33	.254
3	MMSE	.099	.028	3, 51	1.58	.215
4	Resilience	.167	.068	4, 50	4.10	.048
5	Combination			4, 50	2.51	.053

^a DV=Zarit Burden Interview score. ^b N= 55. ^c Significance = 0.05

Hypothesis 1 testing. Hypothesis 1 stated: There will be an inverse relationship between the functional status of the stroke patient (Barthel Index score) and caregiver burden (Zarit Burden Interview score). Step 2 of the regression analysis results were $F(2, 52) = 1.33$, $p = 0.254$. The relationship was negatively related per the t-score ($t = -1.154$), and the zero order correlation matrix findings, but the correlation did not reach statistical significance in the regression analysis. Hypothesis 1 was not supported.

Hypothesis 2 testing. Hypothesis 2 stated: There will be an inverse relationship between the cognitive status of the stroke patient (Mini-Mental State Exam score) and caregiver burden (Zarit Burden Interview score). Step 3 of the regression analysis results were $F(3, 51) = 1.58$, $p = 0.215$. The relationship was not negatively related per the t-score ($t = 1.257$), nor the zero order correlation matrix findings, and the correlation did not reach statistical significance in the regression analysis. Hypothesis 2 was not supported.

Hypothesis 3 testing. Hypothesis 3 stated: There will be an inverse relationship between caregivers' resilience (Resilience Scale score) and caregiver burden (Zarit Burden Interview score). Step 4 of the regression analysis results were $F(4, 50) = 4.10$, $p = 0.048$. Caregivers' resilience was negatively related to caregiver burden level per t-score ($t = -.263$) and the zero order correlation matrix and significantly correlated in the regression analysis. Hypothesis 3 was supported.

Hypothesis 4 testing. Hypothesis 4 stated: A significant amount of variance in caregiver burden (Zarit Burden Interview) will be explained by the combination of stroke patients' functional status (Barthel Index score), stroke patients' cognitive status (Mini-Mental State Exam score), and caregivers' resilience (Resilience Scale score). Step 5 was verified by ANOVA in the

regression analysis, with $F(4, 50) = 2.514, p = 0.053$. The combination of stroke patients' functional status, cognitive status, and caregivers' resilience did not significantly explain the variance in caregiver burden level. Hypothesis 4 was not supported.

Other Findings

Based on the above findings, alternative regression models were performed and analyzed. The first of the alternate models retained the use of the controlling variable, time between stroke and interview, while the second model did not. Beyond that difference, Resilience Scale score, Barthel Index score and Mini-Mental State Exam score were entered into the equation at once into the first two alternate regressions, based on their correlation. This altered from the proposed model which specified the order of entry into the regression equation. The findings of the alternate regression models follow.

Alternate Regression Model I: Controlling variable maintained.

In alternate regression model I, the controlling variable, time between stroke and interview, was entered into the regression equation along with Resilience Scale score, Barthel Index score, and Mini-Mental State Exam score. Regression analysis for this model was $F(4, 50) = 2.514, p = .053$, which did not reach statistical significance. Therefore, regression of the three independent variables, functional status, cognitive status, and caregivers' resilience level, while controlling for time since stroke did not predict a significant amount of the variance in the amount of burden experienced by the caregivers.

Alternate Regression Model II : Controlling variable removed from equation.

In alternate regression model II, the regression equation was performed without the controlling variable, amount of time since stroke, when entering the three independent variables of Resilience Scale score, Barthel Index score and Mini-Mental State Exam score. The alternate regression model II results were $F(3, 52) = 2.666, p = .057$. This demonstrated that the alternate model II, regressing functional status, cognitive status and caregivers' resilience on burden score did not significantly predict the amount of burden experienced by caregivers.

Summary of Data Analysis

This chapter presented the analysis of the data gathered in this study. Characteristics of stroke patients and their caregivers were presented. Analysis of the tools and their reliability in this study were presented. Each of the tools utilized demonstrated high levels of reliability.

Both the t-scores and the zero-order correlation matrix demonstrated a significant correlation between caregiver Resilience Scale scores and Zarit Burden Interview scores only. Barthel Index scores and Mini-Mental State Exam scores were not significantly related to ZBI scores.

Hypothesis testing was conducted, and one of the four hypotheses was supported. Hypothesis 1 stated that functional status would be negatively correlated with caregiver burden level. Although functional status and caregiver burden were negatively related, the relationship was not significant. Hypothesis 1 was not supported.

Hypothesis 2 stated that cognitive status would be negatively correlated with caregiver burden level. Cognitive status and caregiver burden were not negatively related, and the relationship was not significant. Hypothesis 2 was not supported.

Hypothesis 3 stated that caregiver resilience would be negatively correlated with caregiver burden level. Caregiver resilience was significantly correlated with caregiver burden, and the correlation was negative. Hypothesis 3 was supported.

Hypothesis 4 stated that the combination of stroke patients' functional status, cognitive status and caregiver's resilience would explain a significant amount of the variance in caregiver burden. The combination of these factors did not reach significance in predicting caregiver burden. Hypothesis 4 was not supported.

Finally, two alternate regressions were performed. In the first of the alternate regressions, the three independent variables of MMSE score, BI score, and RS score, along with the controlling variable, time between stroke and interview, were regressed on ZBI score, but not in a hierarchical manner. This regression did not significantly predict the amount of variance in caregiver burden level.

In the second alternate regression the three independent variables of MMSE score, BI score, and RS score were regressed on the dependent variable ZBI score, but without the controlling variable previously used. This was not performed in a hierarchical manner. Again, this regression did not significantly predict the amount of variance in caregiver burden.

CHAPTER V

Findings, Discussion, and Conclusions

Introduction

Despite advancements in the treatment of acute stroke in the past 20 years, an increasing number of persons continue to experience stroke each year, due largely to the aging of the American population. These stroke survivors live with the chronic disabilities that result, and are predominantly cared for in the home environment with the assistance of an unpaid caregiver, who is often a family member. The utmost concern for these individuals is the continuation of this caregiving environment, providing a setting in which the stroke patient can survive without negative sequelae to either themselves or their caregivers.

One of the concepts most widely researched in the caregiver population is the negative outcome of caregiver burden. Much of the research on caregiver burden in long-term caregiving has been performed with Alzheimer's disease caregivers; however, the caregiving demands of an Alzheimer's patient are significantly different than those of a stroke patient, due to the differences in the onset, progression, and final outcome of the two diseases.

Numerous studies have evaluated the caregiver burden of stroke caregivers, but there has been no consensus as to which factors most contribute to its development. This situation has been further complicated by use of numerous tools to measure burden, as not all studies have measured the same components of burden. Finally, the use of the term "burden" in research studies as an overarching construct rather than a finite measurable concept has complicated the identification of contributing factors as well.

The following research was intended to add to the body of knowledge on stroke caregiver burden and discern the relationship between the stroke patients' functional and cognitive disabilities and the burden of their caregiver. Additionally, this study sought to explore if a relationship between the caregivers' personal resilience level and caregiver burden exists.

This study utilized a descriptive correlational design with purposive sampling to gather data on both stroke patients and their informal caregivers to achieve the goals of the study. With the cooperation of a local stroke center in the mid-Atlantic area, potential study participants were identified and asked if they would participate in a one-time visit in their homes for an interview at least two weeks after the stroke patient returned home. Seventy-eight caregiving dyads were recruited from one stroke center. Ultimately, 56 stroke patient/informal caregiver dyads were interviewed in this study. Caregivers were contacted by telephone to set up the interview at a date and time of their choosing, and generally were within a week's time of the telephone call.

Purpose

The purpose of this study was to investigate the relationship of stroke patients' functional and cognitive status, and caregivers' resilience level with caregivers' burden. Four research questions provided the focus of this study, and four hypotheses were formulated to discern the relationship between the variables. This chapter will discuss the findings of data analysis, conclusions drawn from the study results, and implications for the results.

Findings

Research Questions and Hypotheses

The research questions, and the hypotheses designed to answer them were as follows:

Q1. What is the relationship between the functional abilities of stroke patients and the level of burden experienced by their caregivers? Hypothesis 1: There will be an inverse relationship between the functional status of the stroke patient and caregiver burden. Although the Barthel Index scores and the modified Zarit Burden Interview scores were negatively related, the relationship did not reach statistical significance [$F(2, 52) = 1.33, p = 0.254$]; therefore, Hypothesis 1 was not supported. This means that the patients' functional status did not contribute significantly to the amount of burden experienced by the caregivers in this study's sample.

Q2. What is the relationship between the cognitive function of stroke patients and the level of burden experienced by their caregivers? Hypothesis 2: There will be an inverse relationship between the cognitive status of the stroke patient and caregiver burden. The Mini-Mental State Exam scores were not negatively related to the modified Zarit Burden Interview scores, and the relationship did not reach statistical significance [$F(3, 51) = 1.58, p = 0.215$]; therefore, Hypothesis 2 was not supported. This means that the patients' cognitive status did not contribute significantly to the amount of burden experienced by the caregivers in this study's sample.

Q3. What is the relationship between caregivers' resilience and their level of caregiver burden? Hypothesis 3: There will be an inverse relationship between caregivers' resilience and caregiver burden. Resilience Scale scores were negatively related to the modified Zarit Burden

Interview scores and reached statistical significance [$F(4, 50) = 4.10, p = 0.048$]. Hypothesis 3 was supported. This means that in this sample, the caregivers' personal resilience level was a significant factor in determining their level of burden.

Q4. How much of the variance in caregiver burden is explained by stroke patients' functional status, stroke patients' cognitive status, and caregivers' resilience? Hypothesis 4: A significant amount of variance in caregiver burden will be explained by the combination of stroke patients' functional status, stroke patients' cognitive status, and caregivers' resilience. Regression analysis revealed that the Barthel Index scores, combined with the Mini-Mental State Exam scores and the Resilience scores did not significantly predict the variance in the modified Zarit Burden Interview scores [$F(4, 50) = 2.514, p = 0.053$]. Hypothesis 4 was not supported. Therefore, the combination of the functional state and cognitive state of the patient with the personal resilience of the caregiver was not predictive of a significant amount of variance in burden level.

The regression model summary is seen in Table 9.

Discussion

Demographics findings

This study evaluated 56 caregiver and stroke patient dyads. Comparison of this study's participants is made to those in the National Alliance of Caregivers' 2009 study (NAC, 2009). The NAC's study involved caregivers and care-recipients of many health concerns, and is considered to be a reliable source of data for both. In this study, the majority (57.1%) of the stroke patients/care recipients were females who averaged 60.2 years of age. The NAC's

national trends also reflect that the majority (62%) of care-recipients are female, but slightly older with an average of 69.3 years of age (2009, p. 4). Therefore, the care recipients in this study were nine years younger than those seen in the NAC study.

Caregivers in this study were predominantly female (67.9%) and averaged 53.9 years of age. Compared with the NAC's national trends, which showed 66% of caregivers to be female with an average age of 49.2 years of age, the caregivers in this study were four years older (2009, p. 4). Less than half of the caregivers (48.2%) in this study were the spouse or former spouse of the stroke patient for whom they were providing care. The NAC's most recent report did not provide statistics for the number of caregivers to adults that are married to the patient, but did state that caregivers aged 65 or older were more likely to be providing care to their spouse than younger caregivers (2009, p. 18). Although both Caucasian and African Americans were included in the sample, data related to the category of race were not collected.

A significant number of the primary caregivers were the child of (26.8%, n = 15) or parent to (10.7%, n = 6) the stroke patient in this study's sample. Nonfamily members comprised only 3.2% (n = 2) of the informal caregivers, significantly less than those reflected in the NAC's study, where 14% of caregivers were nonfamily (2009, p. 18). Only 3.6% (n = 2) of this study's caregivers also had a part-time paid assistant for caregiving, which enabled them to work outside the home. Nationally, 35% of caregivers use paid assistants to help them provide care, which is a decrease from earlier years (NAC, 2009, p. 32). However, 35.7% (n = 20) of caregivers in this study reported that "others" helped them to provide care, anywhere from 2 to 70 hours per week, with a mode of eight hours per week. Approximately one-third (35.7%, n =

20) of the informal caregivers in this study also had hired household help such as maid services with a mode of two days per month.

Multiple of the stroke caregivers were caring for one to three children under the age of 18 (21.4%, $n = 12$) at the same time. Of those caregivers, three were providing care for children in preschool, one for a child in elementary school, five for a child in middle school, and one for a child in high school. Finally, three caregivers reported caring for children from more than one of the listed categories. The NAC reflects a greater percentage of caregiving households in which children under the age of 18 are in the home, with 37% of all caregivers concurrently caregiving for an adult while raising their children (2009, p. 67). Independent t-test analysis revealed no significant difference [$t(54) = .540, p = .59$] in the caregiver's total burden score for those caregivers with underage children in the home (mean = 10.67, S.D. = 5.867) and those without children (mean = 12.14, S.D. = 8.881) with Levene's test for equality of variances significance equal to .187 in this study.

A significant majority of the caregivers in this study (80.4%, $n = 45$) reported that caregiving does not interfere with their ability to do things that are important to them. Of those who reported difficulty, the most commonly reported individual activity interfered with was personal care outings such as getting a haircut or going to see their physician (8.9%), and a similar number reported that caregiving interfered with more than one category of activity.

A large percentage (69.6%, $n = 39$) of the caregivers surveyed reported that they were members of a church, and 89.2% of that group stated that their caregiving did not interfere with their abilities to attend church services. Church membership has been an indicator of positive adaptation to the caregiving role. For example, in her qualitative study of commitment to

caregiving of older adults, Piercy (2007) noted that all of the caregivers ($n = 45$) who had strong commitments to caregiving for their elderly family members had certain characteristics in common. Among those characteristics were a strong moral, religious base and the conviction that providing compassionate care for the elder at home was the best solution. The highly committed caregivers held affectionate feelings for the elder, and embraced the role of caregiver. The caregivers viewed caregiving as a gift, an opportunity for growth, and a logical manifestation of their beliefs and who they were as individuals. Furthermore, the participants viewed obstacles to their caregiving as challenges they were able to manage. They had supportive spouses and families, were accepting of the changes brought to their lives by the role, and adapted to the role well. In evaluating the difference between those caregivers who belonged to a church and those who did not, Levine's test for equality of variances was significant ($F = 9.2, p = .004$) indicating significant differences in the groups. There was greater variance in the burden scores in those who did not belong to a church ($n = 17, \text{mean } 14.00, \text{S.D.} = 11.737$) than in those who did belong to a church ($n = 39, \text{mean } 10.87, \text{S.D.} = 6.220$). However, the independent t-test analysis of this sample revealed no significant difference [$t(20.0) = 1.037, p = .31$] in the level of caregiver burden in those caregivers who belonged to a church and those who did not belong.

Twenty-two caregivers (39.3%) indicated they had the opportunity for respite time. This parallels the 20 (35.7%) caregivers in the study who had unpaid others help them provide caregiving, added to the two (3.6%) caregivers who had hired care assistants. The specific amount of time a caregiver felt they needed for respite was not evaluated. Currently, 68% of informal caregivers report they have at least one other unpaid person helping them to provide

care (NAC, 2009, p. 30). There was not a significant difference [$t(53) = .092, p = .93$] in the level of burden experienced between those who reported having opportunity for respite ($n = 22$, mean 11.82, S.D. = 7.932) and those who reported having no respite opportunities ($n = 33$, mean 12.03, S. D. = 8.698).

The physical health of both the stroke patient and caregiver was determined with several questions. For each, a question was asked to list any health problems or conditions they had, and what medications they take. The names of medications were asked because, in the researcher's experience, patients often do not list health problems which are controlled by medication, such as hypertension, believing it to no longer be a health concern. Conditions listed were evaluated against medications to discern if any disorders were not listed. Additionally, the caregiver was asked if their conditions made it difficult for them to provide care.

Over three-fourths of the stroke patients reported more than one category of health disorder (78.6%, $n = 44$) in addition to the stroke. Among those patients who reported a singular comorbidity other than stroke, the most commonly reported disorder was cardiovascular disorders (12.5%, $n = 7$). Most caregivers (66.1%, $n = 37$) reported having at least one physical condition, with a cardiovascular concern most commonly reported (16.1% of sample, $n = 9$). Sixteen caregivers (28.6%) reported having more than one health concern. However, 32.1% ($n = 18$) of caregivers reported no health problems, and took no medications on a daily basis. Caregivers largely reported (89.3%, $n = 50$) that their physical conditions did not interfere with their ability to care for the stroke patient. The remaining 10.7% ($n = 6$) reported primarily orthopedic/connective tissue disease as the reason that caregiving difficulty was experienced, one of which reported more than one disorder caused difficulty in providing care. However, an

independent t-test revealed there was a significant difference [$t(54) = -2.8, p = .008$] in the level of burden between those caregivers who reported that their own physical condition made caregiving difficult to provide care ($n = 6$, mean 20.17, S.D. = 12.271) and those whose physical condition did not cause difficulty in caregiving ($n = 50$, mean 10.72, S.D. = 7.241) with Levene's test for equality of variances equal to 0.09.

Van den Heuvel, de Witte, Schure, Sanderman and Meyboom-de-Jong (2001) evaluated stroke caregivers ($n = 212$) to determine factors significant to the development of caregiver "burn-out" assessing the outcomes of caregiver mental health, vitality and strain (subjective burden only). The majority of the stroke caregivers were female spouses of the stroke patient, with a mean age of 64 years, who had been in caregiving for an average of three-and-a-half years. Caregiver mental health and vitality were both negatively affected by poorer caregiver general health. Female caregivers who were younger, not in good health, and were taking care of a stroke patient with significant behavioral, cognitive and emotional consequences of stroke were at the highest risk of burnout. Caregivers' satisfaction with social support was also significantly related to all three of the outcome variables. Hence, both social support and the health of the caregiver were important to the success of the caregiving situation. Bugge, Alexander and Hagen (1999) had similar findings when they evaluated factors in development of strain in 153 stroke caregivers. Caregivers were primarily women (73%), with a mean age of 60. They found that the caregivers' general health, vitality, and social functioning were significantly related to strain (subjective burden) at one, three and six months post-stroke. As this study showed a significant difference in the level of burden between those who reported their physical

condition made it difficult to provide care and those who did not report difficulty, this parallels the findings of Bugge, Alexander, and Hagen (1999).

Functional Status and Caregiver Burden

The average functional status of stroke patients was high in this study with 73.2% (n = 41) of patients achieving a Barthel Index score of 85 (of 100 possible), indicating minimal functional impairment in the majority of the stroke patients. Although 39.3% (n = 22) of the sample achieved a perfect score for functional status, the remaining 60.7% (n = 34) of the sample required assistance in at least one ADL. Similarly, NAC statistics (2009, p. 6) reflect that 58% of caregivers to adults assist with at least one ADL.

A Barthel score of 80 or less, indicating that the patient potentially required assistance with up to four or more ADLs (or was unable to perform more than one ADL even with assistance) correlates with an increased burden level in the National Alliance for Caregiving's Level of Care Index (NAC, 1997). The Level of Care Index (LOCI) evaluates a combination score for hours of caregiving provided weekly with the types and numbers of ADLs and/or IADLs assisted with. The score is used to predict the amount of burden that the caregiver is assuming in the role, but actually only reports the objective component of burden, not incorporating the subjective experience of burden into the scoring. In that manner, the LOCI, evaluates burden differently than the modified Zarit Burden Index that is used in this study.

Providing assistance with two or more ADLs, and assisting the stroke patient for up to eight hours a week places the caregiver at a moderate level of burden per the LOCI. In developing the LOCI, factor analysis showed that financial hardship, emotional stress and physical strain did not impact the intensity of the caregiving experience, and that only actual time

spent in caregiving (weekly) and the types of care provided (in ADL and IADL assistance) were factors in the level of care provided (NAC, 1997, p. 39). In evaluating Taiwanese caregivers, Kao and Acton (2006) found that an increased need for assistance with activities of daily living was one of the factors associated with higher levels of caregiver burden (p. 860), paralleling the findings of the NAC in developing the LOCI. However, cognition and gender of the caregiver, along with social factors were also found to be contributors to burden in Kao and Acton's study, which are not reflected in the LOCI. It must be noted that cultural and societal differences exist between this study's sample and that of the Taiwanese caregiving study which may affect the amount of burden experienced by caregivers.

The contribution of functional status in development of caregiver burden remains unclear, as various researchers have different findings. This study found that although functional status was negatively related to caregiver burden, but it did not rise to significance at alpha equal to 0.05. This may, in part, be explained by the fact that many of the stroke patients in this study were functionally intact.

Van Exel, Koopmanschap, van den Berg, Brouwer and van den Bos (2005) evaluated contributing factors to burden in 151 stroke caregivers. They found that assistance with four ADLs (assisting with hygiene, toileting, mobility, and feeding) was significantly related to substantial levels of caregiver burden. Other contributing factors to burden included the amount of daily time in caregiving, the need to watch the patient and to perform activities specific to the stroke patient such as arranging visits to their physician. In like fashion, Choi-Kwon, Kim, Kwon, and Kim (2005) evaluated 147 caregivers and stroke patients, found that patients' significant functional disability was among the predictors for higher levels of caregiver burden.

Cognitive Status and Caregiver Burden

Cognitive status scores of the care recipients in this study ranged from 5 to 30. A mean score of 24.3 for MMSE score was found in the participants, with 19% of the sample achieving scores of 30, implying no cognitive impairment. In Folstein, Folstein and McHugh's original publication of the Mini-Mental State Exam (1975, p. 192), a mean score of 27.6 was found in patients without cognitive impairment (mean age 73.9 years) and 9.7 in patients with dementia (mean age 80.8 years). While they did not establish specific scores for varying levels of cognitive impairment, they cited that an MMSE score of 20 or less was only found in patients with dementia or significant mental illness, and not in normal elderly persons.

The average age of patients within this study was 60.2 years, well below the age of the patients evaluated by Folstein, Folstein, and McHugh (1975). As a result, this sample would be expected to fall within the normal cognitive status range on the MMSE, unless impaired by the stroke. Based on Folstein et al.'s norms (1975), 83.9% of the patients in this study fell within the normal range for mental state as scored by the MMSE, while 16.1% of the sample was demented as the result of their stroke. This lends possible support to the findings of Folstein, et al. (1975). A slightly greater amount of cognitive impairment was seen relative to NAC's national statistics, that include dementia, confusion, and Alzheimer's disease patients together for total cognitive impairment prevalence of 12% (2009, p. 5). The LOCI did not evaluate cognitive status of the care recipient as a possible contributing factor in the development of burden.

There was a non-significant relationship between cognitive status and burden as tested at alpha equal to 0.05 in this study. Improved cognition would not be expected to increase burden level. However, in Zarit, Todd, and Zarit's (1986) longitudinal study of 64 caregivers of

demented patients, they found the cognitive scores of demented patients to be significantly correlated with caregiver burden. After two years of caregiving, better scores of patients on two tests of cognition and memory were unexpectedly correlated with more caregiver burden (p. 263).

Alternately, Kao and Acton (2006) found that stroke caregivers (n=148) experienced significantly increased burden relative to the stroke patients' aphasia and worse level of orientation. Choi-Kwon, Kim, Kwon, and Kim's (2005) evaluation of stroke caregivers and stroke patients also found that significant cognitive impairment was associated with higher levels of caregiver burden.

Muraki et al. (2008) compared the caregivers of 916 stroke patients, dementia patients, and elderly non-demented, non-stroke persons to determine the contributing factors to the development of caregiver burden. Caregiving for both stroke patients and dementia patients were associated with increased amount of burden; however, caregiving for demented stroke patients did not result in a higher level of burden than caregiving for either dementia, or stroke patients individually. Hence the contribution of stroke to burden in the caregiving of a patient with dementia was not significant, implying that the contribution of dementia to caregiver burden was of much greater significance than that of functional impairment.

Resilience and Burden

The only factor evaluated in this study which reached statistical significance with caregiver burden was caregiver resilience. Wagnild (2009) interprets low resilience levels as a score of 120 or less, moderate to high resilience as 121-145, and high resilience as scores of greater than 145. Resilience of the caregivers in this study was high with an average score of

150.98 out of a possible score of 175. An independent t-test showed no significant difference [$t(54) = .035, p = .972$] in the resilience level between male ($N = 18, \text{Mean} = 150.94, \text{S.D.} = 16.512$) and female ($N = 38, \text{Mean} = 150.74, \text{S.D.} = 22.654$) caregivers, with Levene's test for equality of variances significance equal to 0.890. Again, there are no comparative articles that actually measure resilience and its effect on stroke caregiving.

In their article discussing the psychometric evaluation of the RS, Wagnild and Young (1993) found the tool measures two contributing factors, which together define the construct of resilience: personal competence, and acceptance of self and life. Factor I, personal competence, is evaluated through answers to 17 of the 25 questions, while Factor II, acceptance of self and life, is evaluated through the remaining eight questions. The questions are intermingled in the tool, rather than in separate sections. Complete statements for the 25 item tool are seen in Appendix C. However, when splitting the questions into the two factors, analysis changed slightly.

Resilience Factor I: Personal Competence

Analysis of Resilience Factor I: Personal Competence is provided in Table 10. The Cronbach's alpha for Factor I (0.930) in this study was lower than the total instrument and the corrected item/total correlations changed (0.463 to 0.782). The question which had the lowest mean score in Factor I was number 9 which stated "I feel I can handle many things at a time" ($\text{Mean} = 5.64, \text{S.D.} = 1.299$). This indicated that caregivers agreed less strongly with this statement than they did on other questions in Factor I. However, it is noted that the mean score of 5.64 (of a possible 7) remains a relatively high score. The Factor I question with the highest mean score was number 18, which stated "In an emergency, I'm someone people can generally

rely on” (Mean = 6.46, S.D. = 0.894). The question with the lowest corrected correlation for Factor I was question 20 which stated “Sometimes I make myself do things whether I want to or not” (0.463). Again, the Factor I analysis shows a high level of internal consistency in the 17 questions and a high level of correlation between the individual questions and the total score on Factor I questions.

Resilience Factor II: Acceptance of Self and Life

Analysis of the Resilience Scale’s Factor II is provided in Table 11. Factor II assessed the remaining eight questions of the Resilience Scale with the same scoring method as in Factor I. The Cronbach’s alpha for Factor II was 0.83, which is less than scores for the entire tool and for Factor I, but still demonstrated reliability through excellent internal consistency. Corrected correlations remained strong in Factor II, again demonstrating that the answers on the individual questions correlated well with the total score.

Table 10.

Analysis of the Resilience Scale Factor I: Personal Competence^a

<u>Item Name</u>	<u>Range</u>	<u>Mean^b</u>	<u>S.D.</u>	<u>Item/Total^c</u>
Q1. Make plans	1-7	6.04	1.008	.617
Q2. Manage somehow	1-7	6.27	1.000	.693
Q3. Depend on myself	1-7	6.29	1.140	.592
Q4. Interest is important	1-7	6.29	1.091	.664
Q5. On my own	1-7	6.41	1.318	.547
Q6. Proud accomplishments	1-7	6.32	1.029	.623
Q9. Can handle by self	1-7	5.64	1.299	.715
Q10. Determined	1-7	6.39	1.039	.736
Q13. Difficult times	1-7	6.07	1.248	.676
Q14. Self-discipline	1-7	5.91	1.225	.686
Q15. Keep interested	1-7	6.13	1.046	.720
Q17. Belief hard times	1-7	6.09	1.339	.782
Q18. Rely on	1-7	6.46	.894	.579
Q19. Look at situation	1-7	6.29	.909	.589
Q20. Make myself do	1-7	5.70	1.334	.463
Q23. Find my way out	1-7	6.13	.974	.690
Q24. Enough energy	1-7	5.75	1.297	.588
<u>Total score possible</u>	<u>17-119</u>	<u>104.16</u>	<u>13.294</u>	

^aCronbach's alpha=.93. ^bActual means. ^cCorrected item/total correlation.

The question in Factor II with the lowest mean score (4.89, S.D.=2.333) and the lowest corrected correlation (.460) was question 11, which stated, "I seldom wonder what the point of it all is." This question confused some of the caregivers when they read it, as several asked what the question meant. They were not guided to answer the question in any way, other than to

respond to how they felt about the question as worded (as noted in the instructions). This confusion may have contributed to the lower scores on this specific question.

Table 11.

Analysis of the Resilience Scale Factor II: Acceptance of Self and Life^a

Item Name	Range	Mean ^b	S.D.	Item/Total ^c
Q7. Take in stride	1-7	5.59	1.535	.525
Q8. Friends with myself	1-7	6.20	1.285	.683
Q11. Wonder the point	1-7	4.89	2.333	.460
Q12. One day at a time	1-7	5.64	1.589	.558
Q16. Laugh	1-7	6.21	1.232	.633
Q21. Life meaning	1-7	6.41	1.172	.757
Q22. Do not dwell	1-7	5.73	1.368	.541
Q25. Ok if don't like	1-7	6.14	1.381	.527
Total score possible	8-56	42.82	8.246	

^aCronbach's alpha=.83

^bActual means.

^cCorrected item/total correlation.

Question 21 which stated, "My life has meaning", displayed the highest mean score (6.41, S.D. = 1.172), and the highest corrected item to total correlation (0.757) for Factor II. This meant that caregivers were most strongly in agreement with this statement relative to their personal lives and that the score on this question correlated strongly with the total score achieved on the tool.

Caregiver Burden

The average caregiver burden score was low to moderate in this study with a mean score of 11.9 (S.D. = 8.283) of a possible 48, and a mode of 8. Scores ranged from zero (no burden) to

41(high) in this sample. Bedard et al.'s (2001) study identified burden as "high" with a score on the modified ZBI of 17 or greater, but stated their study could not assume to be the norm. Assuming that score to be indicative of high burden, 19.6% of caregivers (N= 11) reported high levels of burden in this study. However, no definitive levels for defining high vs low burden have been set in the literature. Only three caregivers (5.4%) reported experiencing no burden by recording a total score of zero for the entire tool. An independent t-test showed there were no significant difference [$t(54) = .349, p = .728$] in total burden level between male (N = 18, Mean = 12.4, S.D. = 7.594) and female (N = 38, Mean = 11.6, S.D. = 8.701) caregivers, with Levene's test for equality of variances significance equal to 0.808.

Studies have shown varying results as to the impact of gender of the caregiver on caregiver burden. Zarit, Todd, and Zarit (1986) evaluated caregivers of cognitively impaired patients over a two-year period, with equivalent numbers of male (n = 31) and female (n = 33) caregivers. Female caregivers initially reported higher levels of burden than male caregivers; however, two years after beginning caregiving, their level of burden had significantly decreased and was comparable to that of the male caregivers. White, Mayo, Hanley and Wood-Dauphinee (2003) found that although male and female stroke caregivers' (N = 97) total burden scores remained constant over a two-year time period, further evaluation revealed that female caregivers experienced more burden specifically on tasks that related to managing the caregiving needs relative to the demands of their non-caregiving responsibilities than did male caregivers. Kao and Acton (2006) subsequently evaluated a sample of 148 caregivers of stroke patients and found that female caregivers reported higher burden scores than males.

The modified Zarit Burden Interview used in this study reflects two different components of burden: personal strain and role strain, which correspondingly reflect subjective and objective burden. The first nine questions of the 12-item modified ZBI reflect personal strain, while the last three questions address role strain.

Caregiver Burden Factor I: Personal Strain

Factor I measured the amount of personal strain contributing to the overall burden level. The first nine of 12 questions on the ZBI comprise the personal strain factor. The questions in Factor I with the highest mean were “1. Do you feel that because of the time you spend with _____ that you don’t have enough time for yourself?”, and “2. Do you feel stressed between caring for _____ and trying to meet other responsibilities (work/family)?” The mean score for each was 1.5, with the S.D. equal to 0.954 in the first question and 1.062 in the second question. Although this is still a minimal amount of burden, it indicates that, of these nine questions regarding personal strain, more caregivers find the lack of time for themselves and the stress of competing responsibilities to be the highest factors contributing to personal strain, and burden. The question with the lowest mean score was “6. Do you feel that your health has suffered because of your involvement with _____?” with a mean score of .54 (S.D. = .830). This means that most people did not find their health had worsened due to their caregiving and that this question contributed the least to their personal strain score.

Analysis of the modified Zarit Burden Interview’s Factor I is shown in Table 12. The Cronbach’s alpha for Factor I (0.90), indicating a high level of internal consistency, and corrected item to total correlations (range of 0.566 - 0.798) indicated that the questions on Factor I correlated well with the entire tool and final burden score.

Table 12.

Analysis of the modified Zarit Burden Interview's Factor I: Personal Strain^a

Item Name	Range	Mean ^b	S.D.	Item/Total ^c
Q1. Time for myself	0-4	1.50	.953	.705
Q2. Stressed responsibilities	0-4	1.50	1.062	.688
Q3. Angry	0-4	.88	.916	.643
Q4. Relationships	0-4	.70	.872	.566
Q5. Strained	0-4	.77	.972	.798
Q6. Health suffered	0-4	.54	.830	.688
Q7. No privacy	0-4	.75	1.083	.600
Q8. Social life	0-4	.79	1.004	.611
Q9. Lost control	0-4	.64	1.103	.669
Total score possible	0-36	8.05	6.535	

^aCronbach's alpha=.90^bActual means.^cCorrected item/total correlation.**Caregiver Burden Factor II: Role Strain**

Factor II measures the second component of burden, role strain. The last three questions of the ZBI on the 12-item tool constitute Factor II. This tool was graded as previously mentioned, with scores ranging from 0-4 for each question, with higher overall scores indicating more burden.

Analysis of the modified Zarit Burden Index's Factor II is shown in Table 13. Cronbach's alpha (0.67) for Factor II was lower than Factor I and the overall tool, but remained an indication of strong internal consistency. In evaluating the individual scores, these three questions are very close in mean (1.23-1.34) as are the standard deviations (1.083-1.175). All three of the Factor II questions reflected mean scores greater than one, as did the two strongest

indicators on the Factor I analysis. When considered with the corrected item to total correlations, this indicated that these slightly higher numbers more significantly contributed to the total score on the ZBI.

Table 13.

Analysis of the modified Zarit Burden Interview's Factor II: Role Strain^a

Item Name	Range	Mean ^b	S.D.	Item/Total ^c
Q10. Uncertain	0-4	1.23	1.175	.683
Q11. Doing more	0-4	1.34	1.083	.328
Q12. Do better job	0-4	1.27	1.168	.421
Total Score	0-12	3.84	2.655	

^aCronbach's alpha=.67.

^bActual means.

^cCorrected item/total correlation

Conclusions

Caregiver resilience level was high in this study, and was shown to be significantly related to caregiver burden. This study demonstrated that the level of resilience possessed by caregivers significantly explained the variance in burden they experienced. Past studies that have explored the impact of personal resilience on the outcome of caregivers and stroke patients have not actually measured resilience but rather factors assumed to be components of resilience. The Resilience Scale (Wagnild & Young, 1993), which has been shown to be a valid and reliable tool, effectively measured the resilience of stroke caregivers in this study.

Overall, stroke patients' functional and cognitive levels did not contribute to the prediction of the amount of caregiver burden experienced in this study. The stroke patients who

participated in this study were largely functionally and cognitively intact, with a few exceptions. Although they did not all score perfect scores on the tests of functional and cognitive status, most required a minimal amount of assistance or oversight from their caregivers.

The level of caregiver burden reported in this study was also relatively low. There was not a difference between female and male caregivers in burden level, nor between those caregivers who reported church membership and those who did not belong to a church. Burden was not significantly different in the homes of caregivers who were concurrently providing care to children and those without the responsibility for underage children. Finally, the availability of respite care did not make a difference in the amount of burden experienced in this study.

The only demographic variable that made a significant amount of difference in the amount of caregiver burden experienced was the report that the caregivers' physical condition made it difficult to provide care. Those who reported that their own physical condition made it difficult to provide care had significantly higher burden scores than those who reported no physical difficulty.

Much of the research done on caregiver burden reflects that burden is a complex construct. It is likely that burden is multifactorial, situational, and not easily captured by a single tool. Until the factors that contribute to burden are clearly defined, it is unlikely that we will fully discover the factors that ameliorate burden.

Recommendations

Based on the findings of this study, the following recommendations are made:

1. More evaluation of caregivers' health and physical ability is needed in the decision to discharge a stroke patient to home, and reevaluation is needed at regular intervals to ensure the caregivers' continued health and abilities.
2. Additional studies of caregiver resilience should be conducted to validate the role of resilience as a mediating factor in prevention of caregiver burden.
3. Replication of existing studies is needed to help identify which tools are most effective in evaluating caregiver burden, to allow for better comparison between results of stroke caregiving studies.
4. A study should be conducted with caregivers of patients who are more functionally or cognitively impaired as the result of stroke, yet deemed capable of home-care. This could possibly show different results from this study.
5. Replication of this study with a larger, multi-site study with more control over study enrollment is needed.
6. Additional research is needed to determine the contributing factors to burden in stroke caregiving.

Appendix A

THE BARTHEL INDEX by Mahoney, F. I., & Barthel, D. (1965).

	<i>With Help</i>	<i>Independent</i>
1. Feeding (if food needs to be cut up = help)	5	10
2. Moving from wheelchair to bed and return (includes sitting up in bed)	5-10	15
3. Personal toilet (wash face, comb hair, shave, clean teeth)	0	5
4. Getting on and off toilet (handling clothes, wipe, flush)	5	10
5. Bathing self	0	5
6. Walking on level surface (or if unable to walk, propel wheelchair) *score only if unable to walk	10 0*	15 5*
7. Ascend and descend stairs	5	10
8. Dressing (includes tying shoes, fastening fasteners)	5	10
9. Controlling bowels	5	10
10. Controlling bladder	5	10

A score of 0 is given in all of the above activities when the patient cannot meet the criteria as defined.

DEFINITION AND DISCUSSION OF SCORING (of BI)

1. Feeding

10= Independent. The patient can feed himself a meal from a tray or table when someone puts the food within his reach. He must put on an assistive device if this is needed, cut up the food, use salt and pepper, spread butter, etc. He must accomplish this in a reasonable time.

5= Some help is necessary (with cutting up food, etc., as listed above)

2. Moving from wheelchair to bed and return

15= Independent in all phases of this activity. Patient can safely approach the bed in his wheelchair, lock brakes, lift footrests, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, if necessary, to transfer back, and return to the wheelchair.

10= Either some minimal help is needed in some step of this activity or the patient needs to be reminded or supervised for safety of one or more parts of this activity.

5= Patient can come to a sitting position without the help of a second person but needs to be lifted out of bed, or if he transfers with a great deal of help.

3. Doing personal toilet

5= Patient can wash hands and face, comb hair, clean teeth, and shave. He may use any kind of razor but must put in blade or plug in razor without help as well as get it from drawer or cabinet. Female patients must put on own makeup, if used, but need not braid or style hair.

4. Getting on and off toilet

10= Patient is able to get on and off toilet, fasten and unfasten clothes, prevent soiling of clothes, and use toilet paper without help. He may use a wall bar or other stable object for support if needed. If it is necessary to use a bedpan instead of a toilet, he must be able to place it on a chair, empty it, and clean it.

5= Patient needs help because of imbalance or in handling clothes or in using toilet paper.

5. Bathing self

5= Patient may use a bath tub, a shower, or take a complete sponge bath. He must be able to do all the steps involved in whichever method is employed without another person being present.

6. Walking on a level surface

15= Patient can walk at least 50 yards without help or supervision. He may wear braces or prostheses and use crutches, canes or a walkerette but not a rolling walker. He must be able to lock and unlock braces if used, assume the standing position and sit down, get the necessary mechanical aides into position for use, and dispose of them when he sits. (Putting on and taking off braces is scored under dressing.)

10= Patient needs help or supervision in any of the above but can walk at least 50 yards with a little help.

6a. Propelling a wheelchair

5= If patient cannot ambulate but can propel a wheelchair independently. He must be able to go around corners, turn around, maneuver the chair to a table, bed, toilet, etc. He must be able to push a chair at least 50 yards. Do not score this item if the patient gets a score for walking.

7. Ascending and descending stairs

10= Patient is able to go up and down a flight of stairs safely without help or supervision. He may and should use handrails, canes, or crutches when needed. He must be able to carry canes or crutches as he ascends or descends stairs.

5= Patient needs help or supervision of any one of the above items.

8. Dressing and undressing

10= Patient is able to put on and remove and fasten all clothing, and tie shoes laces (unless it is necessary to use adaptations for this). The activity includes putting on and removing and fastening corset or braces when these are prescribed. Such special clothing as suspenders, loafer shoes, dresses that open down the front may be used when necessary.

5= Patient needs help in putting on and removing or fastening any clothing. He must do at least half the work himself. He must accomplish this in a reasonable time. Women need not be scored on use of a brassiere or girdle unless these are prescribed garments.

9. Continence of bowels

10= Patient is able to control his bowels and have no accidents. He can use a suppository or take an enema when necessary (as for spinal cord injury patients who have had bowel training).

5= Patient needs help in using a suppository or taking an enema or has occasional accidents.

10. Controlling bladder

10= Patient is able to control his bladder day and night. Spinal cord injury patients who wear an external device and leg bag must put them on independently, clean and empty bag, and stay dry day and night.

5= Patient has occasional accidents or cannot wait for the bed pan or get to the toilet in time or needs help with an external device.

A score of 0 is given in all of the above activities when the patient cannot meet the criteria as defined above.

Appendix B

“Now I would like you to subtract 7 from 100. Then keep subtracting 7 from each answer until I tell you to stop.

What is 100 take away 7?” (93) _____
If needed, say “keep going”. (86) _____
If needed, say “keep going”. (79) _____
If needed, say “keep going”. (72) _____
If needed, say “keep going”. (65) _____

*(**alternate item, spelling the word “WORLD” backwards, should only be administered if the examinee refuses to perform the Serial 7s task.)*

****Alternate:** Spell WORLD forward, then backward”. Correct forward spelling if misspelled, but score only the backward spelling.

_____ (D = 1) _____ (L = 1) _____ (R = 1) _____ (O = 1) _____ (W = 1)

.....

RECALL: maximum score 3; one point for each correct remembered word. SCORE _____

What were those three words I asked you to remember? (Do not offer any hints.)

(APPLE) _____
(PENNY) _____
(TABLE) _____

.....

NAMING: maximum score 2; one point for each correct answer. SCORE _____

“What is this?” (point to a pencil or pen) _____

“What is this?” (point to a watch) _____

*(**alternative common objects may be substituted and noted, e. g. eyeglasses, chair, keys)*

.....

REPETITION: maximum score 1 SCORE _____

“Now I am going to ask you to repeat what I say. Ready? “NO Ifs, ANDS, OR BUTS”. Now you say that.” (Repeat up to five times but score only the first trial)

COMPREHENSION: maximum score 3, one point for each correct action.

SCORE _____

“Listen carefully because I am going to ask you to do something. Take this paper in your right hand (pause), fold it in half (pause), and put it on the floor (or table)”.

Take in right hand _____

Fold in half _____

Put it on the floor (or table) _____

READING: maximum score of one point.

SCORE _____

“Please read this and do what it says.” (show examinee the words on the stimulus form).

CLOSE YOUR EYES _____

WRITING: maximum score of one point.

SCORE _____

“Please write a sentence.” (If examinee does not respond, say “Write about the weather.”)

Place a blank piece of paper (unfolded) in front of the examinee and provide a pen or pencil. Score 1 point if the sentence is comprehensible and contains a subject and a verb. Ignore errors in grammar or spelling.

DRAWING: maximum score of one point. Score 1 point if the drawing consists of two 5-sided figures that intersect to form a 4-sided figure.

SCORE _____

“Please copy this design.” (Display intersecting pentagons on the stimulus form.)

TOTAL SCORE _____

Maximum score is 30

Assessment of patient’s level of consciousness: circle one

Alert/responsive

Drowsy

Stuporous

Comatose/unresponsive

Appendix C

The Resilience Scale

Date: _____

Please read the following statements. To the right of each you will find seven numbers, ranging from "1" (Strongly Disagree) on the left to "7" (Strongly Agree) on the right. Circle the number which best indicates your feelings about that statement. For example, if you strongly disagree with a statement, circle "1". If you are neutral, circle "4", and if you strongly agree, circle "7", etc.

	Strongly Disagree			Strongly Agree			
1. When I make plans, I follow through with them.	1	2	3	4	5	6	7
2. I usually manage one way or another.	1	2	3	4	5	6	7
3. I am able to depend on myself more than anyone else.	1	2	3	4	5	6	7
4. Keeping interested in things is important to me.	1	2	3	4	5	6	7
5. I can be on my own if I have to.	1	2	3	4	5	6	7
6. I feel proud that I have accomplished things in life.	1	2	3	4	5	6	7
7. I usually take things in stride.	1	2	3	4	5	6	7
8. I am friends with myself.	1	2	3	4	5	6	7
9. I feel that I can handle many things at a time.	1	2	3	4	5	6	7
10. I am determined.	1	2	3	4	5	6	7
11. I seldom wonder what the point of it all is.	1	2	3	4	5	6	7
12. I take things one day at a time.	1	2	3	4	5	6	7
13. I can get through difficult times because I've experienced difficulty before.	1	2	3	4	5	6	7
14. I have self-discipline.	1	2	3	4	5	6	7
15. I keep interested in things.	1	2	3	4	5	6	7
16. I can usually find something to laugh about.	1	2	3	4	5	6	7
17. My belief in myself gets me through hard times.	1	2	3	4	5	6	7
18. In an emergency, I'm someone people can generally rely on.	1	2	3	4	5	6	7
19. I can usually look at a situation in a number of ways.	1	2	3	4	5	6	7
20. Sometimes I make myself do things whether I want to or not.	1	2	3	4	5	6	7
21. My life has meaning.	1	2	3	4	5	6	7
22. I do not dwell on things that I can't do anything about.	1	2	3	4	5	6	7
23. When I'm in a difficult situation, I can usually find my way out of it.	1	2	3	4	5	6	7
24. I have enough energy to do what I have to do.	1	2	3	4	5	6	7
25. It's okay if there are people who don't like me.	1	2	3	4	5	6	7

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Appendix D

Zarit Burden Interview, modified (Bedard, et al., 2001); (Zarit, Reeve, & Bach-Peterson, 1980)

The following is a list of statements which reflect how people sometimes feel when taking care of another person. Please indicate how often you feel that way.

1. Do you feel that because of the time you spend with _____ that you don't have enough time for yourself?

Never Rarely Sometimes Quite Frequently Nearly Always

2. Do you feel stressed between caring for _____ and trying to meet other responsibilities (work/family)?

Never Rarely Sometimes Quite Frequently Nearly Always

3. Do you feel angry when you are around _____?

Never Rarely Sometimes Quite Frequently Nearly Always

4. Do you feel that _____ currently affects your relationship with family members or friends in a negative way?

Never Rarely Sometimes Quite Frequently Nearly Always

5. Do you feel strained when you are around _____?

Never Rarely Sometimes Quite Frequently Nearly Always

6. Do you feel that your health has suffered because of your involvement with _____?

Never Rarely Sometimes Quite Frequently Nearly Always

7. Do you feel that you don't have as much privacy as you would like because of _____?

Never Rarely Sometimes Quite Frequently Nearly Always

8. Do you feel that your social life has suffered because you are caring for _____?

Never Rarely Sometimes Quite Frequently Nearly Always

9. Do you feel that you have lost control of your life since _____'s illness?

Never Rarely Sometimes Quite Frequently Nearly Always

10. Do you feel uncertain about what to do about _____?

Never Rarely Sometimes Quite Frequently Nearly Always

11. Do you feel you should be doing more for _____?

Never Rarely Sometimes Quite Frequently Nearly Always

12. Do you feel you could do a better job in caring for _____?

Never Rarely Sometimes Quite Frequently Nearly Always

Appendix E

Demographic data collection sheet for caregivers

Please provide some basic information about you and the person for whom you provide care. This information will be kept completely confidential.

1. Name: _____
2. Address: _____

3. Telephone number: _____
4. Marital Status (circle): Single Married Widowed Separated Divorced
If married, is the person for whom you provide care your spouse? _____
If married, how many years have you have been married? _____ years
If you are not married to the person you are providing care to, what is your relationship? _____
5. Your age: _____
6. The care recipient's age: _____
7. Does the care recipient attend regular rehabilitation/therapy sessions? Yes No
If so, how many days a week does s/he attend? _____
8. Does the care recipient attend day time group opportunities, such as senior day care?
9. Do you have a paid skilled assistant come in to help you provide care? Yes No
If yes, how many days a week are they helping you? _____
How many hours in a week are they helping you? _____
What sort of things does your assistant do for you and the care recipient?

10. Do you have other persons (besides the paid skilled assistant) who assist you in providing care? Yes No

If yes, how many days a week do they help? _____

How many hours in a week are they helping you? _____

Are these helpers related to either of you by blood or marriage?

Yes No

11. Do you have someone who assists you with household chores (house cleaning or grocery shopping for example)? Yes No

If yes, how many days a month do you have help with chores? _____

12. Do you belong to a church? Yes No

If yes, does your caregiving interfere with your ability to attend church services?

Yes No

13. Does your caregiving keep you from doing things that are important to you? (such as hair appointments, shopping, or others) Yes No

If yes, what specific activities are you unable to do?

14. Do you have any health problems or conditions? Yes No

If yes, what health problems or conditions do you have? _____

15. Are you taking any prescription medications? Yes No

If yes, what medications do you take? _____

16. Does your own physical condition make it difficult to provide care? Yes No

If yes, what physical problems do you have? _____

17. Besides the stroke, does the care recipient have any health problems? Yes No

If yes, what other health problems does s/he have? _____

18. What medications does the care recipient take? _____

19. When did the care recipient have their stroke? (month/year) _____

20. Was the care recipient disabled before the stroke? Yes No

21. Did the care recipient have any mental illness or dementia before the stroke?

Yes No

22. Do you have the opportunity to have periods of respite from caregiving (someone comes to relieve you of your caregiving responsibilities so that you can travel, or rest for more than a day)?

Yes No

23. Are you currently employed outside of the home?

Yes No

24. Do you have dependent children under the age of 18 living with you in your home at this time?

Yes No

If yes, how many children under 18 live with you currently? _____

If yes, please list the ages of the children who live with you. _____

Thank you for this information. It will assist in the analysis of the information you have provided.

Appendix F



THE CATHOLIC UNIVERSITY OF AMERICA

*School of Nursing
Washington, D.C. 20064
202-319-5400
FAX 202-319-6485*

Informed Consent Form for the Caregiver

Title of Study: The Relationship of Stroke Patients' Functional and Cognitive Status, and Caregivers' Resilience to Caregiver Burden

Investigator: Margaret D. Nolan, RN, MS

Supervisor: Jean Toth, RN, PhD

Telephone number to call if questions arise: Margaret D. Nolan [REDACTED]

Description and Purpose of this study: I understand that the purpose of this research study is to gain knowledge about how to better give care to persons who have had a stroke. I understand that Ms. Nolan is conducting this research in partial fulfillment for the requirements for a doctoral degree.

Procedure: I understand that I will be asked to complete three questionnaires. One questionnaire will ask me to provide basic information about my age, marital status, health, and demographics information. The second questionnaire will ask about my emotional strength; the third will ask about how well I am coping with the caregiving process. I understand that this process is expected to take up to 45 minutes.

Risks to me: The risks of my participation are minimal. I understand that I may potentially experience mild emotional discomfort as the result of completing these questionnaires, and that I may experience the inconvenience of the loss of my time while completing the forms. I also understand that I may experience some physical discomfort from sitting for the time required to complete the questionnaires. I understand that Ms. Nolan is an experienced clinician, and that she will be able to evaluate me and assist me with emotional discomfort that I may experience should the need arise. If I experience significant emotional discomfort, I can contact the crisis hotline at 1-800-273-TALK (8255).

Benefits to me: I understand that this study will not directly benefit me, however, it is thought that there may be benefits to other caregivers like me that result from what is learned from this research. The information I provide may also help nurses and physicians to better understand the needs of stroke caregivers in the future.

Cost to me: I understand that there is no cost to me for participating in this study, and also that I will not be paid for my participation.

Confidentiality: I understand that the questionnaires I complete will be coded by number and that the results will be kept separately from my name and consent form, so that my specific answers will not be directly linked to my name. I further understand that the forms I complete will be maintained in a locked file for protection of my privacy. I understand that any information about me obtained as a result of my participation in this research will be kept as confidential as legally possible. I understand that my research records, just like hospital records, may be subpoenaed by court order or may be inspected by federal regulatory authorities. I further understand that evidence of abuse or neglect must be reported to proper authorities, as is mandated by law.

Right to Refuse or Discontinue Participation: I understand that I am under no obligation to participate in this study, and that my participation is completely voluntary. I understand that I may refuse to participate or discontinue my participation at any time without penalty or loss of benefits or treatment to which I am entitled. I understand that if I choose to not participate in this study, it will not affect my relationship with my health care providers, or the health care providers of the person whom I care for, in any way.

I have had an opportunity to ask any questions about the research and/or my participation in the research, and these have been answered to my satisfaction. I have read and understand this consent form and give my permission to participate in the study.

I have received a signed copy of this consent form
I volunteer to participate in the above study.

Signature

Witness signature

Date

Date

Any complaints or comments about your participation in this research project should be directed to the Secretary, Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Services, The Catholic University of America, Washington, D.C. 20064; Telephone ([REDACTED])

Appendix G



THE CATHOLIC UNIVERSITY OF AMERICA

*School of Nursing
Washington, D.C. 20064
202-319-5400
FAX 202-319-6485*

Informed Consent Form for the Care Recipient

Name of Study: The Relationship of Stroke Patients' Functional and Cognitive Status, and Caregivers' Resilience to Caregiver Burden

Investigator: Margaret D. Nolan, RN, MS

Supervisor: Jean Toth, RN, PhD

Phone number to call if questions arise: Margaret D. Nolan [REDACTED]

Description and Purpose of this study: I understand that the purpose of this research study is to gain knowledge about how to better give care to individuals who have had a stroke. I understand that Ms. Nolan is conducting this research in partial fulfillment for the requirements for a doctoral degree.

Procedure: I understand that I will be asked questions about the effects of my stroke. I understand that I will be evaluated by Ms. Nolan as to my physical abilities and my thinking abilities. I understand that this will take approximately 45 minutes.

Risks to me: The risks of my participation are minimal. I understand that I may potentially experience mild emotional discomfort as the result of this evaluation and that I also may experience the inconvenience of the loss of my time during this evaluation. I also understand that I may experience some physical discomfort from sitting for the time required to answer these questions. I understand that Ms. Nolan is an experienced clinician, and that she will be able to evaluate me and assist me with any emotional discomfort that I may experience should the need arise. If I experience significant emotional discomfort, I can contact the crisis hotline at 1-800-273-TALK (8255).

Benefits to me: I understand that this study will not directly benefit me, however, it is thought that there may be benefits to other caregivers and stroke patients like me

that result from the information gained in this research. The information I provide may also help nurses to better understand the needs of stroke caregivers in the future.

Cost to me: I understand that there is no cost to me for participating in this study, and also that I will not be paid for my participation.

Confidentiality: I understand that the questionnaires I complete will be coded by number and that the information will be kept separately from my name and consent form, so that my specific answers will not be directly linked to my name. I further understand that the forms I complete will be maintained in a locked file for protection of my privacy. I understand that any information about me obtained as a result of my participation in this research will be kept as confidential as legally possible. I understand that my research records, just like hospital records, may be subpoenaed by court order or may be inspected by federal regulatory authorities. I further understand that evidence of abuse or neglect must be reported to proper authorities, as is mandated by law.

Right to Refuse or Discontinue Participation: I understand that I am under no obligation to participate in this study, and that my participation is completely voluntary. I understand that I may refuse to participate or discontinue my participation at any time without penalty or loss of benefits or treatment to which I am entitled. I understand that if I choose to not participate in this study, it will not affect my relationship with my health care providers in any way.

I have had an opportunity to ask any questions about the research and/or my participation in the research, and these have been answered to my satisfaction. I have read and understand this consent form and give my permission to participate in the study.

I have received a signed copy of this consent form.
I volunteer to participate in the above study.

Signature

Witness signature

Date

Date

Any complaints or comments about your participation in this research project should be directed to the Secretary, Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Services, The Catholic University of America, Washington, D.C. 20064; Telephone [REDACTED]

Appendix H



THE CATHOLIC UNIVERSITY OF AMERICA

*School of Nursing
Washington, D.C. 20064
202-319-5400
FAX 202-319-6485*

December 1, 2009

My name is Margaret D. Nolan, RN, MS and I am a doctoral student at The Catholic University of America's School of Nursing. As part of the requirements for my doctoral dissertation, I am conducting a nursing research study. The purpose of this study is to gain insight into informal caregiving of stroke patients who have been discharged to their homes. Stroke and stroke caregiving are of particular interest to me because stroke has affected the lives of many of my patients, as well as my own family.

This letter is intended to serve as an invitation to you to participate in this study. The study will address factors that are associated with the daily lives of both the stroke patient and the person who provides them the most assistance in their daily life. The study has been approved by The Catholic University of America's Committee for the Protection of Human Subjects, and by the Institutional Review Board of this hospital.

Inclusion in this study requires both the stroke patient and the caregiver to be participants, and involves a single visit to your home at least two weeks after discharge. During that brief visit, the caregiver will be asked to fill out several forms, and the stroke patient will be administered two brief tests that indicate what effects the stroke has had on their abilities.

If you are interested in participating in this study, please contact me at [REDACTED] (cell phone) or [REDACTED] (home). You also can ask your neurologist to have me contact you, if you so desire. Thank you so much for considering participating in this study.

Sincerely,

Margaret D. Nolan, RN, MS

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