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EXPERIENCES OF STRESS AND COPING OVER TIME BY CAREGIVERS OF  
STROKE SURVIVORS: A MIXED-METHODS APPROACH

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A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN NURSING

THE UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT HOSUTON

SCHOOL OF NURSING

BY

FANG YE, MSN, ANP, RN

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AUGUST, 2016

## Acknowledgements

I would like to acknowledge the many people who given me guidance and help in completing my dissertation work at The University of Texas Health Science Center at Houston. This research work would not have been possible without support of my dissertation committee members.

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## **Abstract**

### **Experiences of Stress and Coping Over Time by Caregivers of Stroke Survivors: A Mixed-Methods Approach**

FANG YE, MSN, ANP, RN

AUGUST, 2016

**Background:** Caregivers of stroke survivors often experience physical and mental stress, decreased physical and emotional well-being, high burden of care, social isolation, and neglecting self-care. The majority of previous research studies have identified caregiver experiences during the first one-to-two years post stroke. Little is known about caregiver experiences beyond the first two years of the post- stroke recovery trajectory, indicating a need for longitudinal study of their experiences over time.

**Purpose:** The aims were to 1) investigate caregiver experiences of stress and coping over 5-7 years post stroke using quantitative methods, and 2) explore through qualitative methods their stress and coping experiences over time and the concordance or divergence of qualitative and quantitative findings using a mixed-methods approach.

**Methods:** This study was a secondary data analysis of a randomized clinical trial, CARES (Committed to Assisting with Recovery after Stroke), between 2001-2005 and its follow-up study (between 2008-2011). A longitudinal follow up study was utilized to explore experiences of stress and coping over time by spousal caregivers of stroke survivors at baseline, 3, 6, 9, and 12 months post stroke and 5-7 years later. A mixed-methods,

triangulated approach with a convergent QUAN-QUAL design, was used to obtain different but complementary data on caregiver stress and coping experiences over time.

**Results:** Caregivers (N = 30) were primarily female (n =22, 73%) with a mean age of 58.8 and 33% were minorities. The range of mean perceived stress scores (PSS) was from 12.8-15.7 indicating caregivers experienced an average level of stress over time. The PSS scores gradually decreased with the lowest score at 5-7 years post stroke with a 1.5-point drop in PSS scores. However, the changes were small and not statistically significant ( $p = .32$ ).

The range of mean scores on the Family Crisis Oriented Personal Evaluation Scale (F-COPEs) was from 104.4 -119.9 implying spousal caregivers adopted multiple coping strategies. An inverse relationship between PSS and F-COPEs was statistically significant ( $p = .01$ ) indicating higher coping associated with lower perceived stress, and such relationship did not change over time ( $p = .90$ ). There was not a significant change over time in total coping scores ( $p = .53$ ); however, a significant decrease over time was noted in two subscales – Acquiring Social Support (ASS) ( $p = .02$ ), and Mobilizing Family Support (FBS) ( $p = .03$ ). This finding was supported by qualitative data as caregivers noticed that social support gradually decreased over time.

There was no significant change in PSS measurement over time, which is in agreement with the qualitative findings as four major categories of stress-related themes persisted through all stages of the stroke recovery trajectory. However, there were different sources

leading to stress at different times. Their emotional stress evolved over time from struggling with the survivors' personality changes, high caring demands, fear of recurrent strokes, unpreparedness and uncertainty of what the future would bring during the early stage of stroke recovery, to feeling lonely and sad about the loss of a supportive spousal relationship, and to suffering in silence and becoming more depressed for some caregivers at 3-6 months and 1 year post stroke, respectively. At 5-7 years post stroke, emotional stress was more related to the survivors' depressive symptoms and fear of inability to fulfill the caring role due to their own declining health. Caregivers also expressed financial stress throughout all stages of stroke recovery.

Common themes related to coping included: 1) religious and spiritual support with faith in God was utilized across all stages of the stroke recovery trajectory; 2) a problem-solving coping approach was more commonly adopted during early days of caregiving; 3) emotion-focused coping approach was consistently utilized over time as a way of relieving stress; 4) other coping strategies utilized all the time included being positive and grateful, and having a break from the caring situation in order to continue in caregiving role.

Across semi-structured interviews, spousal caregivers reported a variety of sources of stress and coping behaviors. The majority of spousal caregivers that experienced a low stress level also reported a high score of coping measurement, indicating an agreement between qualitative and quantitative findings based on the reported stress and coping themes.

**Conclusions:** Spousal caregivers continued to experience stress along with decreased social support as time progressed post-stroke, but these experiences evolved over time. Therefore, further research is needed to corroborate these findings and thus offer opportunities for researchers and clinicians to incorporate these findings to help spousal caregivers cope better at different stages of the stroke recovery trajectory.

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## Summary of Study

Caregivers of stroke survivors often experience physical and mental stress, decreased physical and emotional well-being, high burden of care, social isolation, and neglect of self-care. The majority of previous research studies have identified caregiver experiences during the first one-to-two years post stroke. Little is known about caregiver experiences beyond the first two years of the post- stroke recovery trajectory, indicating a need for longitudinal study of their experiences over time. Therefore, the aims of this study were to 1) investigate caregiver experiences of stress and coping over 5-7 years post stroke using quantitative methods, and 2) explore through qualitative methods their stress and coping experiences over time and the concordance or divergence of qualitative and quantitative findings using a mixed-methods approach.

The study proposal describes study specific aims, background and significance, research design and methods, and research participant risk and protection. The Human Subject Protection approval letter from the University of Texas Health Science Center at Houston Committee for Protection of Human Subjects (CPHS) was obtained in September 2012. Appendix C contains the approval letter. The proposal was defended in August 2013.

A preliminary study was conducted to test the feasibility of using the convergent QUAN-QUAL approach to triangulate both quantitative and qualitative findings with a sample size of 30 caregivers of stroke survivors. A parallel tracks approach was utilized to conduct analysis separately through the steps of data reduction and transformation and then bringing them together for synthesis in the interpretation stage. After the initial

quantitative and qualitative analyses, side-by-side comparisons were utilized to convey the merged results by presenting them in a discussion or in a summary table. After completing the pilot work, the investigator in consultation with the dissertation committee decided that the triangulated method was feasible for a larger scale of study. No changes in the methods or procedures were made after the pilot work. However, in order to enhance the objectivity of interpretation of the study, detailed audit trails were used during the data analysis and synthesis for documentation of the decision-making process.

Study results are presented in two manuscripts describing experiences of stress and coping over time by caregivers of stroke survivors using a mixed-methods triangulated approach. In Manuscript A, *Experiences of Stress and Coping over Time by Caregivers of Stroke Survivors* – a quantitative study, demonstrated that caregivers continued to experience stress along with decreased social support over an average of 5-7 years post stroke. There was not a significant change over time in stress and total coping over time; however, there was a significant decrease over time in two subscales of coping scales – acquiring social support and mobilizing family support. This finding was supported by qualitative data as caregivers noticed that social support gradually decreased over time (described in Manuscript B).

Manuscript B, *Experiences of Stress and Coping over Time by Caregivers of Stroke Survivors* – a mixed-methods study, explored through qualitative methods their stress and coping experiences over time and the concordance or divergence of qualitative and quantitative findings using a triangulated approach. The qualitative findings indicated

that four major categories of stress-related themes persisted through all stages of the stroke recovery trajectory. However, there were different sources leading to stress at different times. Their emotional stress evolved over time. Across semi-structured interviews, spousal caregivers reported a variety of sources of stress and coping behaviors. The majority of spousal caregivers that experienced a low stress level also reported a high score of coping measurement, indicating an agreement between qualitative and quantitative findings based on the reported stress and coping themes.

This study was a secondary data analysis focusing on stress and coping experiences of stroke caregivers who previously completed the Committed to Assisting with Recovery after Stroke (CAREs) study at baseline, 3-, 6-, 9-, and 12- month post stroke and also completed a follow-up (Faith, Hope, and Life Satisfaction -- FHLS) study 5-7 years after its completion. Dr. Sharon Ostwald, Professor Emerita was the principal investigator of both studies. CAREs was an intervention study using advanced practice nurses and therapists to provide education, training, support, counseling, and community linkages for stroke survivors and caregivers in home settings. Its follow-up study, FHLS, was conducted to better understand faith, hope and life satisfaction in the stroke recovery trajectory.

Appendix A contains Faith, Hope, and Life Satisfaction study interview questions. Appendix B and C contain summaries of stress and coping related themes over time and Comparison of Information from Interviews and the quantitative findings on stress and coping measurements, respectively. Appendix D contains the Human Subject Protection approval letter from the University of Texas Health Science Center at Houston

Committee for Protection of Human Subjects (CPHS). Appendix E is made of study documents used in the collection of data for CARES and FHLS studies, including the demographic form, the Perceived Stress Scale (PSS) and the Family Crisis Oriented Personal Scales (F-COPEs). Appendix F contains the operational manual describing the coding process and data management. The investigator's Curriculum Vitae is in the last section.

**Experiences of Stress and Coping Over Time by Caregivers of  
Stroke Survivors: A Mixed-Methods Approach**

**A Dissertation Research Proposal**

**The University of Texas Health Science Center at Houston**

**School of Nursing**

**Fang Ye, MSN, ANP, RN**

**August, 2013**

## **Experiences of Stress and Coping Over Time by Caregivers of Stroke Survivors: A Mixed-Methods Approach**

### **Specific Aims**

Stroke remains the leading cause of death and long-term disability worldwide (Roger et al., 2011). The rising aging population and advancing medical therapy for acute stroke suggest that there will be an increase in the number of stroke survivors potentially living with disabilities. About one third of this population requires care by their family members (Kerr & Smith, 2001). Over the decades, research studies have mainly identified caregiver experiences related to caregiving during the first one-to-two years poststroke. Study findings showed that caregivers often reported physical and mental stress, decreased physical and emotional well-being, and high burden of care. Stressors related to caregiving are often persistent, unpredictable and uncontrollable (Aldrich, 2011). Caregivers also reported having less time for families and social activities, neglecting self-care, feeling increased emotional stress, and experiencing a decline in their own health (Aldrich, 2011). There is also evidence to indicate that caregiver stress may impede the recovery process of stroke survivors (Han & Haley, 1999).

However, little is known about caregiver experiences beyond the first two years of poststroke recovery trajectory. Over the years, little attention has been given to explore experiences of stroke caregivers over time, and almost no studies have explored this population more than two years poststroke. This proposed study will be a secondary data analysis of the randomized control clinical trial, Committed to Assisting with Recovery after Stroke (CAREs) study between 2001 and 2005, and its follow-up study between

2008 and 2011, using a mixed, quantitative and qualitative triangulated method. The major purpose of this study is to explore how stress and coping experienced by stroke caregivers evolve over time (5-7 years post stroke).

### **Specific Aims**

1. To explore experiences of stroke caregivers related to stress and coping over time, an average of 5 – 7 years poststroke.

#### Hypotheses:

- a. Stroke caregivers will experience a change in the stress and coping experiences at different stages of the stroke recovery process.
  - b. Caregiver stress will be predicted by socio-demographic variables (age, gender, race/ethnicity, socioeconomic status, health insurance coverage).
  - c. Caregiver stress will be correlated to coping variable.
2. To examine the relationship between qualitative and quantitative findings associated with stress and coping variables.

This study is designed to fill the gaps in knowledge regarding family caregivers' experiences of caregiving-related stress and coping skills 5-7 years post stroke. The long-term goal is to employ the findings in stress management, thereby promoting caregivers' own health.

### **Background and Significance**

There are 15 million people worldwide who suffer a stroke each year, and 10 million are survivors (McKay, Mensah, Mendis, & Greenlund, 2004). In the United States, approximately 795,000 patients experience first or recurrent strokes annually



(NSA, 2011). By 2020, stroke and heart disease are expected to be the leading cause of death and disability worldwide, with the number of fatalities estimated to expand to over 20 million a year. By 2030, the rate will increase to more than 24 million a year (World Health Organization [WHO], 2011). According to the National Stroke Association [NSA] (2011), only 10% of stroke survivors recover almost completely; 25% recover with minor impairments; and, 40% experience moderate to severe impairments requiring special care. During the first year of post-stroke recovery, up to 80% of stroke survivors return to their communities and homes, and one third of this population requires care by family members (Kerr & Smith, 2001). It is estimated that the demand for caregivers will increase due to the growing aging population in the next few decades (Aldrich, 2011). This demand could also be related to shorter hospital stays, poor hospital discharge plans, changes in insurance policies, and advancing medical home technology (Aldrich, 2011). Therefore, the anticipated increase in stroke survivors with disability will impose a huge burden on the families of stroke survivors and their caregivers, the community, and the healthcare system. Given stroke's high incidence and mortality rates, there will be a large portion of survivors living with significant residual physical, cognitive, and psychological disabilities (Gresham, 1990).

Because of the continuing shift from institutional care to community care, family members are becoming the primary caregivers of stroke survivors; therefore, support and education for caregivers have been increasingly critical to influence not only themselves, but also the quality of life of stroke survivors (Visser-Meily, Post, Schepers, & Lindeman, 2005). Thus, family caregivers need to learn skills to assist stroke survivors

with various impairments while adapting to the changes that result from caregiving (Bakas, Austin, Jessup, Williams, & Oberst, 2004).

Being a caregiver is demanding and challenging, both physically and mentally. Because of the abrupt onset of a stroke, it often results in sudden life changes in the roles and responsibilities of the stroke survivor and the caregiver. In general, the caregiver assumes or takes over multiple responsibilities that the stroke survivor is no longer able to accomplish. Such changes can potentially impact the physiological and psychosocial well-being of caregivers. Research studies have reported that caregivers had a higher risk of depression (Cuijpers, 2005), higher levels of stress hormones (de Vugt, et al., 2003), and lower levels of global health, when compared with non-caregivers (Vitaliano, Zhang, & Scanlan, 2003). Caregivers of stroke survivors also had experienced physical and mental distress, social isolation, burnout, and poor quality of life (van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001). More significantly, Schultz and Beach (1999) reported that older spousal caregivers had a 63 percent greater risk of mortality within four years than non-caregiving control groups.

Coping, well recognized as a mediating factor, has been found to be significantly related to stress. There is ample evidence showing that stress was found significantly, positively correlated with emotional-focused (avoidance) coping style and negatively associated with problem-focused (active) coping style (Papastavrou et al., 2007; Norizan & Shamsuddin, 2010; Treharne et al., 2007). A negative relationship between stress and coping resources has also been suggested (Wu, Li, Zhu, Li, & Wang, 2010; Santos, Barros, & Carolino, 2010), indicating that caregivers who cope better with challenges

related to daily caregiving tasks experience less stress. Thus, it is important to help caregivers understand the nature, stressfulness, and effectiveness of coping with caregiving-associated problems during the different stages of recovery trajectory in order to reduce negative experiences associated with caregiving and to promote caregivers' own health.

Since the majority of research has focused on stroke survivors and caregivers during the first year or two years of poststroke, little is known about factors, which contribute to caregiver stress and coping experiences two years poststroke. To date, almost no longitudinal studies have explored caregivers' experiences over time two years poststroke. Moreover, none have utilized a mixed methods approach to explore this unique population two years poststroke. Therefore, the need for a long-term follow up study of caregivers is evident in order to have a better understanding of caregiver stress and coping experiences during the long-term trajectory of the recovery process. The study proposed herein will be a secondary data analysis and will focus on a previous intervention research, CARES, which was conducted between 2001 and 2005, and the CARES follow-up study. It is the first study using a quantitative and qualitative triangulated approach to explore caregivers' stress and coping experiences 5-7 years post stroke. This study is significant because it can potentially help to elucidate potential strategies to help stroke caregivers cope with daily stress.

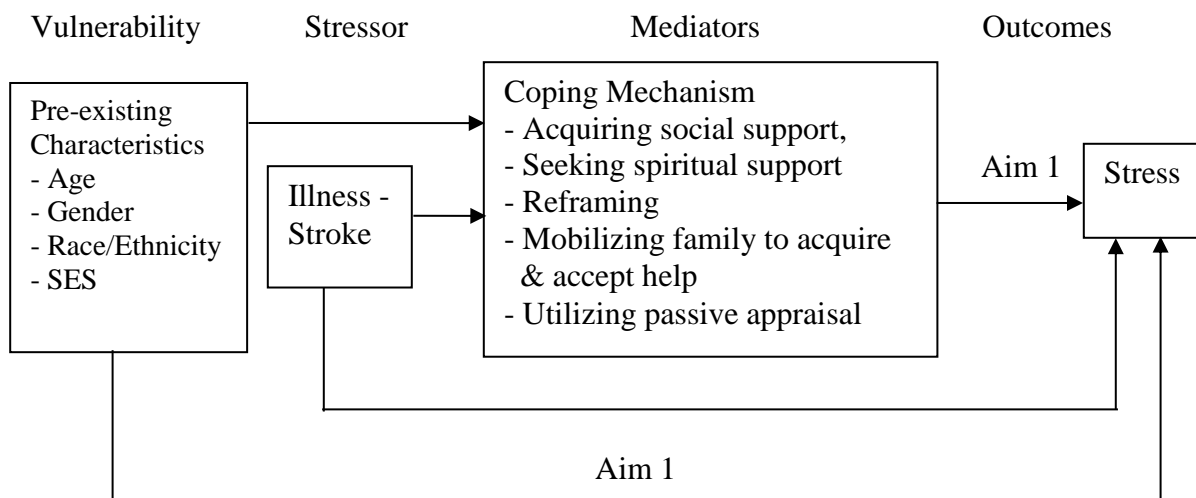
Committed to Assisting with Recovery after Stroke (CARES ) was an intervention study using an advanced practice nurse (APN) with the assistance of an interdisciplinary team to provide education, support, skills training, counseling, and social and community

linkages for stroke survivors and caregivers in home settings. 159 couples were enrolled and followed for 24 months. They were divided into intervention and usual care groups to test differences of change across variable measures at baseline, 3-, 6-, 9-, and 12-months. The overall purpose of CARES was to improve function and quality-of-life of stroke survivors and reduce stress and other caregiving-related negative experiences of caregivers. Shortly after the completion of the CARES research, participants who completed 12 months of data collection were recruited for participation its follow-up study: Faith, Hope and Life Satisfaction (FHLS) in stroke survivors and spousal caregivers, a mixed-methods study. Data collection began in 2008 using the same instruments employed in the CARES study to collect quantitative data. In-depth, semi-structured interviews were conducted after questionnaires were completed. Currently, data collection is complete and is in the data analysis stage. The primary goal of the FHLS is to better understand faith, hope and life satisfaction in the stroke recovery trajectory, and the secondary goal is to determine the relationship between the quantitative data obtained by questionnaires and the qualitative data obtained by interviews.

This proposed study will examine the state of the FHLS study caregivers an average of 5-7 years post-stroke, using a mixed triangulated approach to explore their stress and coping experiences during different stages of the stroke recovery process. It will help to identify factors impacting caregivers' capabilities to cope with stress and sources of stress on a daily basis for a long period of time. It can then provide evidence-based data to guide future studies. The overall goal of this descriptive QUAN-QUAL,

triangulated, mixed methods study is caregivers' stress and coping experiences evolution over time 5 – 7 years poststroke.

A model of stress-coping for family caregivers adapted from the Transactional Stress and Coping theory by Lazarus and Folkman (1984) provides the conceptual framework for this proposed study. The model proposes that external demands (stressors) are manageable through the coping process. Under the guidance of this framework, the caregivers' psychosocial outcomes are a response to exposure to a stressor (caregiving), and their vulnerability will be buffered by coping resources. Therefore, these combined factors may impact health and well-being directly and indirectly through coping strategies.



*Figure 1.* Stress-Coping Conceptual Framework

## **Preliminary Studies**

**Pilot work.** The purpose of this pilot study was to test the feasibility of using the convergent QUAN-QUAL approach to triangulate both quantitative and qualitative findings. A mixed-method, triangulated approach with a convergent QUAN-QUAL design was utilized to obtain different but complementary data on the same topic in order to have a better understanding of caregiver experiences over time (Creswell & Plano Clark, 2011). It is the first study using a quantitative and qualitative triangulated approach to explore caregivers' stress and coping experiences over time. This pilot project was a secondary data analysis focusing on stress and coping experiences of stroke caregivers who previously completed the Committed to Assisting with Recovery after Stroke (CAREs) study (baseline, 3-, 6-, 9-, and 12- month post stroke) and also completed a follow-up (Faith, Hope, and Life Satisfaction --FHLS) study 5-7 years after its completion. Caregivers who completed the CAREs study between 2001 and 2005 also participated in the follow-up (FHLS) study will be included in the study. However, only five participants were randomly selected and included in the data analysis for this pilot project to test the feasibility of the proposed QUAN-QUAL triangulation approach. The primary outcome variable was caregiver stress, which was assessed by the Perceived Stress Scale (PSS). The primary independent variable was coping strategies utilized by the caregivers who were asked to complete the Family Crisis Oriented Personal Evaluation Scales (F-COPEs) assessment. The PSS and F-COPEs instruments were completed for both CAREs and FHLS study. The PI of FHLS conducted a semi-structured interview using an interview guide (see Appendix A).

**Data Analysis.** A parallel tracks approach was utilized to conduct analysis separately through the steps of data reduction and transformation and then bringing them together for synthesis in the interpretation stage (see figure 1). This approach allows researchers to reconcile discrepancies in interpretation that might have occurred in studies used only one of the research methods (Li, Marquart, & Zercher, 2000). After the initial quantitative and qualitative analyses, side-by-side comparisons were utilized to convey the merged results by presenting them in a discussion or in a summary table.

**Results.** Caregivers (N =5) had an average age of 63.9 years (SD = 13.2 years) ranging from 52 to 80 years, and 3 (60%) were minorities. The PSS scores range from 0 - 40 with the higher the scores, the worse the stress. Caregivers reported a range of 2-22 caregiving-related stress with an average score of being 12 on the PSS measurement. The F-COPEs range from 50-130, higher scores indicate better problem-solving and behavioral skill, while lower scores indicate a shortage of general coping strategies. On the F-COPEs, the participants' scores ranged from 100 to 129. The mean score was 113.4 indicating that participants had good coping resources and skills.

A majority of themes expressed by participants was related to stress resulted from caring stroke survivors and strategies utilized to cope with stress. Themes emphasizing caregiver stress include: physical strain, emotional strain, financial strain, time constraints, changes in spousal relationships, and cognitive impairments of stroke survivors. Themes address coping behaviors including: family/social support, spirituality/faith in God/prayer, being active, let go of worries/protectiveness, learning to deal with difficulty/disability, and pragmatism.

Across semi-structured interviews, family caregivers reported a variety of sources of stress and coping behaviors. The majority of participants who reported a low stress level also reported a high score of coping measurement, which is consistent with the mediating effects of coping on stress; however, it is interesting to note that two out of five participants who experienced high stress levels had indicated good problem solving and behavioral strategies evidenced by the high scores of F-COPEs measurements. These two caregivers particularly addressed the spirituality and religious support as their major coping resources. Overall, qualitative findings are in agreement with quantitative results.

**Recommendations.** Several limitations should be noted in this study. First, the sample size was small with only five participants; the sample may also be biased toward persons who already had knowledge about stroke and sought information. Thus, a more diverse sample needs to include people from different geographic areas providing some representation of cultural differences. Second, as with most qualitative studies, the interpretation of transcripts may be biased by the experience of the researcher. To enhance the objectivity of interpretation of the study, this writer will need to continue to document audit trails for thought and decision-making process. Third, although using a convergent triangulation method is feasible for a mixed-methods dissertation project, there is a lack of clear criteria for determination of the relationship between qualitative and quantitative findings in the literature. It seems that it is appropriate to use the major categories of caregiver stress themes identified in previous studies (such as physical, emotional, and financial strains of caregiving) and five subscales of F-COPEs as the



foundation for comparison of qualitative and quantitative findings in a larger scale of study.

### **Innovation**

The proposed study introduces innovation in its research design and its objectives. Caregivers are a unique population and are facing many challenges. As previously mentioned, caregivers have reported physical and mental issues related to caregiving. The majority of previous studies have only explored the impacts of caregiving between one and two years post discharge. Thus, this study is novel and innovative because:

- First, it is a longitudinal study to follow-up on caregivers who participated in the previous intervention study; therefore, it can help to explore any changes across stress and coping measures at baseline, 3-, 6-, 9-, 12- month and current time (on average 5-7 years poststroke), using repeated measures over time during the stroke recovery process.
- Second, it uses a QUAN-QUAL, triangulated, mixed method to have a better understanding of caregivers' experiences related to coping with stress. The semi-structured in-depth interviews at the current time will be explored, and findings will be compared to quantitative measures. A triangulation using meta-matrix method will be utilized to examine the relationship between quantitative and qualitative findings.
- Third, almost no research studies in the field have explored stroke caregivers' experiences across a long time period using a triangulated mixed method.

Therefore, this study will add a unique body of knowledge to the current research field.

## **Research Design and Methods**

### **Design**

This proposed study will be a secondary data analysis and will focus on stress and coping experiences of stroke caregivers who previously completed the CARES study and also completed a follow-up study 5-7 years after its completion. This study will use a descriptive, mixed-method, triangulated approach. This methodology allows for obtaining different, but complimentary, data via quantitative and qualitative data collection process, thus, providing a more thorough and complete understanding of experiences of stroke caregivers (Creswell & Plano-Clark, 2011). Data were collected through questionnaires and semi-structured interviews. Both qualitative and quantitative data will be analyzed separately first. Then, a meta-matrix method will be performed to explore a triangulation of the findings, and therefore, determine the relationship between the quantitative and qualitative findings.

### **Sample**

For this study, a family caregiver is defined as the person identified by the stroke survivor as providing the majority of care. Caregivers who completed the CARES study between 2001 and 2005 also participated in the CARES follow-up study will be included in this study. For the CARES research, participants were recruited from hospitals and rehabilitation facilities in the Texas Medical Center in Houston after a stroke diagnosis

was confirmed. All the data were collected in the participants' homes or a comfortable place chosen by participants.

**Inclusion criteria.** Subjects, who previously completed the 12 month data collection in the aforementioned CARES study, were eligible to participate the follow-up research. To be eligible to participate in the CARES study, participants had to meet the following inclusion criteria: 1) were 50 years and older; 2) were either caring for a stroke survivor who was discharged home after rehabilitation, or were no longer caring for any such stroke survivor due to the latter's being deceased; 3) lived within 50 miles of the Texas Medical Center; 4) could be reached by telephone at home; 5) were able to communicate in English; and 6) consented to the study.

**Exclusion criteria.** Stroke survivors who were staying in a nursing home or were on hospice care, and either member of the couple with severe psychopathological issues resulting in inability to cooperate with the study were excluded for the study. The stroke survivor who had a life expectancy of less than six months or who was globally aphasic preventing communicating and the ability to consent to the study was also excluded.

The inclusion and exclusion criteria for the FHLS study were the same as those of the CARES study. Participants who completed the 12 month data collection in the CARES study were eligible to participate in the FHLS research.

### **Data Collection and Management Procedures**

**Variables and methods of measurement.** The following instruments were completed for both CARES and FHLS study. The primary outcome variable was caregivers' stress which was assessed by the Perceived Stress Scale (PSS). The primary

independent variable was coping strategies utilized by the caregivers who were asked to complete the Family Crisis Oriented Personal Evaluation Scales (F-COPEs) assessment.

**Perceived stress scale -10 (PSS).** Caregivers' stress experiences will be measured by the PSS 10 which was used in the CARES study. The PSS is designed to assess the degree of stress as individuals respond to demanding life events and is theoretically appropriate for its measurement (Cohen, Kamarak, & Mermelstein, 1983). Study participants are asked to rate their stress level, based on a 5-point Likert scale, within the range of 0 (never) to 4 (very frequently). The total score is the sum of all items from 0 to 40. The higher the score, the worse the stress (Cohen, Kamarak, & Mermelstein, 1983). There are two versions of the survey: PSS-10 and -14. It is reported that the PSS 10-item version has a higher internal consistency (0.78) and that the Cronbach's alpha has reached the value of 0.75 (Cohen & Williamson, 1988). In the past, the test-retest correlation has been as high as 0.85 at six weeks follow-up assessment (Cohen, Kamarak, & Mermelstein, 1983). The PSS has been used in studies with stroke caregivers (Ostwald, et al., 2009) and validated in family caregivers of older adults with heart failure yielding a Cronbach's alpha of 0.86. In addition, construct validity has been supported by the correlation between the PSS and the Center for Epidemiological Studies Depression Scale (CES-D) ( $r = 0.7, p < 0.01$ ) (Schwarz & Dunphy, 2003). Thus, it is chosen for this proposed study.

**The family crisis oriented personal evaluation scales (F-COPEs).** Caregivers' coping strategies will be assessed by the F-COPEs. The F-COPEs was used in the CARES study. It is based on family stress theory and developed to help identify family resources

and perceptions and integrate them into coping skills (McCubbin, Thompson, & McCubbin, 1996). The F-COPEs measures effective problem-solving attitudes and behavior which families develop to respond to stressful situations (McCubbin, Olson, & Larsen, 1981). It consists of 30 coping behaviors and is grouped into five subscales, including acquiring social support, seeking spiritual support, reframing, mobilizing family to acquire and accept help, and passive appraisal. The F-COPEs is a 5-point Likert scale, which ranges from (1) strongly disagree to (5) strongly agree. This tool can be used to assess family members 12 years of age and older (Birenbaum, 1991), and has been studied in caregivers (Smith, 1994) and in families of persons diagnosed with cardiovascular diseases (Nolan, et al, 1992; Brott & Adams, 1989; Wity, Pessin, Kaplan, & Caplan, 1994). The Cronbach's alpha and the four week test-retest for the subscales range from 0.63 to 0.83, and from 0.61 to 0.95, respectively. For the total scale, the Cronbach's alpha is .86 and reliability over 4 to 5 weeks is .81 (McCubbin, Thompson, & McCubbin, 1996).

### **Methods of Data Collection**

The FHLS research used a mixed-methods approach and data were collected in participant homes or in a place where the participant felt comfortable through semi-structured interviews and questionnaires. All participants completed questionnaires and interviews.

**Qualitative data collection.** Caregivers who agreed to participate in the quantitative components of the study were also asked to participate in semi-structured interviews. Interviews followed after participants completed questionnaires. Interviews

were also conducted at a different time and place most convenient for caregivers. Participants were only interviewed once. The Principle Investigator (PI) of the FHLS study was the primary interviewer for qualitative data collection. Analytic notes were recorded during and immediately following each interview. Information such as body language, environmental details, and self-evaluation of each interview were added to the analytic notes. These notes will be utilized to augment data collection and will also permit an on-going dialogue to help the researcher understand when saturation has been reached (Emersion, Fretez & Shaw1995). Approval was obtained from the Institutional Review Board (IRB) of the University, and a formal written consent was obtained from participants before data collection.

***Interview.*** The PI of the FHLS study conducted a semi-structured interview using an interview guide (see appendix A). The interview began with asking broad questions, such as “how is everything going since the stroke has happened;” “how would you describe your experience of caring for your family member who’s had a stroke;” “what aspects of your life have changed being a caregiver;” and, “what has been stressful for you being a caregiver?” Next, specific probes occurred, for instance, “what has helped you the most to cope with these changes?” Or, more specifically, “are there particular skills or resources that worked well for you,” and followed by, “tell me more about it,” or “can you give me some examples?” The broad questions can elicit general information about the caregivers’ experiences, while probes elicit specific information about their experiences associated with the study purpose. The sequence of interview questions was flexible based on the interviewer’s judgment. The home-based interview was preferred

because it could maximize the caregiver's feelings of comfort and relaxation in a familiar environment. It was estimated that each interview lasts approximately 40 to 60 minutes based on previous similar studies (Smith, Gignac, Richardson, & Cameron, 2008; Green & King, 2009).

### **Quantitative data collection.**

*Demographic data.* Potential participants were asked their permission to use the demographic data and other health-related data which were collected in the CARES study, including age, gender, ethnicity, educational level, employment status, type of insurance and family income. If there were any changes, new information was collected and updated in the database.

*Questionnaires.* The aforementioned questionnaires were used to measure predictors and outcome variables in the CARES study. Thus, caregivers were asked to complete the same questionnaires for the FHLS research study. The PI and a research nurse assisted persons as necessary based on their needs. The questionnaires were offered in paper and pencil format in large print in order to accommodate sensory deficits, if any. The instructions of how to complete this type of questionnaire format were given at the time of collecting data. If the participants became tired, another time for data collection was rescheduled.

### **Data Management**

Protected health information of subjects was entered into a double password protected computer database with restricted access to the system. Access was limited to the investigators. All the forms were checked for data completeness before entering into

the database. In addition, data were saved on CDs and imported to SPSS/SAS software for statistical analysis.

Interview data were audio taped and were transcribed by the interviewer following each interview. All the audio tapes were saved as audio files in a restricted access, password-secured computer. The transcription was verified for accuracy by the research team. Once it was validated against the original audio tape, the recording was erased. All identifiable information such as name and address was removed from the transcripts and stored by ID number in a locked file. The text, without identifiable information, was entered into Atlas.ti software 5.0 Windows for data management. The transcriptions were stored in a password-secured computer with restricted access to the PI and study team, including the PI's academic advisor and other dissertation committee members.

### **Data Analysis**

**Quantitative data analysis.** A descriptive analysis of caregivers' demographics will be performed. Missing data will be excluded listwise. Current caregivers will be compared to those who are no longer caregivers to see if there are any differences. The t-test or nonparametric test for independent samples will be performed to compare the caregiver versus non-caregiver groups for continuous variables. In addition, paired t-test will be used to determine if any differences exist between time points within the groups.

The variables of age, gender, ethnicity, socioeconomic status, education level, PSS and F-COPEs scores will be analyzed using the following statistical methods. Repeated measure analysis will be performed to determine the change in stress and



coping variables between the baseline, 3, 6, 9, and 12 month, and current time points. In particular, linear mixed models (Brown & Prescott, 2006) will be used to analyze the scale scores over time. More specifically, one particular model will be designed to analyze each scale; and age, gender, and ethnicity will be included in the models as covariates in order to assess their impact on the stress and coping over time. Pearson correlation coefficients will be calculated to examine the relationships between themes (related to coping strategies) and coping variable.

**Qualitative data analysis.** Qualitative data will be analyzed by using content analysis method which occurs simultaneously with data gathering (Sandelowski, 2000). Content analysis is a method used to analyze written, verbal or visual communication information (Cole, 1988). It is also known as a systematic and objective means of describing and quantifying phenomena (Downe-Wamboldt, 1992; Sandelowski, 1995). It allows researchers to test theoretical issues to promote understanding of the data through distilling words into fewer content-related categories (Elo & Kyngas, 2008). It is assumed that words, phrases, and the like share the same meaning when classified into the same categories (Cavanagh, 1997). It aims for obtaining a condensed and broad description of the phenomenon based on the outcomes of the analysis (Elo & Kyngas, 2008).

The transcripts of each interview were placed in the Atals.ti software 5.0 for Windows. The analysis will begin with the bracketing of personal experiences and previous thoughts with regards to stroke caregivers' stress and coping experiences. A coding process will be developed after reading and rereading the interview transcriptions and will be revised accordingly as new information is obtained. Atlas.ti software will be

used to help code and categorize data separately with the PI. Codes will then be sorted into categories according to relationships and linkages or shared characteristics between different codes. The tentative categories will be discussed and revised by the PI and the PI's academic advisor based on reflection and agreement. At each stage of data analysis, the PI will also record impressions and any personal thoughts in the analytic notes, which will then be further analyzed during continuing data processes.

Finally, themes related to caregivers' stress experiences and coping strategies will be achieved. Patterns will be explored between themes and caregiver versus no longer caregivers. Peer briefing will also be assured between the PI and the PI's academic advisor in order to ensure that the interpretations are consistent with the data. All the findings will be verified by the PI's academic advisor who has experience in qualitative interviewing.

**Triangulation.** The meta-matrix method will be used to look for patterns among the quantitative and qualitative findings. The method has been utilized to facilitate reviews of literature (Garrard, 1999) and to analyze the complex data in social science (Miles & Huberman, 1994). The meta-matrix approach enables a linkage of data sets and occurs following traditional quantitative and qualitative data analyses (Wendler, 2001). It includes development of the matrix itself; transcription of data into the matrix; coding data and noting reflections; identifying common phrases; and, separating patterns and processes (Wendler, 2001). These processes provide an opportunity to evaluate all the qualitative data alongside the quantitative data in an all-at-once methodology of triangulation (Wendler, 2001). It facilitates triangulation because it allows researchers to

return to the raw data and to meld data across data sets (Wendler, 2001). Therefore, this method can help determine if quantitative measurements of F-COPEs and PSS are in agreement with the related themes respectively.

The data will be displayed in the table below, which is adapted from Wendler's model.

Questionnaire Scores	Codes	Themes	Analytic Notes	Other Comments

### **Limitations**

Limitations for the study will include limited generalizability due to relatively small sample size and persons chosen to participate may have characteristics. The sample in this study was comprised of older adults, and therefore, the study results may not be applicable to other age groups. However, the homogeneity of sample may enhance the internal and external validity of the study findings. Another potential limitation is self-reported data which may pose validity concerns. Although the nature of secondary data analysis limits the access to numbers of variables, the QUAN – QUAL triangulated methodology will help to thoroughly illustrate the experience of stroke caregivers in stress and coping during stroke recovery process.

### **Research Subject Risk and Protection**

This proposed study will be a secondary data analysis of the original CARES study (Ostwald: R01NR0035316) and the FHLS study (Ostwald, PI) and as such risks associated with the study will be only minimal. All subjects provided informed consents

for their participation of the two studies. Studies had been approved by the University of Texas Health Science Center at Houston Committee for the Protection of Human Subjects Internal Review Board (CAREs IRB Number HSC-SN-00-003; approval date July, 2001 and the follow-up study FHLS HSC-SN-08-0397; approval date August 15, 2008). Data of both CAREs and FHLS studies are managed by the investigator of this proposed project, who is currently working with the PI of the original studies. To ensure the anonymity of the participants, all data will remain de-identified and kept on a password-protected computer which are only accessible to the investigator and the dissertation committee.

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From: "Ye, Fang" <Fang.Ye@uth.tmc.edu>  
To: "Craig Zercher" <czerche@wested.org>  
Sent: Tuesday, July 5, 2016 9:07:58 PM  
Subject: Permission to use a mixed-methods figure

Dear Dr. Zercher,

My name is Fang Ye, a doctoral nursing student at the University of Texas Health Science center at Houston. I am writing to ask for your permission to use one of a mixed-methods figure that was published in 2000 --"Conceptual issues and analytic strategies in mixed-methods of preschool inclusion" in the Journal of Early Intervention. I adapted the figure and try to use it in my dissertation with your permission.

The authors of this article were Drs. Shouming Li, Jules. M. Marquart, and you. I couldn't find the first or second author's contact info. I am hoping that you could grant me to use it or if you could provide me with the other two authors' contact info, I'll really appreciate it.

Thank you!

Fang Ye

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Hi Fang Ye,

On behalf of the other authors, I grant you permission to use the figure described in your email below and to adapt it as needed to fit your approach. Please cite the original article in reference to the figure. Thank you for contacting us and good luck with your study!

Craig Zercher

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**Experiences of Stress and Coping Over Time by  
Caregivers of Stroke Survivors**

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### Abstract

**Background/ Objectives:** Caregivers of stroke survivors often experience physical and mental stress, decreased physical and emotional well-being, high burden of care, social isolation, and neglecting self-care. The majority of previous research studies have identified caregiver experiences during the first one-to-two years post stroke. Little is known about caregiver experiences beyond the first two years of the post- stroke recovery trajectory, indicating a need for longitudinal study of their experiences over time. Therefore, the purpose of this study was to investigate caregiver experiences of stress and coping over 5-7 years post stroke.

**Methods:** This study was a secondary data analysis of a randomized clinical trial, CARES (Committed to Assisting with Recovery after Stroke), between 2001-2005 and its follow-up study (between 2008-2011). A longitudinal follow up study was utilized to explore experiences of stress and coping over time by spousal caregivers of stroke survivors at baseline, 3, 6, 9, and 12 months post stroke and 5-7 years later. Repeated measures of quantitative data on stress and coping of caregivers of stroke survivors were analyzed.

**Results:** Caregivers (N = 30) were primarily female (n =22, 73%) with a mean age of 58.8 and 33% were minorities. The range of mean perceived stress scores (PSS) was from 12.8-15.7 indicating caregivers experienced an average level of stress over time. The PSS scores gradually decreased with the lowest score at 5-7 years post stroke with a 1.5-point drop in PSS scores. However, the changes were small and not statistically significant (p = .32).

The range of mean scores on the Family Crisis Oriented Personal Evaluation Scale (F-COPEs) was from 104.4 -119.9 implying spousal caregivers adopted multiple coping strategies. An inverse relationship between PSS and F-COPEs was statistically significant ( $p = .01$ ) indicating higher coping associated with lower perceived stress, and such a relationship did not change over time ( $p = .90$ ). There was not a significant change over time in total coping scores ( $p = .53$ ); however, a significant decrease over time was noted in two subscales – Acquiring Social Support (ASS) ( $p = .02$ ), and Mobilizing Family Support (MFS) ( $p = .03$ ).

**Conclusions:** Spousal caregivers continued to experience stress along with decreased social support as time progressed post-stroke. These results support caregiver stress could be lessened if appropriate interventions were tailored to their special needs during different stroke recovery stages. Further study is indicated that would develop effective timely interventions for both stroke survivors and their caregivers over time.

## **Experiences of Stress and Coping Over Time by**

### **Caregivers of Stroke Survivors**

#### **Introduction and Purpose**

Stroke has been reported as the fourth leading cause of death and as the leading cause of long-term adult disability in the United States (American Heart Association, [AHA], 2013). As the population ages and medical advancements result in lower stroke mortality, it is anticipated that there will be an increase in the number of stroke survivors who live with various degrees of disabilities, leading to reduced quality of life and ability to remain independent. The increase in life expectancy with disability will likely impose a huge burden on the families of stroke survivors, the community, and the healthcare system. Because of the continuing shift from institutional to community care, family members have become the primary caregivers of stroke survivors; thus, caregiver support and education are increasingly critical to influence quality of life for both caregivers and stroke survivors (Visser-Meily, Post, Schepers, & Lindeman, 2005).

Over the past decades, the majority of research studies have identified caregiver experiences during the first one to two years post-stroke. Stressors related to caregiving are often persistent, unpredictable, and uncontrollable (Aldrich, 2011; Haley, Roth, Hovater, & Clay, 2015). It has also been reported that caregivers often experience physical and mental stress, decreased physical and emotional well-being, high burden of care, social isolation, and neglecting self-care (Bakas et al., 2014). Caregiver stress has been shown to cause declining health and increase risk of mortality, as well as interfering with rehabilitation of stroke survivors (Bakas, et al., 2014); it also recognized as a leading

cause of stroke survivor institutionalization (Bakas, et al., 2014). Therefore, a wide range of intervention studies have sought to reduce or prevent detrimental aspects of caregiving (Kramer, 1997; Legg et al., 2011). The effects of these interventions have been inconclusive (Legg et al., 2011), likely due to failure to recognize caregiver needs over a long period of time during the survivors' recovery trajectory since the majority of research studies have mainly focused on the first one to two years post-stroke. Thus, little is known about caregiver experiences beyond the first two years of the post-stroke recovery trajectory. A long-term follow-up study of caregivers is needed to develop a better understanding of caregiver stress and coping experiences over time. Therefore, the purpose of this study was to investigate caregiver experiences of stress and coping over five to seven years post stroke.

### **Review of Literature**

There are 15 million people worldwide who suffer a stroke each year; 10 million are survivors and five million are left with various degrees of permanent disability (World Heart Federation Organization, 2015; McKay, Mensah, Mendis, & Greenlund, 2004). In the United States, approximately 795,000 patients experience first or recurrent strokes annually (Dariush et al., 2015). Only 10% of stroke survivors experienced almost complete recovery; 25% recovered with minor impairments; and 40% experienced moderate to severe impairments requiring special care (National Stroke Association [NSA], 2016). During the first year of post-stroke recovery, up to 80% of stroke survivors returned to their communities and homes, and one third of this population required care by family members (Wilkinson, et al., 1997). Recent studies found that



around 30% of the survivors still suffer significant functional limitations five years post stroke (Luengo-Fernandez et al., 2013; Pallesen, Pedersen, & Holst, 2014).

Stroke often leaves survivors with prolonged chronic care needs. Due to a shift from institutional to at-home care following hospital discharge, the family assumes greater responsibility for assisting loved ones who suffer from the disease. Over time, the complexity of the disease can lead to considerable physical, emotional, and psychological distress in family caregivers, along with increasing functional dependence, cognitive disability, and behavioral problems in stroke survivors (Clarke, 2009). Research to date has contributed greatly to our understanding about many aspects of the caregiving experience and its impact on the caregiver, especially with respect to negative outcomes (i.e., stress, burden) associated with the role.

Studies have shown that caregivers of stroke survivors experience physical and mental distress, social isolation, burnout, poor quality of life (van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001), deterioration of health status due to neglecting self-care (Aldrich, 2011), a more restrictive social life, and poorer well-being (Han & Haley, 1999; Low et al., 1999; Visser-Meily et al., 2005; Wyller et al., 2003). It has also been reported that caregivers of stroke survivors suffer increased risk of coronary heart disease (Lee, Colditz, Berkman, & Kawachi, 2003) and increased mortality (Christakis & Allison, 2006; Schulz & Beach, 1999) when compared to noncaregivers. In addition, caregivers often reported having less time for families and social activities, having difficulty doing housework and coping at work, and experiencing a deterioration of family relationships (Watanabe et al., 2015).

More recent evidence points to serious consequences of long-term caregiving; however, to date, few longitudinal studies have analyzed changes in caregiver stress, burden, or strain over long periods of time after stroke. The majority of studies only collected data over a period of one to two years following the stroke or hospital discharge (Rigby, Gubit, & Phillips, 2009; Gaugler, 2010). In general, the findings have been relatively consistent. A recent study that followed spousal caregivers for three years post stroke revealed a significant decline in the level of caregiver burden over time; however, 43% of the caregivers still reported significant strain at the final evaluation (Visser-Meily et al., 2009). Similar findings of decreased perceived stress in the combined groups of caregivers were also reported in a randomized clinical trial with no significant differences between the caregiver groups at six or 12 months post stroke (Ostwald et al., 2014). A recent population-based case-control study found that caregivers of stroke survivors had considerable caregiver stress at nine months post stroke with a diminishing trend over a period of 36 months after the stroke when compared with demographically matched noncaregivers (Haley, Roth, Hovater, & Clay, 2015). Jaracz et al. (2015) also found considerable burden in 44 and 30% of the caregivers at six months and five years post stroke, respectively; the average value on the general strain subscale of the total caregiver burden scale declined significantly. However, 50% of those who reported severe burden at six months still scored above the cut-off point for high burden at five years.

Caregivers of stroke survivors from different ethnic/racial backgrounds can have different experiences due to family dynamics and structure, cultural norms, and living arrangements (Hinojosa, Zsembik, & Rittman, 2009). It has been reported that caregiving

strain may be reduced in families with more members available to provide care (Hinojosa et al., 2009). For instance, caregiver networks of Puerto Rican stroke survivors were significantly larger than those of Whites or African Americans. They tended to have multiple caregivers, were more likely to rely on children—especially coresident children—with a child rotation pattern (Hinojosa et al., 2009). Family caregivers of Latino stroke survivors had poorer mental health compared to those of White and Black patients (Perrin, Heesacker, Uthe, & Rittman, 2010). African American caregivers had better mental health than Whites (Clay et al., 2013), suggesting some resilience to caregiving stress (Clay et al., 2008). In addition, caregivers who were female, younger, and had significantly lower educational attainment and income were more likely to report a subsequent history of stroke, chronic lung disease, depressive symptoms, and more overall health problems (Haley et al., 2015).

As a result of medical advancements, increasing numbers of stroke survivors living with various degrees of deficits require long-term care and negative effects associated with caregiving may also be long-lasting. Consequently, longitudinal studies are needed to understand the progression of stroke and the multiple-care needs over health-related transitions. The development of dementia, repeated hospitalizations, and falls make the caregiving process increasingly complicated over time (Gaugler, 2010). During the first year post discharge from inpatient rehabilitation, 50% of stroke survivors reported adverse events resulting in death or admissions to the emergency department, hospital, or long-term care facility (Ostwald, Godwin, Ye, & Cron, 2013). Psychological challenges that caregivers face do not necessarily become less complicated over time,

even if caregivers become more confident in their ability to support stroke survivors (Cameron & Gignac, 2008).

Caregiving challenges may arise, change, or continue over a long period of time. Although these are not all of the potential effects of caregiving that could be explored through longitudinal research, they do provide examples of critical changes that may result from caregiving (such as stressors or negative emotional consequences) but can only be detected and quantified by measurement over time. Longitudinal studies would also provide valuable insight into the evolution of caregiving.

### **Theoretical Framework**

A model of stress-coping for family caregivers adapted from the family stress and coping theory by McCubbin and McCubbin (1987) provided the conceptual framework for this study. The model proposes that external demands (stressors) are manageable through the coping process. Within this framework, patient and caregiver physical and psychosocial outcomes result from exposure to a stressor (stroke) and their vulnerability is buffered by coping resources. The theory, therefore, suggests that improvements in caregiver well being could be attributable to reduction of stressor (e.g., stroke survivor recovery) or improvement in caregiver appraisal and coping skills with experience (Veiser-Meily et al., 2009).

Therefore, the purpose of this study was to explore experiences of stress and coping by caregivers of stroke survivors over a period of five to seven years post stroke. The tested hypotheses were: (1) caregivers will experience a change in stress and coping experiences over time; (2) caregiver stress/coping experiences will be predicted by socio-

demographic variables (age, gender, ethnicity, socioeconomic status, and health insurance coverage); and (3) caregiver stress will be negatively correlated with caregiver coping at each time point following stroke.

## **Methods**

### **Study Design**

This study was a secondary analysis of data collected for a randomized controlled trial, Committed to Assisting with Recovery after Stroke (CAREs), conducted between 2001 and 2005 (Sharon K. Ostwald, PI, R01NR05316), and its follow-up study, Faith, Hope, and Life Satisfaction (FHLS). CAREs was an intervention study using advanced practice nurses (APNs) along with occupational and physical therapists to provide education, support, skills training, counseling, and social and community linkages for stroke survivors and caregivers in home settings. The overall purposes of CAREs were: to improve the perceived health of spousal caregivers by increasing their coping skills and use of social supports to decrease depression, stress, and burden; and to improve the perceived health of stroke survivors by decreasing depression and negative impacts of the stroke on their lives and increasing their cognitive and physical functioning and mutuality. The study followed 159 couples (stroke survivors and their spousal caregivers) randomized into either a group receiving mailed information for 12 months or a group receiving the mailed information and a six-month home-based intervention (Ostwald et al., 2014).

Demographic data were collected from the spouse at baseline and subsequent assessments were collected in the couples' homes at 3, 6, 9, and 12 months post-

discharge. Couples who completed the initial 12 months were asked to complete surveys at 18 and 24 months, and couples who completed 24 months of data collection were recruited for participation in the subsequent FHLS study.

Data collection for the mixed-methods FHLS study began in 2008 (five to seven years post discharge, on average) using the same instruments employed in the CARES study to collect quantitative data, as well as additional instruments to assess hope and faith. In-depth, semi-structured interviews were conducted after questionnaires were completed. Data collection was completed in 2011. The primary goal of the FHLS was to better understand faith, hope and life satisfaction in the stroke recovery trajectory, and the secondary goal was to determine the relationship between the quantitative data obtained using questionnaires and the qualitative data obtained through interviews.

This secondary data analysis focused on the stress and coping experiences of stroke caregivers who previously completed the CARES study at baseline, 3, 6, 9, and 12 months post stroke and the follow-up (FHLS) study five to seven years later. Repeated measures of quantitative data on to stress and coping of stroke survivor caregivers over time were analyzed.

### **Subjects/Recruitment**

For this study, a family caregiver was defined as the spouse of a stroke survivor. Caregivers who completed the CARES study between 2001 and 2005 and also participated in the follow-up (FHLS) study were included in this secondary analysis. For the CARES research, participants were recruited from five healthcare systems in the Texas Medical Center in Houston, Texas after a confirmed stroke diagnosis. The CARES

study recruiter reviewed medical charts to determine the eligibility. Oral and written information were provided to eligible subjects before obtaining written informed consent. Schulz et al. (2006) published a detailed description of the study recruitment/retention process, as depicted in Figure 1.

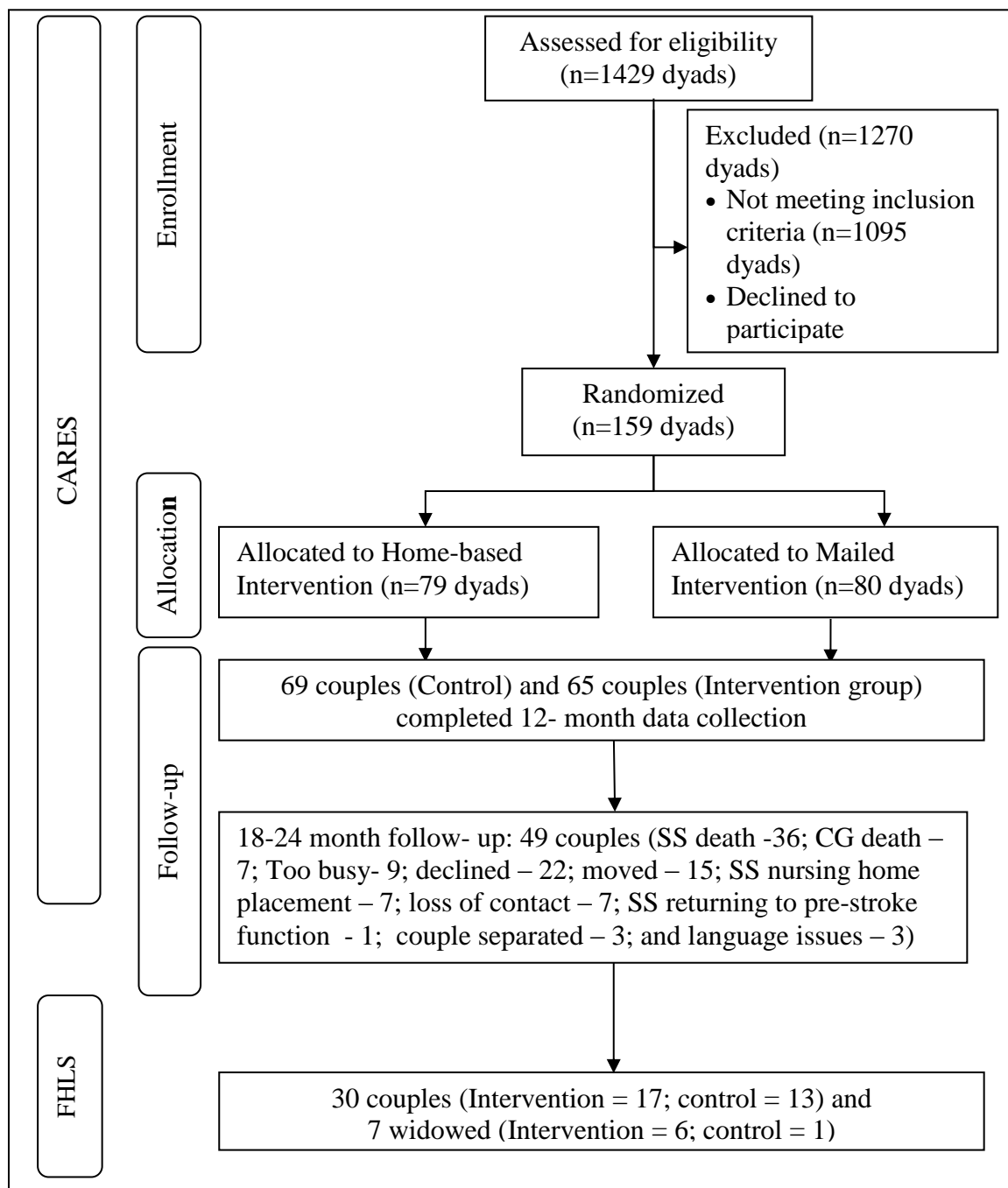


Figure 1. Trial Profile



**Inclusion criteria.** Couples participating in the CARES study met the following inclusion criteria:

- one member of the couple had a diagnosis of stroke within the previous 12 months and was admitted to the hospital from home;
- the stroke survivor required assistance with daily activities;
- the stroke survivor was discharged home;
- both members of the couple were able to communicate in English;
- the stroke survivor was 50 years or older;
- the couple lived within 50 miles of the Texas Medical Center and could be reached by telephone at home; and
- both members of the couple were able to consent to the study.

**Exclusion criteria.** Subjects were excluded if:

- the stroke survivor had a comorbidity that would take priority over stroke rehabilitation;
- either member of the couple had severe psychopathology that would interfere with the intervention;
- the stroke survivor had a life expectancy of less than six months; or
- the stroke survivor was globally aphasic preventing communication and the ability to consent to the study.

The inclusion and exclusion criteria for the FHLS study were the same as those of the CARES study. Participants who had previously completed the 12 month data collection in the CARES study were eligible to participate in the follow-up FHLS

research. A letter about the FHLS was mailed to potential participants by the research nurse and those who indicated interest and met inclusion criteria were contacted by telephone to further explain this study and answered questions. The research nurse scheduled and tracked in-person data collection for participants who agreed to take part in the study.

The present study included participants who completed the FHLS study (n=30). Caregivers who were no longer providing care to their spouses due to the survivor's death, nursing facility placement, relocation, or were lost to follow up were excluded from the data analysis (n=7).

### **Methods of Data Collection**

The research nurse in the CARES study and the research nurse and the PI in the FHLS study collected data in participants' homes by appointment. Participants in the quantitative components of the study were also asked to participate in semi-structured interviews after completion of questionnaires.

### **Variables and Methods of Measurement**

The following instruments were completed for both the CARES and FHLS studies. The primary outcome variable of this secondary analysis was caregiver stress, which was assessed using the Perceived Stress Scale (PSS). The primary independent variable was coping strategies used by the caregivers was assessed using the Family Crisis Oriented Personal Evaluation Scales (F-COPEs).

**Perceived stress scale-10.** The PSS is designed to assess the degree of stress as individuals respond to demanding life events (Cohen, Kamarak, & Mermelstein, 1983).

Study participants are asked to rate their stress levels based on a 5-point Likert scale with a range of 0 (*never*) to 4 (*very frequently*). The total score is the sum of all items and can range from 0 to 40. The higher the score, the worse the stress; scores 0-11 indicate low stress level, scores 12-15 indicate average stress level, and scores  $\geq 16$  indicate high stress level (Cohen, Kamarak, & Mermelstein, 1983). The PSS has two versions, PSS-10 and -14; however, the 10-item version has been reported to have a higher internal consistency (0.78) and a Cronbach's alpha value of 0.75 (Cohen & Williamson, 1988). In the past, the test-retest correlation has been as high as 0.85 at a six weeks follow-up assessment (Cohen, Kamarak, & Mermelstein, 1983). The PSS has been validated in family caregivers of older adults with heart failure yielding a Cronbach's alpha of 0.86. In addition, construct validity has been supported by the correlation between the PSS and the Center for Epidemiological Studies Depression Scale (CES-D;  $r = 0.7, p < 0.01$ ; Schwarz & Dunphy, 2003). Cronbach's alpha coefficient for the PSS was 0.85 in the CARES study (Ostwald et al., 2009).

**The family crisis oriented personal evaluation scales (F-COPEs).** Caregiver coping strategies were assessed using the F-COPEs, which is based on family stress theory and was developed to help identify family resources and perceptions and integrate them into coping skills (McCubbin, Thompson, & McCubbin, 1996). The F-COPEs measure effective problem-solving attitudes and behaviors that families develop in response to stressful situations (McCubbin, Olson, & Larsen, 1981). The instrument measures 30 coping behaviors grouped into five subscales including: acquiring social support (ASS), seeking spiritual support (SSS), reframing, mobilizing family to acquire

and accept help (MFS), and passive appraisal (PA). Coping skills are rated using a 5-point Likert scale that ranges from 1 (*strongly disagree*) to 5 (*strongly agree*). The total F-COPEs score ranges from 29-145, and subscale scores range from 9-45 for ASS, 4-20 for SSS, 8-40 for reframing, 4-20 for MFS, and 4-20 for PA. This tool can be used to assess coping skills among family members 12 years of age and older (Birenbaum, 1991), and has been studied in caregivers (Smith, 1994) and in families of persons diagnosed with cardiovascular diseases (Nolan, Brown, Pierce, Lepley, & Ohler, 1992; Brott & Adams, 1989; Wity et al., 1994). The Cronbach's alpha and four-week test-retest values for the subscales range from 0.63-0.83 and from 0.61-0.95, respectively. For the total scale, the Cronbach's alpha value is .86 and reliability over four to five weeks is 0.81 (McCubbin, Thompson, & McCubbin, 1996). The Cronbach's alpha value for the CARES study was 0.84 (Ostwald, Bernal, Cron, & Godwin, 2009).

### **Data Analysis**

Descriptive statistics (mean, standard deviation, range, and percentage) were calculated for demographic, stress, and coping variables, including the F-COPEs total scale and subscales. Quantitative data from both CARES and FHLS were analyzed to determine whether spousal caregivers of stroke survivors experienced any changes in stress and coping over an extended period of time. Repeated measures analysis with linear mixed models (Brown & Prescott, 2006) was utilized to test for changes in stress and coping experiences at baseline, 3, 6, 9, and 12 months, and 5-7 years post stroke. A separate model was used to analyze the dependent variable (stress), and additional linear mixed models were used to test the independent variable—coping (including total

FCOPE and its five subscales)—and its relationship with stress over time. Age, gender, SES, ethnicity, and insurance coverage were included in each model as covariates to assess their impact on stress and coping over time. All data analyses were performed using the SAS program for Windows version 9.4 (2014).

## **Results**

### **Sample Characteristics**

The demographic profile of caregivers at baseline is shown in Table 1. The majority of spousal caregivers were female ( $n=22$ , 73%) and their mean age was 58.8 years (SD 11.32 years, range 42.8-85.2 years) at baseline. Sixty-seven percent of participants were Caucasian and 33% were minorities, primarily African American and Hispanic, which is representative of the general population in the Houston, Texas area. The mean score on the socio-economic status (SES) scale of 45.1 (SD 13.6, range 19.5-66.0) was calculated based on participant occupation and education using Hollingshead's formula (Hollingshead, 1979), indicating that the participants were from diverse socio-economic backgrounds. The majority of stroke survivors had comprehensive health insurance coverage including government and/or private insurance ( $n=25$ , 83%), however the remaining 17% had potentially high out-of-pocket costs that could result in greater financial burden and increased caregiver stress. These sample characteristics were comparable to those of the groups observed by Ostwald et al. (2014).

Table 1

*Participant Characteristics at Baseline for Caregivers (n=30)*

Variable		$\bar{X}$	SD
Age		58.8	11.3
Socioeconomic Status		45.1	13.6
		N	%
Gender	Male	8	27
	Female	22	73
Ethnicity	African-Amer.	5	17
	Asian	1	3
	White	20	67
	Hispanic	4	13
Insurance coverage	Comprehensive	25	83
	Inadequate	5	17

**Caregiver Perceived Stress Outcome**

The perceived stress scores of caregivers were analyzed to examine changes over time. The range of mean PSS scores was 12.8-15.1, indicating that our caregivers experienced an average stress level over 5-7 years of post-stroke caregiving. The highest mean PSS scores were noted at baseline (14.3) and at the 3-month follow-up (15.1). The scores gradually decreased over time with the lowest scores observed at the 5-7 years post stroke follow-up (See Table 2). Although spousal caregivers demonstrated a 1.5 point drop in PSS scores over time, the changes were small and not statistically significant ( $p=0.32$ ). In addition, socio-demographic variables of caregivers (age, gender, ethnicity, stroke survivor's insurance coverage, and SES) were not found to be statistically associated with PSS scores over time.

Table 2

*Mean Change Over Time on the PSS and the F-COPEs for Caregivers of Stroke Survivors*

Month	PSS		F-COPEs	
	Mean	SD	Mean	SD
Baseline (at discharge)	14.3	6.5	111.7	16.4
3 months	15.1	8.6	111.1	18.7
6 months	13.4	7.2	109.8	14.3
9 months	13.1	7.7	110.7	16.3
12 months	13.1	6.4	119.9	14.4
60 months	12.8	8.6	104.4	12.6
(5-7 yrs post discharge on average)				

### **Caregiver Perceived Coping Changes Over Time**

Analysis through the 5-7 year post stroke follow-up indicated that there was no significant change ( $p=.50$ ) in total coping scores over time. However, there was a significant change over time in two subscales of the F-COPEs instrument, the ASS ( $p=.02$ ) and MFS ( $p=.03$ ), with an estimated 3.6 and 1.9 point drop between the baseline and 5-7 years post stroke time points for the ASS and the MFS subscales, respectively. There was no significant change over time in the remaining three subscales of the F-COPEs instrument (see Tables 2 and 3)—reframing ( $p=.80$ ), SSS ( $p=.80$ ), and PA ( $p=.47$ ).

Table 3

*Mean Change Over Time on the F-COPEs and its Subscales for Caregivers of Stroke Survivors*

Month	Total FCOPEs		ASS		Reframing		SSS		MFS		PA	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Baseline	111.7	16.4	32.1	7.0	31.9	5.6	15.0	4.0	15.0	2.7	14.8	3.7
3 months	111.1	18.7	31.4	8.0	31.8	6.1	15.7	4.5	14.7	3.6	14.1	4.1
6 months	109.8	14.4	30.6	6.8	32.0	5.1	15.5	3.9	14.5	3.0	14.2	3.6
9 months	110.7	16.3	30.5	7.4	31.8	4.7	15.7	3.9	14.7	3.0	15.0	3.1
12 months	111.9	14.4	31.3	6.3	32.2	4.3	15.9	3.5	14.8	3.3	14.6	3.3
60+ months (5-7 yrs post stroke)	104.4	12.6	28.1	6.2	32.8	4.6	15.6	4.4	13.1	3.0	14.8	3.4

### **Relationship of Socio-demographic Variables to Stress/Coping**

The socio-demographic variables were tested for possible predictors of caregiver stress over time. No statistically significant association was found between these variables—age, gender, ethnicity, socio-economic status, and health insurance coverage—and total coping over time. However, there was a positive association between the SES demographic variable and PA score ( $p=.04$ ) with a slope estimate of .10.

### **Relationship Between Stress and Coping Over Time**

A significant inverse association was found between coping and stress scores ( $p=.01$ ; see Table 4), where higher coping scores (F-COPEs) were correlated with lower perceived stress scores (PSS). Such relationship didn't change over time ( $p=.90$ ). The negative slope of -.10 means that a 1-point increase in F-COPEs score was associated



with an approximate .10-point decrease in PSS scores. This relationship remained the same when socio-demographic covariates were included in the analysis.

**Table 4**

*Relationship between Stress and Coping Over Time (n=30)*

	Stress		
	DF	F value	P
Time	5	0.35	.88
Coping	1	7.48	.01
Coping x time	5	0.32	.90

### Discussion

This study sought to explore stress and coping among caregivers of stroke survivors over five to seven years post stroke. The specific aims were to better define characteristics of caregiver stress and five types of coping strategies including ASS; reframing; SSS; MFS; and PA. The majority of spousal caregivers were female and Caucasian, which is similar to other caregiver studies. None of the demographic variables were significantly associated with stress or total coping scales over time. Caregivers of stroke survivors often experienced, on average, moderate stress that was persistent and did not change over time. This is consistent with published findings, as these individuals are often overwhelmed physically, emotionally, and financially by the complexity of their caregiving roles. Our study showed that caregivers of stroke survivors did not experience statistically significant changes in their stress levels over time. A consistent level of stress persists over the duration of caregiving, which may explain associated long-term negative health outcomes (Byun & Evans, 2015) including chronic stress (Ostwald et al., 2009), hypertension and angina (White et al., 2003), and depression (Berg et al., 2003).

Similarly, Godwin et al. (2013) found that caregivers experienced a consistent average burden over time beyond two years post stroke. Ostwald and colleagues (2009, 2014), however, reported that caregivers experienced significantly reduced stress over a 12-month follow-up period following rehabilitation discharge. There are a couple of reasons: first, Ostwald et al. only reported their measurements one year post stroke; second, they had a much larger sample size; and third, our participants were 5-7 years older than in the initial study.

Jaracz et al. (2015) also observed a trend toward declining levels of overall burden over time. Haley et al. (2015) found that stroke caregivers reported considerable distress at nine months post stroke, but diminished over a period of 36 months. The current study identified the highest caregiver PSS scores three months post stroke followed by a downward trend, with the lowest PSS scores five to seven years post stroke, although the observed change was not statistically significant. These findings might suggest that the first few months of caregiving are the most challenging, followed by a decrease caregiving stress that might be explained by stress and coping theory (Haely et al., 1996; Haley, Levine, Brown, & Bartolucci, 1987) through reduction of stressors (i.e., stroke survivor recovery) or improvement in caregiver appraisal and coping skills with experience (Visser-Meily et al., 2009). The hypothesis of adaptation, which posits that caregivers will adjust to the new post-stroke situation and find ways to handle the primary problem (i.e., the patient's health) and secondary caregiving demands, could also explain some of these findings (Fernandez-Ballesteros, 2003). Nevertheless, Jaracz et al. (2015) emphasized that a substantial proportion of the caregivers still

experienced significant burden (29.5%) at five years post stroke. Adriaansen et al. (2011) also reported a pattern of persistent caregiver stress at three years after stroke.

Coping with stress is critical for caregivers of stroke survivors (Minnes et al., 2000) in terms of adjustment to the caregiver role and improving or maintaining their own quality of life (Larson et al., 2005; van den Heuvel et al., 2001). There was a significant association between stress and coping variables ( $p=.01$ ) that did not change over time ( $p=.90$ ), indicating that caregivers with positive coping skills consistently experienced less stress over the stroke survivor recovery trajectory.

The total F-COPEs and subscales were used to measure caregiver coping in the areas of: ASS, reframing, SSS, MFS, and PA. In this study, F-COPEs scores remained stable with no statistical changes in the total coping scale over time. However, we found a significant decrease from baseline in ASS and MFS at five to seven years after stroke. The findings here may suggest decreased ability to mobilize family support and acquire social support over time. Similar findings reported by Adriaansen et al. (2011), including a significant decrease in social support at three years after stroke reflecting reduced social activities outside the home, decreased visitors when stroke recovery was prolonged (Green & King, 2009; Forsberg-Warleby, Moller, & Blomstrand, 2004), and decreased involvement of others as family members return to their own routines (Jacobson, 1986).

Although Ostwald et al. (2009) found increased ability to use available social support at one year after the stroke event, they also reported that the actual number of people available to provide assistance decreased significantly during that time, which could explain the trend of decreased ASS and MFS scores over five to seven years post

stroke. It has been reported that caregivers sometimes lose contact with their support networks due to stroke-related disabilities making transportation more difficult, little energy for social interactions because of the amount of the time required to provide care, or loss of connections to others because they do not feel that they are being understood (Secrest, 2000). In this study, it was not clear whether caregivers sought less help from their support networks because they had adapted and were more confident in their caregiving roles, or if social resources had become less available over time because of a shrinking network or perceived lack of willingness to assist in caregiving. The reduction in accepting help and acquiring social support is important and requires further study to identify contributing factors.

A significant positive correlation was found between the SES covariate and PA score ( $p=.04$ ) with a slope of .10, suggesting that caregivers with higher SES scores tend to use PA more than caregivers with lower SES. Ostwald et al. (2009) pointed out that caregivers who used PA coping strategies believed that luck had an important role in events, that trouble with solving problems would still exist no matter what they did, and that problems would disappear if they waited long enough.

### **Limitations**

This study had several limitations. First, the small sample size limits generalizability of the results. In addition, the study participants were older at baseline and changes associated with advancing age may account for some of the observed negative aspects of caregiving (Mirowsky & Ross, 1992). The study does not assess the potential impact of behavioral and psychological symptoms of stroke survivors on their

caregivers. Finally, large longitudinal studies are needed to achieve a deeper understanding of factors related to stress in caregivers and how those stressors may change over time and life stage.

### **Conclusion**

This study examined caregiver stress and coping experiences over time and demonstrates that caregivers of stroke survivors experience persistent stress from baseline through five to seven years post stroke with no significant decrease in stress over time. Healthcare professionals should be aware of the continued, persistent negative impact on long-term caregivers of stroke survivors in order to enhance physical and psychological wellbeing, as well as quality of life, among those individuals. Negative consequences of caregiving should be addressed and appropriately managed, and caregivers should be educated about these potential negative impacts and available community support resources.

This study is significant because it explored stress and coping over time by caregivers of stroke survivors and identified caregiver needs at the onset of stroke recovery and at 3, 6, 9, and 12 months, and 5-7 years post stroke. The results provide information on the long-term outlook for caregivers of stroke survivors, as well as a point of reference for adjusting and improving short-term intervention strategies. This information may promote the development of policies that benefit and improve wellbeing of family caregivers. It may also result in better understanding of the impacts on the family caregivers of stroke survivors and development of intervention strategies to help stroke caregivers cope with daily stress. Reduction of stress contributes to improved

quality of life among caregivers as well as stroke patients, and may decrease the need for long-term institutionalization. Tailoring of appropriate interventions to specific caregiver needs at different stages of stroke recovery could reduce caregiver stress and additional study is needed to inform development of effective and timely interventions for both stroke survivors and their caregivers.

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**Experiences of Stress and Coping Over Time by Caregivers of  
Stroke Survivors: a Mixed-Methods Approach**

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## Abstract

**Background/ Objectives:** Caregivers of stroke survivors often experience physical and mental stress, decreased physical and emotional well-being, high burden of care, social isolation, and neglecting self-care. The majority of previous research studies have identified caregiver experiences during the first one-to-two years post stroke. Little is known about caregiver experiences beyond the first two years of the post- stroke recovery trajectory, indicating a need for longitudinal study of their experiences over time. Therefore, the objective of this study was to explore through qualitative methods their stress and coping experiences over time and the concordance or divergence of qualitative and quantitative findings using a mixed-methods approach.

**Methods:** This study was a secondary data analysis of a randomized clinical trial, CARES (Committed to Assisting with Recovery after Stroke), between 2001-2005 and its follow-up study (between 2008-2011). A longitudinal follow up study was utilized to explore experiences of stress and coping over time using a mixed-methods, triangulated approach with a convergent QUAN-QUAL design.

**Results:** Caregivers (N = 30) were primarily female (n =22, 73%) with a mean age of 58.8 and 33% were minorities. The range of mean perceived stress scores (PSS) was from 12.8-15.7 indicating caregivers experienced an average level of stress over time with no statistically significant changes.

The range of mean scores on the Family Crisis Oriented Personal Evaluation Scale (F-COPEs) was from 104.4 -119.9 implying spousal caregivers adopted multiple coping strategies. There was not a significant change over time in total coping scores (p = .53);

however, a significant decrease over time was noted in two subscales – Acquiring Social Support (ASS) ( $p = .02$ ), and Mobilizing Family Support (FBS) ( $p = .03$ ). This finding was supported by qualitative data as caregivers indicated that social support gradually decreased over time.

There was no significant change in PSS measurement over time, which is concordant with the qualitative findings as four major categories of stress-related themes persisted through all stages of the stroke recovery trajectory. However, there were different sources leading to stress at different times. Their emotional stress evolved over time from struggling with the survivors' personality changes, high caring demands, fear of recurrent strokes, unpreparedness and uncertainty of what the future would bring during the early stage of stroke recovery, to feeling lonely and sad about the loss of a supportive spousal relationship, and to suffering in silence and becoming more depressed for some caregivers at 3-6 months and 1 year post stroke, respectively. At 5-7 years post stroke, emotional stress was more related to the survivors' depressive symptoms and fear of inability to fulfill the caring role due to their own declining health. Caregivers also expressed financial stress throughout all stages of stroke recovery.

Common themes related to coping included: 1) religious and spiritual support with faith in God was utilized across all stages of the stroke recovery trajectory; 2) a problem-solving coping approach was more commonly adopted during early days of caregiving; 3) emotion-focused coping approach was consistently utilized over time as a way of relieving stress; 4) other coping strategies utilized all the time included being positive and

grateful, and having a break from the caring situation in order to continue in the caregiving role.

Across semi-structured interviews, spousal caregivers reported a variety of sources of stress and coping behaviors. The majority of spousal caregivers who experienced a low stress level also reported a high score of coping measurement, indicating an agreement between qualitative and quantitative findings based on the reported stress and coping themes.

**Conclusions:** Spousal caregivers continued to experience stress along with decreased social support as time progressed post-stroke, but these experiences evolved over time. Therefore, further research is needed to corroborate these findings and thus offer opportunities for researchers and clinicians to incorporate these indications to help spousal caregivers cope better at different stages of the stroke recovery trajectory.

## **Experiences of Stress and Coping Over Time by Caregivers of Stroke Survivors: a Mixed-Methods Approach**

### **Introduction**

Despite advancements in medical technology, stroke remains one of the leading causes of death and long-term disability among adults, both in the United States and worldwide (American Heart Association [AHA], 2016). The majority of stroke survivors face a wide range of temporal and/or permanent challenges requiring critical support from family caregivers to meet their physical and emotional needs. Stroke, as an abrupt and unanticipated event, necessitates that caregivers rapidly learn to assist stroke survivors with a wide range of deficits and adjust to the alterations in their own lives (Gholamzadeh, Hamid, Basri, Sharif, & Ibrahim, 2014). Negative consequences associated with caregiving have been widely reported and have raised concerns among researchers and policy-makers, as caregivers continuously struggle with adequate self-care and with their capability to provide sufficient care to stroke survivors over time (Vitaliano, Zhang, & Scanlan, 2003). Caring for stroke survivors, especially persons with impairments and disabilities, could cause chronic stress secondary to a lack of balanced caregiving demands and available physiological, psychological, and financial resources (Jaracz, Grabowska-Fudala, Gorna, & Kozubski, 2014).

To date, intervention research generally has not focused on diverse aspects of the care situation that may be associated with changes in caregiver experiences over an extended period of time. Because research has focused primarily on stroke survivors and caregivers during the first one or two years post-stroke, little is known about factors

contributing to caregiver stress and coping experiences beyond two years post-stroke. A long-term follow-up study of caregivers is needed to better understand caregiver stress and coping experiences during the long-term trajectory of stroke recovery. The overall aim of this study was to explore caregivers' stress and coping experiences over time through qualitative methods and the concordance or divergence of qualitative and quantitative findings using a mixed-methods, triangulation approach.

The research questions were:

- a. What stress do caregivers experience over time?
- b. What coping strategies do caregivers experience over time?
- c. What is the relationship between qualitative and quantitative findings of caregiver experiences?

### **Review of Literature**

Due to the complex symptomology of stroke, health impacts on caregivers are striking and often include considerable physical, emotional and psychological distress. There is an estimated increase of up to 27% in risk of stroke (Haley, Roth, Howard, & Safford, 2010) and a 63% higher risk of premature mortality among highly strained spousal caregivers compared with noncaregiving controls (Schulz & Beach, 1999). The emotional impact of caregiving is also profound, with at least a three times greater risk of depression as compared to noncaregiving peers (Cecil et al., 2010; Han & Haley, 1999). Consequently, caregivers with depression suffer increased emotional stress and report poorer perceived health and decreased social participation (Carod-Artal, Ferreira, Trizotto, & Menezes, 2009). Caregiver stress can cause negative health outcomes for

both the caregiver and stroke survivor such as interfering with rehabilitation of stroke survivors, declining health, and increased risk of caregiver mortality (Bakas et al., 2014).

Current literature related to family-caregiving of stroke survivors recommends greater attention on the timing of needs as stroke survivors transition from institutional to community care settings (Greenwood, Mackenzie, Cloud, & Wilson, 2009a). Typically, the current U.S. healthcare system provides services across different settings beginning with acute hospital care, transitioning to inpatient and outpatient rehabilitation, and to community/home care as stroke survivors recover. Increasing emphasis on at-home care after hospital discharge has resulted in increased responsibility of family caregivers for long-term care of stroke survivors' physical limitations, cognitive deficits, and emotional and communication problems through one year after stroke (Ekstam, Johansson, Guidetti, Eriksson, & Ytterberg, 2015).

However, family caregivers are often elderly and need support to cope with the burden associated with caregiving in their daily lives (McPherson et al., 2010; Rigby, Gubitza, & Phillips, 2009; Gosman-Hedstrom & Dahlin-Ivanoff, 2012). Thus, it is imperative to identify caregiver needs, perceptions of stress, and factors that affect their well-being over time as the trajectory of stroke results in prolonged, chronic care needs for survivors. Cameron and Gignac (2008) proposed the "timing it right" conceptual framework to explore changing educational and support needs of stroke survivors and their family caregivers with respect to transition through different phases of care and, ultimately, return to the home. The framework suggests that caregiver needs change as stroke survivors progress across the phases of recovery. The central premise of the

framework is that attention to phase-specific needs will ease transitions, facilitate community reintegration, and ultimately decrease negative outcomes associated with caregiving within the community over an extended period of time (Cameron & Gignac, 2008; Cameron et al., 2013).

A comprehensive understanding of factors that impact quality of life among caregivers of stroke survivors to ensure that they can continue in their caregiving role. The needs of stroke survivors are different and may include a variety of physical (mobility), cognitive (language, memory, and sensory), functional (bathing, dressing, feeding, etc.), emotional, and psychological impairments (Gbiri, Olawale, & Isaac, 2015). Survivor needs change as they progress across the recovery trajectory; thus, understanding how caregivers cope with various stroke-related impairments across time will promote both successful recovery of stroke survivors and emotional and physical well being of caregivers (Low, Payne, & Roderick, 1999). A conceptual framework that draws on existing research and the stroke clinical care pathway, for example the “timing it right” model, is emerging as a basis to systematically differentiate changes in caregiver needs during different stages of stroke recovery and the implications for caregivers.

This study involved a secondary analysis of data from a randomized controlled trial—CAREs—conducted from 2001-2005 and its observational follow-up study—FHLS—conducted between 2008-2011. Please refer to manuscript A for a detailed description of the CAREs and FHLS studies and the quantitative analyses of stress and coping among caregivers of stroke survivors over five to seven years post stroke. In this paper, results from analyses of qualitative data on stress and coping among caregivers of

stroke survivors over time are presented using a triangulated approach. The relationship between qualitative and quantitative findings is also explored.

The aim of this study was to investigate stress and coping experiences of stroke survivor caregivers over a longitudinal time frame and provide a knowledge base for development of appropriately timed interventions. In addition, a mixed-method, triangulated approach using the convergent QUAN-QUAL design was utilized to obtain different but complementary data on the same topic and gain a better understanding of caregiver experiences (Creswell & Plano Clark, 2011). This approach was used to analyze data on the personal experiences of caregivers of stroke survivors and to elicit their views on the major issues and concerns related to caregiver stress and coping strategies over a period of five to seven years post stroke. This study will add a unique body of knowledge to the current research field, which includes few studies of stroke caregivers' experiences across a long time period using a triangulated mixed-method approach. It may also inform development of more effective strategies to help stroke caregivers cope with daily stress.

### **Concept Review**

**Stress.** The Oxford Dictionary (2016) refers to stress as pressure, tension, physical or mental strain. Selye (1974) defined stress as a nonparticular physiological reaction to external or internal demands. According to Lazarus and Folkman (1986), psychological stress is a person-environment relationship or transaction that is appraised by the person as challenging or threatening and in which the demands are beyond coping resources available to the individual. This dynamic relationship is constantly changeable



and bidirectional, involving the production of stressors by the environment and the response of an individual exposed to these stressors. This concept of stress leads to the theory of cognitive appraisal. Cognitive appraisal is defined as a process by which a person evaluates a particular encounter with the environment, estimates the relevance or importance of the situation to them (known as primary appraisal), determines whether the situation requires the mobilization of coping strategies, and assesses whether the necessary strategies are within the means of available coping resources (referred to as secondary appraisal). In addition, this model does not attribute the cause of stress to the stressor, but to the individual's perception of it (Lazarus & Folkman, 1986).

The concept of caregiver stress is multidimensional and includes physical, social, psychological, and financial factors (Bhattacharjee, Vairale, Gawali, & Dalal, 2012). Caregiver stress has been widely studied in nursing research, and is commonly used to describe the burden or strain that caregivers experience when caring for an individual with a chronic illness such as stroke. Caregiver burden, viewed as a dimension of caregiver well-being, is commonly used within academic or research contexts, but still refers to stress that caregivers face when providing care for loved ones with chronic diseases (Llanque, Savage, Rosenburg, & Caserta, 2014). Stress is more often perceived as a global concept, especially in nursing research, and has been frequently used interchangeably with burden (Llanque et al., 2014). Llanque et al. (2014) further stated that much of the literature applies the concept within the context of the psychological and/or physical stress faced by caregivers. In addition, Llanque et al. (2014) reported that the concept has also been used to describe subjective and objective burdens that

caregivers experience. Objective burdens refer to objective indicators of stressors, such as activities of daily living (ADLs) dependencies and stroke survivors' cognitive and physical impairments; while subjective burdens are those for which there is no objective measure, but rather describe caregivers' emotional reactions and appraisals of care demands (Pearlin, Mullan, Semple, & Skaff, 1990).

**Stressor.** Stressors are demands caused by an individual's internal or external environment that disturb balance and therefore impact physical and psychological well being; thus, coping activities are required to restore the lost balance (Lazarus & Cohen, 1977).

**Coping.** Coping is a process by which a person manages the demands that result from a problematic relationship or transaction between individuals and their associated environment (Decker and Borgen, 1993). Coping is defined as cognitive and behavioral efforts that master, reduce, or tolerate internal and/or external demands resulting from a stressful transaction (Folkman & Lazarus, 1980). Folkman and Lazarus (1984) defined coping as an individual's constantly changing cognitive and behavioral efforts to manage specific internal and/or external demands of situations appraised as stressful and as exceeding the person's available resources (Folkman & Lazarus, 1984). They further described coping as process oriented, focused on how an individual thinks and acts within a particular stressful context. Coping is influenced by the person's appraisal of the actual demands and available resources in a stressful condition. Coping is a dynamic process that changes over time as individuals work through various situations and events (Folkman & Lazarus, 1984).

There are two main types of coping—emotion-focused and problem-focused coping—both of which are utilized by individuals to manage stress (Folkman, 1984). According to Lazarus and Folkman (1984), coping has two primary functions, (1) regulating stressful emotions (emotion-focused coping) and (2) altering the person-environment relationship causing the stress and seeking resources to make the situation less stressful (problem-focused coping). Emotion-focused coping refers to a variety of cognitive processes to regulate and decrease negative emotions or distress. These strategies include cognitive distraction, avoidance, minimization, distancing, mediating, and seeking emotional support (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) further stated that emotion-focused coping is commonly utilized to manage emotions in health-related situations, especially when events are perceived as uncontrollable; while problem-focused coping is generally used to directly manage sources of stress in work situations when the situation is perceived as controllable. Problem-solving coping often consists of strategies for gathering information, planning, making decisions, and solving a problem (Lazarus & Folkman, 1984). Problem-solving coping is also known as active coping; while another name for emotion-focused coping is avoidance coping.

Coping strategies can be further classified as positive or negative. Positive coping often involves positive thinking and use of appropriate social supports; while negative coping commonly involves negative thinking and avoidance behaviors (Greeff, Vansteenwegen, & Ide, 2006; Nehram, Chakrabarti, Kulhara, & Sharma, 2005). Communication with family members is an emotion-focused coping strategy (Lazarus & Folkman, 1984) in which information is shared about feelings and thoughts in person, or

via telephone, online social networks, emails, or texting and support and understanding is received (Eaton, Davis, Hammond, Condon, & McGee, 2011).

Acceptance, a form of cognitive restructuring, is another common emotion-focused coping strategy where individuals may change their negative reactions to positive or at least neutral ones based on their appraisals of thinking responses to situations (Lazarus & Folkman, 1984). Caregivers accept their difficult situations as part of their everyday lives, reducing stress by making those events more manageable and ultimately improving their relationships with family members (McCubbin, Olson, & Larsen, 1991).

Passive appraisal, a form of cognitive distraction also considered to be an emotion-focused coping strategy, allows the individual to accept and minimize reactions to stressful events (Lazarus & Folkman, 1984). This coping strategy uses the mental process of distraction using something that can limit attention, prevent concentration, or distract the mind from thinking about the situation. Passive appraisal activities include watching television, relying on luck, feeling helpless about the problem, and believing that time will solve the problem (Eaton et al., 2011).

Avoidance, another emotion-focused coping strategy, is used when family caregivers appraise the threat as uncontrollable or underestimate their capability to cope with it (McCubbin, Olson, & Larsen, 1991). This strategy allows family caregivers to avoid distressing situations by removing themselves physically or refusing to discuss or even think about uncomfortable issues, thus reducing physical and/or emotional contact with the affected family member (McCubbin, Olson, & Larsen, 1991).

The use of religious and spiritual support is another emotion-focused coping strategy. Spirituality is highly individualized and has different meanings to different individuals; it may be expressed intraphysically through values and beliefs; institutionally by seeking advice from a minister or attending and participating in church services, having faith in God, and praying privately and/or with a community (Eaton et al., 2011). Family caregivers also use problem-focused coping strategies such as seeking social support (Lazarus & Folkman, 1984) from healthcare professionals, extended families, friends, churches, or education institutions.

Family caregivers use a wide variety of coping strategies. Thus, identification and understanding of these coping strategies may assist other caregivers in better coping with their situations and ultimately produce the best outcomes for each family (O'Connell, 2006).

### **Relationship Between Stress and Coping**

Coping is well recognized as a mediating factor and has been found significantly related to stress. These two concepts have been investigated in a variety of different contexts and populations. A review of literature reveals ample evidence of a significant positive correlation between stress and an emotionally-focused (avoidance) coping style, and a negative association between stress and a problem-focused (active) coping style (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Norizan et al., 2010; Treharne, Lyons, Booth, & Kitas, 2007). A negative relationship between stress and coping resources has also been suggested (Wu, Li, Zhu, Li, & Wang, 2010; Santos, Barros, & Carolino, 2010), indicating that caregivers who cope better with challenges

related to daily caregiving tasks experience less stress. Thus, it is important to help caregivers understand the nature of caregiving stress and the effectiveness of coping with problems during the different stages of recovery. Helping caregivers cope with negative experiences that may occur during the stroke recovery trajectory can help to promote improved health among caregivers.

## **Methods**

### **Design**

This study involved a secondary data analysis with an emphasis on stress and coping experiences of stroke caregivers who had previously completed both the CARES study (baseline and 3, 6, 9, and 12 months post stroke) and the FHLS follow-up study conducted five to seven years after completion of the CARES study. A mixed-methods, triangulated approach—the convergent QUAN-QUAL design—was utilized to obtain different but complementary data on the same topic and gain a better understanding of caregiver experiences over time (Creswell & Plano Clark, 2011). When methods are mixed in complementary ways, benefits include: converging or corroborating findings; minimizing alternative explanations for conclusions derived from research data; elucidating divergent aspects of a phenomenon (Johnson & Turner, 2003); generating a more accurate and compressive perspective of participants' experiences (Tashakkori & Teddlie, 2003); and more fully encompassing the breadth, depth, and richness of social and health phenomena, thus yielding stronger inferences (Stewart, Makwarimba, Barnfather, Letourneau, & Neufeld, 2008).

Convergent design is a triangulation approach using both quantitative and qualitative methods to obtain results (Creswell & Plano Clark, 2011) and is one of the most common interdisciplinary mixed methods approaches. With this type of design, researchers usually collect and analyze two types of data concurrently and then merge both sets of results into a final overall interpretation (Creswell & Plano Clark, 2011). Therefore, qualitative and quantitative methods were triangulated in this study by directly comparing and contrasting quantitative statistical results with qualitative findings; thus, developing a more complete understanding of the phenomenon (Creswell & Plano Clark, 2011). Qualitative and quantitative data were first analyzed separately, then a meta-matrix method was used to triangulate the findings and determine the relationship between the quantitative and qualitative results.

### **Subjects/Recruitment**

For this study, the family caregiver was defined as the stroke survivor's spouse or significant other. Caregivers who completed both the CARES study between 2001 and 2005 and the follow-up (FHLS) study between 2008 and 2011 were included in this study. Participants in the CARES research were recruited from hospitals and rehabilitation facilities in the Texas Medical Center in Houston, Texas after a stroke diagnosis was confirmed. The CARES study recruiter reviewed medical charts to determine eligibility and provided oral and written information to eligible subjects before obtaining written informed consent. The recruitment process for these studies is fully described in Schulz, Wasserman, & Ostwald (2006). Please refer to manuscript A for detailed description of study inclusion and exclusion criteria.

## Method of Quantitative Data Collection

Please refer to manuscript A for a detailed description of the method for quantitative data collection using the Perceived Stress Scale-10 (PSS) and The Family Crisis Oriented Personal Evaluation Scales (F-COPEs). Data were collected in participant homes for both studies. The research nurse collected brief qualitative data in CARES and the research nurse and principal investigator (PI) collected the qualitative data in the FHLS study. Participants participated in the quantitative and qualitative components of the study interviews after completion of the questionnaires.

**Interview.** Brief structured interviews were conducted by the CARES research nurse at baseline, 3, 6, 9, and 12 months. The 5-15 minute interviews were held in a private room apart from the stroke survivor. Each interview consisted of the following four questions intended to give a snapshot of the stress that caregivers were currently experiencing and how they were coping with it: (1) *How things are going for you?*; (2) *What kind of things have been stressful for you and how do they make you feel?*; (3) *What has helped you the most to cope with these changes?*; and (4) *Have you found any meaning in the experience of living with a stroke that you could share with others?*

In the FHLS follow-up study, the PI and research nurse conducted semistructured interviews using the guide included in Appendix A. The interviews were intended to explore caregiver experiences in greater depth than the short interviews in the CARES study. The interviews were conducted with the couples (as opposed to individuals) and lasted from one to two hours. Each interview began with broad questions such as: *Tell me about your journey since the stroke occurred xxx years ago; What aspects of your life as*



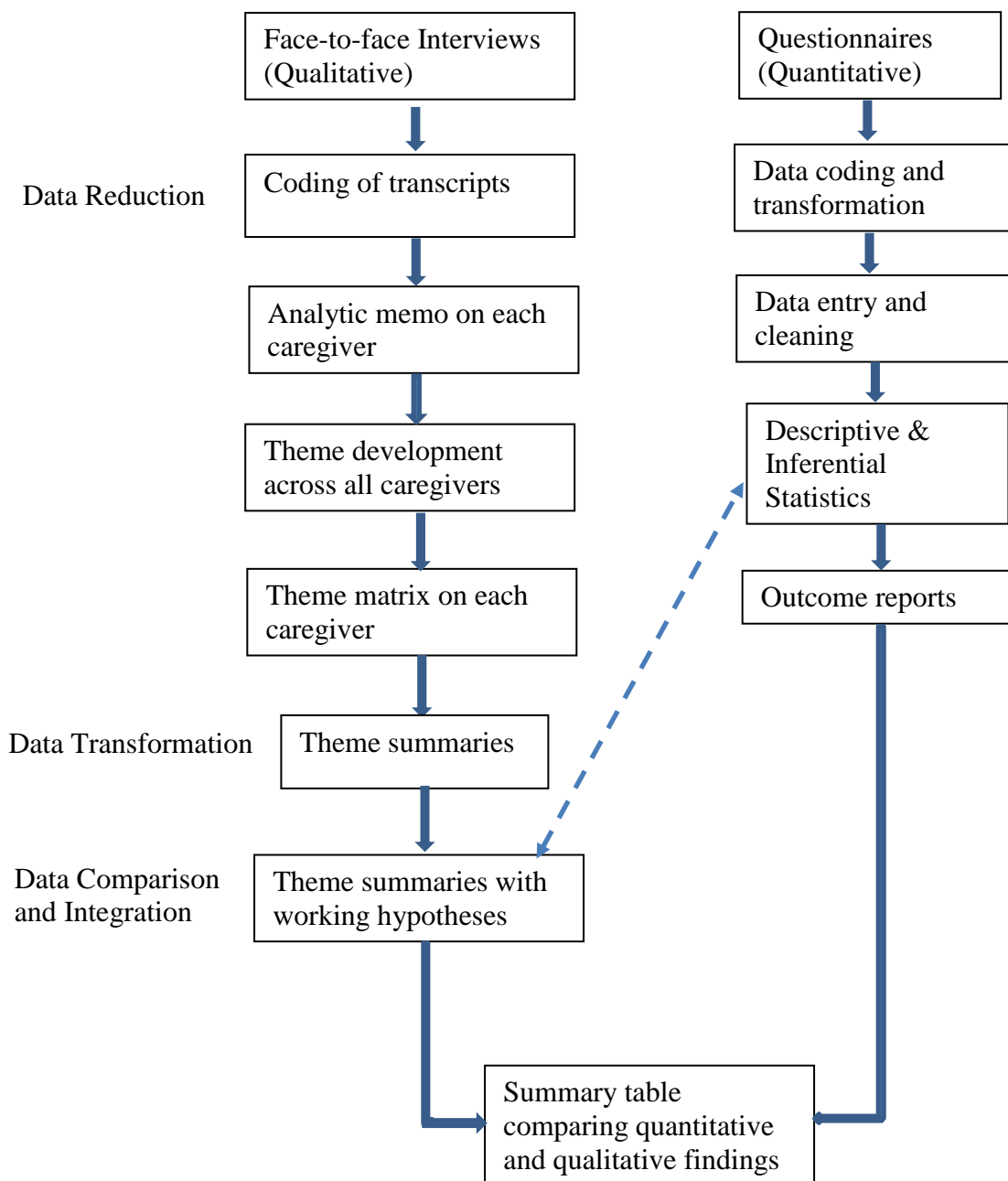
*a couple have been most affected by the stroke?; and What aspects of your life have changed?* The broad questions were followed by specific probes, for instance: *What has helped you the most to cope with these changes?; Are there particular skills or resources that worked well for you: or Tell me more about it.* The broad questions facilitate general information about caregiver experiences, while probes elicit more specific information about experiences related to the study purpose. The sequence of interview questions was flexible based on the interviewer's judgment. A home-based interview was preferred because it could potentially maximize the caregiver's feelings of comfort and relaxation in a familiar environment.

Field notes were recorded and debriefing sessions were held by the PI and research nurse during and immediately after each interview. Information such as body language, environmental details, and self-evaluation of each interview were added to the field notes. These notes augmented data collection and also permitted an on-going dialogue to help the researcher determine when saturation had been reached (Emerson, Fretez, & Shaw, 1995). Saturation was reached when 30 couples and seven widows had been interviewed.

### **Data Analysis**

This study used a parallel tracks approach of conducting analysis separately through the steps of data reduction and transformation and then bringing them together for synthesis during the interpretation stage (see Figure 1). This approach allows researchers to reconcile discrepancies in interpretation that might have occurred in

studies where only one of the research methods was used (Li, Marquart, & Zercher, 2000).



*Figure 1.* Analytic framework for the Parallel Tracks Analysis adapted from Li, Marquart, & Zercher (2000). Copyright 2000 by the Journal of Early Intervention. Used with Permission.

**Quantitative data analysis.** A descriptive analysis of participant demographic characteristics and PSS and F-COPEs variables was performed using the SPSS software for Windows version 23.0 (2015).

**Qualitative data analysis.** Each interview was audiotaped and transcripts were prepared by the CARES research team. The transcripts were compared to the original audiotapes for accuracy and loaded into the Atlas.ti software for Windows 5.0 (2004). Analysis began with the bracketing of personal experiences and previous thoughts regarding caregiver stress and coping experiences. A coding process was developed after reading and rereading the interview transcriptions and revised as new information was obtained. Open coding technique was used to label words and phrases found in the transcript and followed by axial coding, which creates themes or categories by grouping the codes assigned to words and phrases during open coding (Polit & Beck, 2008). At each stage of data analysis, researcher impressions and any personal thoughts were recorded in the analytic notes for further analysis.

The researcher read through transcripts of CARES short interviews and developed themes related to stress and coping experiences. The FHLS study team consisted of the CARES/FHLS PI, a research nurse, and an undergraduate honor student; the researcher for this study read and discussed all of the FHLS interview transcripts and developed themes primarily related to faith, hope, spirituality, and life satisfaction, as well as some stress/coping themes. A psychologist with expertise in religions and spirituality, a minister, and a graduate student in public health were added to the team for some of the analyses. The team met on a monthly basis to discuss findings during 2011-2012. In

addition, the CARES/FHLS PI, the research nurse, an honor student, and the researcher for this study met weekly during 2010 to read through the majority of FHLS transcripts and assess study participants' spirituality and support for religious need. The researcher for this study analyzed the interview transcripts again with an emphasis on stress and coping experiences over time. Interview transcripts from both the CARES and FHLS studies that were not analyzed by the team for stress and coping experiences were reviewed to identify patterns of caregiver stress and coping experiences over time.

***Triangulation.*** In a convergent design, mixed methods researchers often consider the extent of convergence between the quantitative and qualitative results (Creswell & Plano Clark, 2011). After the initial quantitative and qualitative analyses, side-by-side comparisons of the merged results were presented in a discussion or summary table. The quantitative results were first presented, followed by qualitative results in the form of quotes/themes and a comment explaining how the qualitative findings confirmed, refuted, or complemented the quantitative results.

In addition, the meta-matrix method was used to identify patterns among the quantitative and qualitative findings. This approach enables a linkage of data sets following traditional quantitative and qualitative data analyses (Wendler, 2001). It includes development of the matrix itself; transcription of data into the matrix; coding data and noting reflections; identifying common phrases; and separating patterns and processes (Wendler, 2001). These processes provide an opportunity to simultaneously evaluate all qualitative data alongside the quantitative data using a triangulation methodology (Wendler, 2001). The meta-matrix method facilitates triangulation by

allowing researchers to revisit the raw data and meld data across data sets (Wendler, 2001). This method was used to determine whether quantitative measurements of F-COPEs and PSS were in agreement with the respective related themes.

## **Results**

### **Description of the Sample**

Caregivers ( $N=30$ ) were primarily female ( $n=22$ , 73%,) with a mean age of 58.8 years (SD 11.32 years, range 42.8-85.2 years; see Table 1). Sixty-seven percent of the participants were Caucasian, and 33% were from a minority group, primarily African American and Hispanic, which is representative of the Houston metropolitan area (see Table 1). Mean socio-economic status (SES) score was calculated based on participant occupation and education using Hollingshead's formula (Hollingshead, 1979). The mean score for this study was 45.1 (SD 13.6, range 19.5-66.0), indicating that participants were from diverse socio-economic backgrounds.

Table 1

*Participant Characteristics at Baseline for Caregivers (n=30)*

Variable		$\bar{X}$	SD
Age		58.8	11.3
Socioeconomic Status		45.1	13.6
		N	%
Gender	Male	8	27
	Female	22	73
Ethnicity	African-Amer.	5	17
	Asian	1	3
	White	20	67
	Hispanic	4	13
Insurance coverage	Comprehensive	25	83
	Inadequate	5	17

The PSS scores range from 0-40 and higher scores were associated with higher stress levels (see Table 2). Caregivers reported a caregiving-related stress range of 2-35 with an average score of 12.8 on the PSS scale, indicating moderate stress at five to seven years post stroke. The F-COPEs assesses two dimensions of family interaction—internal and external family behaviors. The F-COPEs scores ranged from 50-130, where higher scores indicated better problem-solving and behavioral skills, and lower scores indicated a general shortage of effective coping strategies. Participant F-COPEs scores ranged from 83-124 (see Table 2) at five to seven years post stroke. The mean score was 104.4, indicating that participants had good coping resources and skills. Results of statistical analysis of quantitative data are presented in manuscript A.

Table 2

*Mean Change Over Time on the PSS and the F-COPEs for Caregivers of Stroke Survivors*

Month	PSS		F-COPEs	
	Mean	SD	Mean	SD
Baseline (at discharge)	14.3	6.5	111.7	16.4
3 months	15.1	8.6	111.1	18.7
6 months	13.4	7.2	109.8	14.3
9 months	13.1	7.7	110.7	16.3
12 months	13.1	6.4	119.9	14.4
60 months (5-7 yrs post discharge on average)	12.8	8.6	104.4	12.6

### Qualitative Findings

A majority of themes expressed by participants were related to stress resulting from caring for stroke survivors and the strategies used to cope with it. Themes related to caregiver stress included: emotional stress; physical stress; financial stress; and time constraints. Themes addressing coping behaviors were summarized into four major categories, including: problem-focused coping; emotion-focused coping; and positive thinking. The primary themes identified with respect to stress and coping experiences at baseline, 3, 6, 9, and 12 months, and 5-7 years post stroke are displayed in Appendix B (Table 3).

**Stress-related experiences over time.** Caregiver stress primarily resulted from functioning continuously in the caregiving role since the stroke survivor returned home with minimal or no breaks afforded by respite care or family assistance. Caregivers experienced an obvious physical and emotional toll during the early months that persisted over time throughout all stages of stroke recovery. The range of mean PSS scores was



12.8-15.7, indicating that caregivers experienced an average level of stress. There was no significant change in PSS scores measured over time as described in manuscript A, which is in agreement with the qualitative finding that the four major stress-related themes persisted throughout all stages of the stroke recovery trajectory. However, different sources of stress were identified at different times in the recovery process.

*Emotional stress.* When caregivers were asked about their experiences five to seven years later, the majority expressed that the early weeks and months at home were particularly challenging for them as they were not only facing the physical and emotional aspects of caring, they were also attempting to adapt to drastic changes in their own lives. They often experienced tremendous emotional stress and frustration upon the survivors returning home. Emotional stress during this period was common due to survivor personality change, high care demands, perception of caregiver not doing enough, lack of appreciation from the survivor, fear of recurrent strokes, feeling unprepared, uncertainty about the future, and feeling hopeless about progress. They found that it was difficult to maintain the survivors' level of independence, particularly when the survivor was very dependent and not making an adequate effort to progress or when there were concerns about survivor safety, which persisted up to one year post stroke.

At three to six months post stroke, emotional stress became even more profound among caregivers whose loved ones suffered second or third strokes; deteriorated cognitive function; severe memory impairment; or aggressive, violent, or abusive behaviors toward their spouses or families due to disease progression. They became overwhelmed and described their stress as “feeling the whole world is on my shoulders”

and “I feel like I am alone in the world because I am taking care of everyone and nobody is taking care of me. I can’t do it all, and lot of times, I feel resentful..., I am the one who is suffering and why does it affect me?”

Because of the sudden onset nature of stroke, caregivers often felt incompetent to assume caregiving tasks and lacked confidence about their ability to recognize signs or symptoms during the early period after transition from hospital to home, although discharge preparation was considered an important part of patient care. At three months after discharge one caregiver said, “I just wish I had known what could possibly happen, but they don’t tell you and you don’t know that until you are hit with it.” Some participants expressed their frustrations with medical staff stating, “they do not do much unless you push hard,” while others expressed their reluctance to “bother busy staff” when they appeared to have “so much to do” and their perception that staff did not have time to address their concerns and explain what to expect at home. These frustrations also included difficulty with scheduling follow-up appointments, the billing process, and access to available community assistance resources. This theme of unpreparedness seemed to diminish after three months post discharge; however, for some caregivers, guidance on long-term improvement after completion of therapy was still needed at one year and even at five to seven years post discharge.

The sense of loneliness became more prominent at six months post stroke because a lack of affection and intimacy from their partner made them feel “this was the end, you know, there is nothing in my life, everything is on my shoulders and I really don’t want to go on with life,” causing the caregiver to question “where had my loving my family

gone.” Caregivers also indicated that friends started to disappear around this time. Other themes that emerged around three to six months post stroke were sadness about the loss of a supportive spousal relationship, suffering in silence, and becoming more depressed. This emotional isolation was described as “the hardest part as compared to physical stress” because of a lack of shared decision making, mutual support, intimacy, physical expression of love, and emotional closeness. One caregiver described the change by stating, “I did learn you can’t be a caretaker and a wife at the same time, you have to make to choice, so, I am a caretaker.”

At one year post stroke, the majority of spouses remained very emotionally and physically. However, a majority of caregivers consider emotional stress worse compared to physical exhaustion. The sense of suffering in silence was illustrated by hiding feelings from their spouses and children, feeling sorry for themselves when looking at negatives, and becoming more depressed—with some caregivers requiring medical treatment. They put on a brave face and felt that being strong was the only effective way to deal the day-to-day chores and other care demands.

By five to seven years post stroke, most caregivers had experienced difficult times, but felt they had made it through the worst as the survivor regained strength, memory, and more independence. One survivor stated, “it was very hard for me. I was always stressed, and sometimes I would ask God why, like I said, why me Lord? Why me? Whatever happened to me and him, our life changed, I did go through some very difficult times, almost lost my car, my house, but it was this past 6 years, have been a

roller coaster in my life, I mean, I've been through some, you know hard times, but to me they are over.”

When asked to reflect on their experiences, participants felt that “the low point was at the beginning. It was a fear, what are we dealing with?” Caregivers attributed the greatest stress to fear of uncertainty about what the future would bring, which had declined as caregivers learned more about the disease and became more proficient in caregiving over time. However, they indicated that their emotional stress persisted. As the stroke survivors' conditions evolved over time, caregivers faced new situations. For instance, one participant felt very stressed when dealing with the survivor's unnecessary spending due to cognitive deficits, especially when facing a financial dilemma. Another source of emotional stress was survivors' depressive symptoms (i.e., feeling useless and being a burden to family). Some spousal caregivers even felt angry at themselves for not understanding survivor behaviors and for failure to acknowledge the survivor's efforts causing them to feel guilty and blamed as a result of unrealistic caregiver expectations. Conflicting emotional responses were described, as some caregivers became angry at themselves due to their perceived inability to adequately fulfill the role, while others described resentment toward their caregiving role, “there were days I'd be a little resentful because I had no one to fall back, you don't have help ... I am the victim and he is the survivor” and “there were times when I just really want a little me, a little more time for me, I had days when there wasn't anything, I could do but cry out to God, literally.”

In summary, emotional stress among caregivers evolved over time from struggling with the survivors' personality changes, high care demands, fear of recurrent strokes, and feelings of unpreparedness and uncertainty about what the future would bring during the early stages of stroke recovery to feeling lonely and sad about the loss of a supportive spousal relationship, suffering in silence, and increasing depression for some caregivers at three to six months and one year post stroke, respectively. At five to seven years post stroke, emotional stress was attributed more to survivors' depressive symptoms and to fear of inability to fulfill the caring role due to the caregivers' own declining health.

*Physical stress.* The relentless nature of caring appears to have caused the greatest difficulty after the first few months post stroke. There was an obvious physical toll on caregivers as they adjusted to their new lives. Upon the survivor's return home, caregivers described the demands as "like having babies again" and became fatigued due to sleep deprivation. As caregivers continued to perform the caring role, they were exhausted as "it is accumulative" and often neglected their own needs, which was featured in the following comments: "I am not taking care of myself physically as he has to be taken care of.... I haven't been used to going anywhere without him being with me." Physical strain persisted throughout all stages of the post stroke recovery trajectory as a result of long-term sleep deprivation, reduced social interaction, dealing with setbacks and regression, assuming multiple roles, and ignoring self-care and health maintenance.

**Financial stress.** In the early days after the stroke survivor returned home, many caregivers complained about a lack of financial support and difficulty obtaining applicable resources and coverage from their health insurance company. Because of the numerous follow-up appointments after hospital discharge, bills from the hospital stay and office visits became very demanding on their time and resources. One participant stated, “money is always an issue” and wished they had enough “financial resources to have someone come in here, on certain days and help me with transferring and the bathing ....” The participant further described being overwhelmed by demands stating, “when I am engulfed with, it is like I can’t afford to be sick, and can’t be tired.” As time passed, the majority of caregivers became concerned about elder care after retirement.

**Time strain.** Time strain began in the early months of caregiving. Caregivers felt restricted and/or trapped due to the relentless nature of caring, which continued throughout all the stages of stroke recovery; however, caregivers didn’t comment on it as often in the later stages of stroke recovery. One caregiver shared that once the stroke survivor returns home, “it is difficult to keep up with all the appointments, housework, and work” and felt there was no time for self because of commitments to their children, elderly parents, work, and disabled spouses. Time strain continued to be a serious issue for most caregivers throughout all stages of stroke recovery, as expressed as “feeling constantly on the go,” a “feeling of never getting everything done and rushing in circles and running as you can all the time,” feeling that “everything takes longer and have to allow extra time,” and “it seems we take a step forward and then 10 back.” Travel was also perceived as stressful by some caregivers because it involved complex preparation

including anticipating potential needs on the road, loading and unloading belongings, getting the stroke survivor into and out of the car, restroom accessibility for handicapped persons, packing and unpacking, parking, gasoline, and other demands. As a result, traveling and other leisure activities were limited, especially for caregivers of survivors with significant physical impairments.

**Coping-related themes over time.** As caregivers described different ways of coping with the stress of caring for a stroke survivor, common themes included: (a) emotion-focused coping (use of religious and spiritual support, passive appraisal, acceptance, role adjustment, avoidance [escape and having a break from caring situation], seeking emotional support, etc.); (b) problem-focused coping (gathering information, planning, prioritizing tasks, shifting priorities, allowing extra time for tasks, seeking social support, etc.); (c) positive coping (positive thinking such as hope, optimism, feeling blessed, and being grateful, etc.). These coping strategies were used throughout almost all stages of the stroke recovery trajectory, but adjusted based on situations arising at different times.

***Problem-focused coping strategies.*** Spousal caregivers frequently utilized problem-focused coping strategies during the early days after the survivor returned home and continued consistently throughout all stages of the stroke recovery trajectory in response to different challenges that arose over time. Strategies included planning, being patient, seeking social support, prioritizing tasks, and finding a balance between encouraging survivors to do more and fulfilling the caregiver role. The return home was accompanied by caregiver realization of the stroke survivor's diminished functional

capabilities. The transition to home posed many challenges for both survivors and caregivers and represented an early and essential stage of reintegration into the community after completion of inpatient care. The first months at home were a critical time for caregivers, as they experienced difficulties not only related to practical aspects of caring, but also concerns about their abilities to provide care and changes to their own lifestyle.

***Being patient.*** Caregivers shared that their partners' strokes resulted in many changes to their lives, for instance curtailed outdoor activities or travel due to the stroke survivors' physical impairments such as difficulty with getting in and out of the car. With respect to the practical aspects of caregiving, the majority of caregivers used problem-focused coping to identify and resolve problems, particularly ADLs and maintaining busy schedules, medical appointments, and their own interests and activities during the early period after the stroke survivor returned home. Over time, the caregivers learned to be patient towards their partner and plan ahead to allow extra time for ADLs and bathroom breaks on the road or when going out. They learned to slow down, realizing that "I am getting older, I am not rushing anymore, and you've got to stop all that rushing because there's nothing now that is more important than just taking your time and taking one day at a time." They not only learned to be patient, but also taught their loved ones to have patience. As time progressed, around nine months post stroke and thereafter, spousal caregivers began to consider alternatives for long term care due to concerns about their ability to care for their loved ones as their condition deteriorated over time. Alternatives included nursing home care, daycare programs, downsizing or remodeling the home to



make it more accessible, and living closer to their children. At five to seven years post stroke, planning for retirement was very common.

Learning to compromise and prioritize tasks was another coping strategy that most caregivers found very helpful during the early days of adjustment. One caregiver remarked, “my house is a mess, but I don’t care anymore. I have other things which require my immediate attention.” Caregivers in this study identified the importance of balance between encouraging survivors to do more and ensuring their safety. Although they reported tension due to uncertainty about when and how much support was needed, most recognized the value of encouraging survivors’ re-engagement in activities in order to regain independence. Caregivers indicated using strategies such as backing away from doing too much for the survivor and not feeling guilty for allowing the stroke survivor opportunities to progress, which one caregiver described as “trying to let him do as much as possible and only jump in as needed.” Other participants reported encouraging the survivor to “start thinking about us as a couple and partner;” seeking counseling; and realizing that “he can do more, and he just doesn’t trust it enough to do what I think he needs to do.” They understood that “it was difficult,” but recognized that survivors needed to try doing things for themselves in order to progress, but with help always readily available. A caregiver described encouraging their spouse by telling them, “God is right here waiting on you to holler for help.” At five to seven years post stroke, participants stated that they experienced a transition in their caregiving from “seeing self as a protector ... I am like a lioness toward him. I am always trying to make sure he doesn’t do anything to hurt himself, like climb up on the roof.... I am real observant of

him, I will know what to watch for,” to “I had to push back and let him do more for himself as to a need to back off and let him have his own independence.” However, this transition was not easy for some caregivers; one participant said, “I struggle with that all the time. I teach him to have patience... let him do more. While I am here, I think it is just an old habit of calling me every time, every time those wheels roll.”

One participant reported having to reassure her husband that it was fine to be dependent, “that’s what marriage is all about and that we are together and that I still have him” and reassure him that he was not a burden. However, other caregivers felt that survivors were not trying hard enough to participate in activities and to regain their independence.

*Seeking information and professional help.* Caregivers continued to search for information in order to improve their insight and understanding about stroke, as well as how to help the survivor achieve continued progress over time after returning home. This included seeking information from healthcare professionals, Internet resources, brochures, and other sources. Seeking professional assistance was critical when caregivers suffered negative consequences associated with caregiving, such as depression or emotional distress. Some caregivers had consulted grief and spiritual counselors, started taking medications such as antidepressants, and learned stress management skills to help them cope by five to seven years post stroke. With support from healthcare professionals, they felt they were “not alone.” Some caregivers were also seeking financial assistance from hospitals, for example from hospital charity programs, to help with medical costs.

When asked about their experiences participating in the research study, most described it as a positive experience. One caregiver stated, “I think being in this [CAREs] program helped, not much in what you did, but knowing that other people were watching; it wasn’t that the interventions were often enough to make a difference, but knowing that somehow we were part of something bigger, that we were helping other people.”

***Social support.*** Almost every participant in the study expressed the value of formal and informal support throughout the process of stroke recovery. Support networks including family, friends, external help (i.e., full time aides), support groups, and healthcare professionals were considered a key component of adapting to and maintaining the caregiving role. Support from family and friends was highly valued even up to five to seven years post stroke in helping spouses to cope and adapt to their situations. Practical support with tasks was especially important early in the recovery period, however over time most participants indicated the increasing value of emotional support provided by family, friends, and church members. Some caregivers particularly recognized the support of their children. One participant recalled that, “My daughter was there during it, I think her being there, taking the load off that time she was spending there was very helpful for me, more so to him because I wasn’t worried about it. I knew someone was with him, so and that type of support is a different type of support, it is not as much emotional, as it is actually being there.” To some participants, interactions with church members or friends provided an outlet to “get out and talk” and “get some fresh air.” One caregiver shared, “some of what I want from a friend ...[is to] take my mind

off things, just some fun,” and also indicated simply needing someone that they could “talk to.”

As time progressed, participants reported a gradual decline in social support as “stroke shocked friends into disappearing out of his life.” Caregivers stated that they drifted apart from other couples, no longer received invitations after the stroke, and that neighbors “used to come and visit, but [their support] gradually dies off.” These qualitative findings were reflected by the quantitative measures of two F-COPEs subscales—MFS and ASS—that had significantly decreased scores from baseline to five to seven years post stroke, indicating decreased social support over time.

*Doing more for self.* ‘Feeling trapped’ was noted in early days of caring, “but now I don’t feel trapped anymore” was one caregiver’s response when asked five to seven years post stroke. After tremendous adjustment during the first three months of caregiving, most participants felt the need to start doing things for themselves, which they described as helping to refresh their minds, relieving stress, and helping them to “get back to the point that I can be that good caregiver for him.” They indicated that they started engaging in their own hobbies, participating in exercise and yoga, and enjoying any free time, but nevertheless stated, “I do not do in often.” It was critical for them to resume and maintain their caring roles over time. This new perspective was revealed by one caregiver who said, “as far as him, the things that he forgets to do, it doesn’t bother as much anymore.” One participant said, the stroke survivor “...doesn’t want to participate in the CARES study, but I didn’t give a damn: this was for me. I needed to do

something for me ... it really was ... if you have somebody to talk to ... I couldn't talk to my kids because they didn't understand.”

**Emotion-focused coping strategies.** Spousal caregivers experienced many physical and emotional demands and often felt an overwhelming sense of responsibility for the care of their spouses. For the majority, as time progressed the learning curve became less steep compared to the first three to four months as they adapted to their new roles by becoming more routine-driven and organized. However, in addition to the physical aspects of providing ADLs, the stroke event had forced the caregivers to take responsibility for their spouses. Therefore, after settling into a new routine, their lifestyles changed as they adjusted to their new circumstances caused by the stroke event and its consequences. They accepted that there was no one else who could or who wanted to cope with the care needs of their spouse. As some caregivers said, it was stressful; however, “you have to do what you have to do.” Therefore, acceptance of stroke survivors’ changed abilities was considered an important component of adjusting to the ongoing consequences of stroke and establishing new routines.

**Spirituality.** The majority of participants in the study utilized some form of spirituality and religious support to help them cope with the consequences of their spouses’ strokes over time. For those caregivers, spirituality was fundamental to fulfilling daily caring activities and maintaining mental and physical integrity throughout the course of their caring journeys. In the early days of caregiving, religious coping was primarily illustrated by having faith in God and prayers. Common responses included: “we go for prayers every day,” [we believe] “everything is in God’s hands,” “we are

trying to make it with the Lord's help," and "I have had days where there wasn't anything I could do but just, cry to God, literally... I just say, you know God, you know how many times I've been here? You know, just help me to get through this ... ."

For many participants, their faith and beliefs seemed to increase their ability to cope with caring for their spouses and to tolerate many of the hardships of caregiving. Common religious or spiritual practices included praying to the Lord for good health and presence of mind and having faith in God, which participants explained as "it will keep both of us going" and "just pull us through this time." Other common spiritual practices were nighttime rituals like singing and prayer, which one participant described by stating "now I have my spiritual disciplines that I do: begins with a prayer before I even get out of bed and I do some Yoga with prayers attached." For these caregivers, church attendance or affiliation was not so much about dogma as about the people, the pastor, or geographic convenience.

Some participants indicated that organized religion and spiritual practices (i.e., prayers, rosary, bible study, going to church, listening to pastor/priest, etc.) were important because "it is ritual, it is a sense of belonging and identity." Religious activities provided opportunities for caregivers to talk with different people and refresh their minds. One participant gave an example of their reliance on organized religion as, "we could have never been able to move out that small trailer if it had it not been for people being trusting." Even those kinds of minimal interactions were very uplifting for stroke survivors, who felt grateful, especially when the congregation accepted their disabilities and accommodated their needs. Starting at about nine months post stroke, participants

started attending organized church services. One reason for this timing could be that they had settled into a new life routine, allowing more free time for them to resume some of their routine practices from before the stroke.

At five to seven years post stroke, caregivers indicated that their faith in God and spirituality had evolved over time. Most participants believed that “it [stroke] is part of God’s plan” and “it’s something that happens in your destiny.” Many shared a belief that caregiving was a part of who they were as, “God had a plan for me to be here to take care of somebody. This is part of HIS plan in my life.” They expressed their commitment to “do the will of God” and explained their acceptance of their circumstances stating, “[that is] probably when you need to do more of what you’ve been doing, because that strengthens you too, ... cause God isn’t to blame for [it], it’s something you just cope with.”

*Adjustment.* Upon returning home, spousal caregivers learned “how to adjust my rhythm and pace and schedule to be able to do the things I need to do and keep things going the way I’d like for them to be going.” At three months post stroke, practical role changes appeared to be one of the most common aspects of caregiving. Spouses of survivors adjusted to new responsibilities that were previously in the survivors’ domain, including maintaining household chores, managing finances, and driving—especially for spouses who did not drive prior to the stroke event. As they developed routines to manage the physical tasks, caring became ‘easier’ as described in their comments, “at first you are afraid of the unknown, and then six or nine months later you pretty well know how things are gonna be and you are able to accept it more.” The stroke also

involved lifestyle changes and some caregivers reported, for example, having to give up work or withdraw from volunteer work—partially or completely—in order to fulfill their caring roles.

For the majority of participants in this study, the spousal relationship transitioned into a care provider and care receiver relationship due to a lack of intimacy and affection between the couples. There was not much role adjustment at five to seven years post stroke once the couples had settled into a routine. The focus had shifted to sustaining the evolving relationship and to maintaining stroke survivors safely in the home.

*Acceptance.* Acknowledgement and acceptance of stroke survivors' changed abilities was considered an important component of forming and adjusting to new routines, as well as generating and maintaining a more positive outlook about survivors' recovery trajectory over time. For instance, one caregiver stated, "I don't think things have been, gotten worse since the beginning but I guess it is settling in that things may not change and then I am just going live with the way things are." As time progressed, one survivor indicated having "become more able to accept the things that won't change. I mean he will always have memory problem, and not being able to deal with money." While other spouses learned to accept and understand the survivors' frustration and reminded children that, "he can't help it as it is part of his disability." At five to seven years post stroke, one participant expressed their acceptance as, "I am able to accept things as they are, don't feel like I am trapped in a situation I can't get out of and it has also opened up my eyes and let know that I can go places without having to worry about him and I can send hi with somebody to take of care while I am gone."



*Suppressing or releasing emotions.* Around three to six months post stroke, some caregivers often tried to hide their stress, concerns, or true feelings from their spouses and became “more cautious about speaking in front of him, and not to discourage him.” One participant described their caution as having to “always think before you speak” and many caregivers indicated felt that suppressing their emotions and being more patient enabled them to better cope with the practical tasks of caregiving. Some comments describing this suppression of emotion were, “just do whatever I’ve got to do” and “you just take life as it comes.” Other spouses spoke of the need to “call someone to cry a little bit and say worse fears” and “be honest with what’s going on” in order to release their emotional stress. The need to release emotion seemed to decline after the first six months as most caregivers recognized the need to do more for themselves and found alternative ways to release their emotional stress.

*Avoidance.* Caregivers highlighted the value of having a periodic break or escape throughout the process of the survivor’s recovery. Changes in participation in social and other activities post stroke often imposed an increased time spent together as a couple. Participants expressed the need for a break from each other as they adapted to new routines. One caregiver commented on the need to “get out and so that you can get a different view on things,” and another participant said, “I had time to myself and that’s really what I needed.”

As years of relentless caring passed, most spousal caregivers spoke of their need to escape from home once in a while, and considered it a “healing thing.” They found a variety of ways to escape from their current situations, including:

- getting fresh air when going to the grocery store;
- continuing work as an escape from home;
- having a break when the survivor took trips or visited family;
- enjoying getting out of the house and participating in the CARES research study and knowing where to find information if needed;
- visiting family or business trips and being away from responsibilities at home; and
- shifting priority by ignoring the house being messy and the stroke survivors' stained clothing.

**Positive thinking.** Almost all participants spoke of the intense emotions associated with the adjustment to caregiving, especially in dealing with survivors' behavioral, psychological, or mood changes. The ability to maintain hope and optimism was essential for all caregivers and helped them cope with their caregiving situations. They hoped that stroke survivors could improve and regain their independence and looked forward to having many years to enjoy together. They viewed recovery as a slow process that occurred over time.

**Optimism and realism.** Spousal caregivers spoke of the importance of adopting hope and optimism, adjusting their own expectations, and reassessing their priorities to acceptance of their continued caregiving role. Their adjustment was underpinned by the realization that their lives were now on a different path, however improvement in the survivors' recovery over time and hope for positive future change helped them to cope with their new reality. At three to six months post stroke, caregivers' expectations about

survivors' improvement became slightly more realistic. Their voices could be heard through statements like, "I wish our life was like it was before but I don't think it ever will be, but we will make the best of it because we love each other;" and "I don't have any negatives, and I feel good and positive that it's gonna one day, he will be able to move his left arm as he used to before and walk better."

**Hope.** Hope was one of the most commonly used coping strategies, adopted early on and continued throughout the caring journey. Caregivers spoke of gaining a sense of growth and well being that helped them to keep going in their caring roles. One participant shared feeling that "hope is something you have to have in order to keep going, you have to hold on to the hope ... we are hoping to keep whatever health I do have and hope that my health holds up..." Common hopes expressed by caregivers included hopes for good health, for their loved ones to get better, for next generation, to see their children getting married, to continue making contributions in peoples' lives, and to continue to care for the survivors.

**Gratitude.** After three months of caregiving and thereafter, spousal caregivers found comfort in comparisons to other stroke survivors and counting their blessings with respect to what their partners were able to do after the event as they realized that "there are lots and lots of people worse than us." One caregiver expressed it as, "I thank God that he still has his mind," and that they "cherish" the relationship they still have. Even in cases where survivors had severe disability, caregivers tried to find something about which to be positive.

Some spousal caregivers demonstrated their resilience by viewing the stroke event as having made them rethink their life priorities and value their partner more as expressed by comments like, “I become less worried about housekeeping stuff.” They reframed their lives in positives ways to conserve quality of life and did not let stroke interfere with doing fun things. Some felt fortunate to be able to travel as they struggled to find meaning in unexpected retirement to care for the survivor. A caregiver described the decision to frame their concern about financial needs in the future as, “whatever I am going to do to make sure we have a roof over our heads and food in our bellies, and that the animals are taken care of.”

As participants grew older, they began to realize one advantage of being older as “you realize your own mortality or immortality... time becomes more precious” and noticed that “my attitude toward people has changed ... try to make friends wherever I go ... become a more patient and a more compassionate person.” These changes associated with aging itself helped some caregivers cope with difficult situations.

***Interdependence.*** Compared to caregivers who suffered a sense of loss of spousal relationships, some caregivers treated it as a learning experience of working together and being there for each other; thus, they became more interdependent on each other to “keep each other going.” The caring role was viewed both as a duty, but also a privilege as explained by one participant, “I am so lucky to be able to do it.” As the years passed, some couples felt the stroke didn’t change their relationship, but created a closer relationship “because we have to think more of the other person.” They perceived their loved ones’ support as being as much as they were capable of giving, which helped to

preserve their relationships. The caring role was viewed both as a duty, expressed as “you just keep doing and do what has to be done,” but also as a privilege—“I am so lucky to be able to do it, that’s what I think.”

***Being strong and being doers.*** As a job that no one wants, participants expressed that they had no other option but to be strong, saying “we have to be strong for the kids, so if they see me break down, they get upset. So, if you are not strong, it’s a waterfall effect.” Some caregivers believed that their personal philosophy of being doers had helped them to continue doing the job. They believed that “God helps those that help themselves,” and “I live by golden rules – do unto others as have them do unto you.”

### **Triangulation**

In the semistructured interviews, family caregivers reported a variety of sources of stress and coping behaviors. Of 30 participants interviewed, one was excluded from this analysis because the participant refused to complete the questionnaires. Of 29 participants, 16 reported PSS scores indicating a low level of stress, six participants reported an average level of stress, and seven expressed a high stress level. More than half of participants had mean F-COPEs scores of 104.38 or greater ( $SD=12.59$ , range = 83 -124) indicating that they had adopted multiple coping behaviors to handle difficulties and problems. The higher the scores, the more likely the families were to more successfully adapt to stressful situations; and the lower the scores, the more likely the families were to have inadequate coping resources and experience more difficulties adapting to stressful situations.

When comparing and contrasting quantitative PSS and F-COPEs scores with qualitative findings, the qualitative findings were in overall agreement with the quantitative results. Relationships and comparisons between qualitative and quantitative findings are illustrated in Appendix C (Table 4). The majority of participants who reported low stress levels also reported high scores with respect to coping, which is consistent with the mediating effects of coping on stress. However, there was some discordance between the two measures in 11 of the 29 participants—one male and 10 females. Three participants (one male and two female) who experienced high stress levels had indicated good problem-solving and behavioral strategies as evidenced by the high scores on F-COPEs subscales, which did not support an inverse relationship between PSS and F-COPEs scores. However, their high stress levels and high F-COPEs scores were reflected in their interviews with one exception. One male caregiver had a high stress level as indicated by his PSS measurement, but didn't reveal any stress-related themes in his interview. He also had a high F-COPEs score, indicating good coping skills.

Like many other caregivers, these three participants identified spirituality and religious support as one of their major coping resources and reported engaging in a variety of ritual practices such as bible study, church attendance, gospel radio, prayers, watching televangelists, and talking to God to ask for guidance. They were able to maintain their faith in spite of health difficulties, and shared the similar personality traits of being strong and being doers, which was illustrated in comments like, "I am a go-getter and I try not to let it hold me down" and "you don't have time to just dwell on it, life still going." In addition to being doers, they also actively sought social support and

support from healthcare professionals to sustain their faith in spite of challenges and difficulties.

Discordance between qualitative and quantitative findings was also found in six participants with very low PSS and high F-COPEs scores. This relationship between the two measurements was consistent with the mediating effects of coping mechanisms in managing stress, indicating good coping and behavioral skills. However, low PSS scores were not reflected by the interviews, as these participants still expressed significant stress even though they reported the use of multiple coping strategies.

Two additional caregivers also had discordance between qualitative and quantitative measures, with low PSS and below average F-COPEs scores. These two participants described a wide variety of stressors and indicated using multiple coping strategies. Overall, qualitative and quantitative findings were consistent, providing a broader and more complementary view of caregivers' experiences.

### **Discussion**

This study examines stress and coping experiences of spousal caregivers of stroke survivors over time using a mixed-method of triangulation approach. It was the first study to combine qualitative and quantitative findings on how spouses of stroke survivors cope and adjust to the caring role across the trajectory of stroke recovery. The study sought to provide a deeper understanding and broader view of these caregivers' experiences and challenges during the stroke recovery trajectory.

The spouses in the study grieved for the past, present, and future loss of a relationship with their partner, but the majority of them continued to cope well with

difficulties that arose and expressed a commitment to “take it the way it is and one day at a time.” The majority found meaning in the lived experiences of caring for their spouses as a process of transition, recognition of the loss, acknowledgement of their partners’ changing behaviors, acceptance of a new life together, and coping with these changes despite their grief over loss of the person they knew. Most of them reframed their lives in positive ways to preserve their quality of life and the health of their spousal relationships. They attributed their ability to transition their thinking, change their expectations of life, and continue to perform caring activities by using a variety of coping strategies, which were encompassed in the primary themes identified from the data (Table 2). Their stress- and coping-related experiences revealed a mix of different feelings and emotions, as well as a variety of coping strategies among spousal caregivers over a period of five to seven years post stroke.

Stroke survivors and their family caregivers often experience numerous challenges as they progress along the stroke care continuum—from acute care, to inpatient rehabilitation, to home. The primary goal of this study was to identify spousal caregivers’ experiences as the stroke survivor moves through different phases of the stroke recovery trajectory after returning home. The transition to home posed many challenges for both stroke survivors and caregivers. Graven, Sansonetti, Moloczij, Cadilhac, and Joubert (2013) reported challenges involving increased financial, emotional, and psychological burden after the transition home. The first few months of caregiving have been described as “taking up the role” (White, Poissant, Cote-LeBlanc, & Wood-Dauphinee, 2006) and a time when caregivers try to understand their new roles, rearrange



their daily lives, seek information and support, recognize and learn the skills to meet survivors' needs, and attempt to gain control over their situation (Lutz, Young, Cox, Martz, & Creasy, 2011; Brereton & Nolan, 2002; Greenwood, Mackenzie, Wilson, & Cloud, 2009b).

Becoming a spousal caregiver for the stroke survivor is often associated with numerous life changes, but the first and most prominent is from spouse to caregiver as identified in this study (Cao et al., 2010). The belief that caregivers hold an obligation to assume caring responsibility has been frequently reflected in caregiver research (Quinn, Murray, & Marlone, 2014). The focus of life was completely changed to meet their spouses' needs, which was viewed as fulfilling a strong sense of duty by some caregivers; however the majority of others experienced the change as overwhelming. They indicated the change brought additional responsibilities, many of which they had not previously performed, and required tremendous adjustment to meet the increased demands at the expense of their free time, independence, and emotional and physical health. These findings were consistent with those of previous research studies (Pierce, Steiner, Govoni, Thompson, & Friedemann, 2007). 2007; Cao et al., 2010). As the stroke survivor progressed through the recovery trajectory, their spousal caregivers experienced some changes as well. Backstrom, Asplund, and Sundin (2010) described it as a process of transition, recognition of the loss, and reconciliation of the changes.

Being a caregiver was described as a full-time job, highly demanding, feeling stressed and burned out, and having increased responsibility with decreased personal time (Pierce et al., 2007; Cao et al., 2010). For caregivers in this study, one of the most

challenging difficulties was assisting their partners who suffered physical impairments with their ADLs, as conveyed by remarks such as, “It was really a strain on my back” and “I have been hurting.” The effects of caregiving one-year post stroke were often manifested in physical exhaustion, as well as complaints of lack of sleep, fatigue, and pain (Coombs, 2007). Caregivers also experienced declining health and increased cardiovascular risks (Bakas et al., 2014). However, most caregivers in this study mentioned changes in these experiences over time. As compared to emotional stress, physical stress was a downward spiral. This theme reflects an essential coping mechanism—adjustment and adaptation to a new caregiving routine life after taking on the new role. This phenomenon could be explained by Cameron and Gignac’s (2008) claim that as stroke survivors became more integrated into community and gained greater independence, they ultimately required less care from the caregivers. This reduced demand allowed caregivers to either return to their pre-stroke activity level or adopt a modified activity level.

Caregivers reported persistent emotional stress over time, but identified different sources of stress during different phases of stroke recovery. Emotional stress during the early days of caregiving was associated with the survivor’s personality change, lack of appreciation from the survivor, unpreparedness, worry, fear, hypervigilance, sadness, and uncertainty of what the future would bring. They often felt overwhelmed and inadequate when taking on their new roles and felt the need to “escape” and “take a break.” Caregivers’ emotions ranged from feeling that they had no choice in taking on the demands of caregiving, to feelings of duty and obligation, to feeling grateful for still

being together. These findings were consistent with those of previous studies conducted at one to five years post stroke (Pierce et al., 2007; Cao et al., 2010; Coombs, 2007). Concerns about survivors' safety issues were related to survivors' lack of insight into their own limitations and defensiveness, causing caregivers to feel they needed to protect survivors physically and emotionally at one to three years post stroke (McCarthy & Lyons, 2015). As caregivers were asked to describe their experiences over the course of the first five to seven years post stroke, they indicated that their emotional stress had evolved over time and was more or less related to the survivors' cognitive deficits caused by stroke, such as:

- depressive feelings about unmet goals in functional recovery;
- feelings of uselessness;
- feelings of separation from each other;
- feelings of not being listened to or understood, but not wanting to hear from each other;
- feelings of efforts being unrecognized or resentment about the perceived lack of appreciation;
- feeling alone or of having no one to fall back on.

Caregivers acknowledged the need to learn and adopt good, practical problem-solving strategies in order to master their caregiving roles (Backstrom et al., 2010; White et al., 2007). Participants in this study seemed to use problem-focused coping mechanisms more frequently to resolve challenges related to the practical aspects of caregiving, especially early during the stroke recovery trajectory. Caregivers attempted to

identify current and potential challenges, prioritize tasks, and find resolutions to those problems on a daily basis, allowing extra time to complete difficult tasks. Practical approaches adopted by the caregivers included allowing extra time for trip planning and bathroom breaks and being more patient when travelling, trying to maintain as much as normalcy as possible (Coombs, 2007), and making adjustments that enabled their partners to fully participate (Green & King, 2009).

Backstrom et al. (2010) pointed out that the post stroke transition represented a mourning period for past, present, and future losses during which caregivers had to face an inevitably different future and shift their expectations and values in order to maintain hope and develop a positive outlook. Emotion-focused problem solving strategies—including hope, faith in God, acceptance, gratitude, positivity, and seeking emotional support—were adopted early in the caring journey and consistently utilized throughout all phases of stroke recovery. Most participants indicated that acceptance of the survivor's condition and gratitude that they still had the survivor were key coping mechanisms that helped them get through a difficult time. Caregivers shared that acknowledgment and acceptance of survivors' changed functional capacity was considered an important strategy for establishing new routines, adapting to their new roles, and maintaining a hopeful and positive outlook about the future (Graven et al., 2013; Quinn et al., 2014). As participants mastered caregiving skills and developed more organized daily schedules, they adapted to a new “normal” by settling into a new set daily routines (Pierce et al., 2007).

After the early period of adjustment, the feeling of unpreparedness appeared to diminish starting at three months post stroke. However, the survivor's personality changes and lack of affection led to a profound sense of loneliness for some caregivers by six months post stroke and persisted as couple friends began to grow increasingly distant. To endure their situation, Backstrom et al. (2010) found that the spouses needed to re-evaluate their life goals and values in the changed relationship with their partner. Over time, the participants in this study began to find meaning in the transformed spousal relationship as they acknowledged their partners' changing behavior and subsequently accepted a new way of life together. Some caregivers in this study said that grief over the loss of the person they knew and their past relationship was always present.

These findings were consistent with those of Backstrom et al. (2010). Some participants in this study were able to accept the changes through their faith in God by recognizing their transformed relationship as part of God's plan; however, others felt trapped in an unwanted partnership or caregiver relationship. Some verbalized their feelings about emotions, romance, and intimacy with statements like, "we have a good relationship as a provider and a patient, a relationship as far as a husband and wife is not there" and "inside I feel like that part of my life has gone," and "I am the mother and wife, but not the lover." After one year of caregiving, a sense of suffering in silence and loss of intimacy became prominent for some caregivers. They felt that hiding feelings from their partners and children and being strong for themselves was the only effective way to cope with difficulties and protect the feelings of their partners and family. They felt they could "do nothing about it, just wait and see how things come out day by day."

Despite numerous adjustments in their lives and relationships, the caregivers in this study were very committed to their partners and to maintaining the caregiving role, which was also observed in previous studies (Coombs, 2007).

Caregivers often limited their communication and avoided or concealed their feelings and concerns from their partners, which was also consistent with previous findings (Hinnen, Ranchor, Baas, Sanderman, & Hagedoorn, 2009; Lyons, Jones, Bennett, Hiatt, & Sayer, 2013). Some expressed worry, fear, or sadness about being unwilling or unable to honestly discuss their concerns with survivors (McCarthy & Lyons, 2015). Participants said they were reluctant to share their feelings because they were concerned about protecting the survivor's ego or possibly discouraging them. Caregivers felt sad about the survivor's failure to recognize his or her limitations (McCarthy & Lyons, 2015), struggle to regain their functionality, and depression resulting from permanent stroke-related deficits. Fears of another stroke event, a serious fall, or other accident could also explain emotional distress in both survivors and caregivers.

Although some caregivers suppressed their feelings to protect the survivor or other family members, others expressed a need to release their emotions as a protective buffer (Hinnen et al., 2009; Lyons, et al., 2013). Caregivers expressed the importance of having someone, usually a close friend or someone from church or a support group, with whom they could cry and share their worst fears as a way to release their emotional distress. It was evident that the majority of participants in this study were very "other focused," ignoring their own needs and sacrificing for the good of others, dealing with

setbacks and regression, and neglecting their own self-care and health maintenance. They devoted themselves to their spouses, family, and sacrificing for the good of others and ignoring their own needs, thus raising questions of their own level of self-care and health maintenance. Some participants suffered declining health that contributed, in part, to increased stress with respect to caregiving and employment. Management of career, home life, and scheduling remained major concerns as far as maintaining their effectiveness as caregivers. Caregiving was viewed as “a long-term wearing process” and as relentless both physically and mentally, especially with respect to constant worries about survivors’ safety. Participants indicated that dealing with stroke survivors’ mental disabilities was worse than dealing with physical impairments. This was attributed to increased care demands, spouses’ perceptions that they were not doing enough, complaints that the survivors’ needs were not being met quickly enough, abusive language, anger and physical violence, mood changes/swings, feelings of hopelessness, lack of affection, arguments, or the survivor becoming depressed and feeling useless.

Consistent with the findings of previous caregiver research, spousal caregivers in this study shifted their focus to their partners over the course of the stroke recovery trajectory, putting their own lives/needs aside or on hold, and remaining constantly on standby to protect, support, and ensure that their partners’ needs were met. Over the course of the survivors’ recovery trajectory, caregiver focus shifted from grieving the loss of their relationship with their partner prior to the stroke, to gradually accepting their new way of life together, and finally to worry about their ability to perform the caregiving role in the future due to their own declining health condition. Some participants described

their feelings of commitment to their partner as part of “God’s plan” for them (i.e., to take care of the survivor), despite initial feelings of abandonment and depression. These findings might be explained by the suggestion of Backstrom et al. (2010) that the presence of the other requires the spouse to act ethically as far as how to best take care of another’s life. The contribution of survivors’ perceived failure to acknowledge their limitations, desire to preserve their independence, protection of their ego, underestimation of their impairment, and/or attempts to resume their before stroke activities to the emotional strain of caregivers was consistent with the findings of McCarthy and Lyons (2015).

Previous research also supports the profound sense of loss for spousal caregivers related to the loss of their role, marital relationship, and shared life, as well as the struggle to maintain their vision of ‘us’ as a couple and efforts to regain their identify as a spouse that emerged in the current study (Backstrom, Asplund, & Sundin, 2010; Coombs, 2007). Some caregivers in the study felt the sense of loss more acutely than others and expressed that the loss of the marriage relationship was the most difficult to cope with (Coombs, 2007). However, for some couples the stroke resulted in a closer relationship and greater interdependence on each other as they faced challenging situations together. Although no specific questions were asked during the interview about the marriage relationship before stroke, good quality of the marital relationship prior to the stroke was discussed by participants during the interviews and appeared to be a key factor in successful adjustment to the new life circumstances. For couples who spent a lot of time doing activities together before the stroke, the change in survivor capability due to stroke-



related deficits was more challenging; however, they adjusted well by making every effort to keep their partners in the home and comfortable.

Some spousal caregivers in this study felt that “suffering in silence” helped them to cope with their circumstances, while others simply felt they had no choice and became overwhelmed. They developed a great sense of suffering and wondered, “where has my lovely family gone?” Quinn et al. (2014) pointed out the danger of misinterpreting this approach as an effective coping mechanism in cases where spousal caregivers were actually engaged in avoidance, and suggested that clinicians carefully evaluate spouses who appear to be coping well and actively investigate whether caregivers are appropriately communicating their feelings. Opportunities for spousal caregivers to express their emotions outside of the relationship, for example in a caregiver support group, would be beneficial and encourage healthy coping.

In addition, caregivers experienced a loss of leisure time and freedom, reduced participation in social activities, feelings of confinement, and inability to travel described as “like having babies again.” These losses deeply affected many aspects of their lives. As observed in previous research (Cao et al., 2010), most caregivers in this study reported that lack of time and energy contributed to neglect of their own health, which could explain their inability to fully pursue their own leisure activities. Coombs (2007) and Cao et al. (2010) also reported that caregivers felt guilty when participating independently in activities and leaving their spouses alone at home for any amount of time. They found that caregivers felt a sense of obligation to remain constantly by the survivor’s side resulting from fear of leaving them alone and concern for their safety.

Further research is needed on the prevalence of these feelings of guilt and the caregiving role as a barrier to resuming activities and how to better support caregivers in coping with challenges and feelings.

Contrasting feelings over a period of five to seven years post-stroke included a change in caregivers' focus from putting aside their own needs and concern about not meeting the survivors' needs, to feeling a greater need for self-care in order to sustain the changed relationship into the future (Backstrom et al., 2010). Caregivers in this study started feeling the need to do more for themselves at about six months post stroke. The tendency for spousal caregivers to put their own needs aside commonly occurred early in their caregiving journeys, but there was an increasing realization of the importance of self-care and refocusing on their own needs due to their own declining health and concerns about their inability to continue in the caregiving role as time progressed (Backstrom et al., 2010). This finding has useful clinical implications for healthcare professionals with respect to addressing the needs of the spousal caregiver early in stroke recovery to increase their awareness of their own health and encourage them to focus on their own physical and psychological well-being as time progresses, particularly if a need for long-term caregiving is expected. Additional longitudinal research is needed to explore the timing of this phenomenon within the trajectory of stroke recovery so that caregiver awareness can be increased and timely assistance provided.

Most caregivers in this study verbalized the tension between the survivor and caregiver with respect to when and how much support was needed. Graven et al. (2013) also described the challenge of finding a balance between encouraging survivors to

participate in activities or do more for self and fulfilling the caregiving role. This challenge persisted over time for some caregivers in this study, especially when they felt physically exhausted or suffered declining health. Nevertheless, caregiver experiences may change over time as they adapt to and learn to cope with the caregiving role by mastering caring skills, establishing new routines, incorporating care responsibilities into their daily lives, and developing more effective coping strategies (Greenwood et al., 2009b; Quinn, Murray, & Malone, 2014).

As caregivers realized the importance of their own physical health, there appeared to be a struggle to find balance between doing everything for their spouses and encouraging them to do more for themselves, especially during the early adjustment period. This struggle was gradually resolved over time as the couples created a new “normal” and adapted to a new routine. Caregivers highlighted the value of both formal and informal support throughout the stroke recovery trajectory, which has been reported in numerous caregiver studies. Such support incorporated practical support with tasks, although not always available daily. Participants in this study felt supported physically, and more importantly psychologically, even not asked frequently. Caregivers remarked that having a break and having someone to talk to or cry with was crucial to their continued performance in the caring role (Buschenfeld, Morris, & Lockwood, 2009; Coombs, 2007; White et al., 2007).

The majority of caregivers in this study reported that they did not receive adequate preparation prior to discharge or did not realize it until returning home with concerns of adequate support from health and social services (Kerr & Smith, 2001;

Yeung et al., 2015). In the early months after stroke, a substantial number of caregivers needed increased attention and support from healthcare professionals. A recent review by the Care Quality Commission (2011) also found that the information provided to family caregivers before discharge was inadequate. Inadequate information, knowledge, or skills appeared to be associated with caregivers' hypervigilance or constant worries, especially early in the recovery process. However, the magnitude of caregiver information and training needs changed over time, with the greatest need occurring during rehabilitation and upon return home because of the unpredictable, sudden onset nature of the disease. Participants in this study expressed a need for more education and professional support, especially after the stroke survivor is discharged and returns home. They often felt insufficiently prepared to assume their new caregiver role, as educational resources to help survivors and families learn more about stroke and home care were limited in format, distribution, and availability (Yeung et al., 2015). Yeung et al. (2015) further suggested that although the explanation of the survivor's condition provided by healthcare professionals was sufficient during the acute phase of recovery, as stroke survivors progressed through the stroke recovery trajectory, the focus shifted to regaining lost functionality and reintegration into the community. Participants in this study expressed a need for ongoing guidance about how to sustain continued progress and long-term improvement, especially after completion of therapy. Yeung et al. (2015) found that as stroke survivors and caregivers adjusted to living in the community, they experienced an increased need for information about social welfare, financial, and governmental assistance programs; respite care; therapy; and other community resources to support

home care and promote long-term recovery. Spousal caregivers highly valued healthcare professionals taking the time to explain in detail issues related to the care and condition of the stroke survivor, which has implications for the multidisciplinary team. Efforts by healthcare professionals to communicate with and educate spousal caregivers are important for the stroke survivors' subsequent care, and are also particularly beneficial to the psychological well-being of spousal caregivers (Quinn, Murray, & Malone, 2014). Therefore, additional research is needed to better define caregiver education and information needs across the stroke recovery spectrum.

Social support is known to play an important role in the adjustment of spouses to the caregiver role and in maintaining or improving their quality of life; however, research studies have shown a significant decrease in social support for spousal caregivers during the three years post stroke (Adriaansen et al., 2011). This decrease in social support reflects the difficulty caregivers describe with engaging in social life outside the home due to their reluctance to leave survivors home alone because of guilt and/or worry about safety issues, as well as the gradual decrease of visitors over time (Green & King, 2009; Forsberg-Warleby, Moller, & Blomstrand, 2004; Larson et al., 2005). Emotional and practical support is greatest during the crisis phase just after the stroke event (Jacobson, 1986). As the stroke trajectory lengthened, the involvement of family and friends decreases as everyone returns to their own routines (Adriaansen et al., 2011). This pattern was observed in this study as "friends started disappearing" around six months post stroke; however, the majority of participants adapted well by actively establishing and/or maintaining good social networks, actively seeking professional assistance, and

participating in church and family activities, although most indicated they tried fulfill the caregiving role themselves in order to avoid burdening their adult children. For some caregivers, participating in the CARES study was not only a great source of support, but also a comfort or a relief offering a break from endless caregiving and an opportunity to talk with someone who understood their feelings. Because a considerable number of caregivers experienced caregiver strain over time, further longitudinal research is needed on how to meet the need for social support and provide improved access to healthcare professionals/resources as stroke survivors and spousal caregivers reintegrated into the community.

The majority of spousal caregivers in this study described themselves as being doers or felt they had no choice but to care for their spouse themselves and utilized multiple coping strategies to deal with difficulties and challenges, one day at a time. Over time, participants needed to have, and expressed the importance of, more time for themselves, periodic breaks from their partners, and fresh air in order to regain the strength they needed to continue in their caregiving roles (Quinn et al., 2014). Barriers common to many caregivers were reflected in this study, including reluctance to leave their partners alone because of constant care needs, guilt, or safety concerns. This finding suggests a need for adequate respite care to provide breaks for spousal caregivers who are unable to safely leave their loved ones unattended (Quinn et al., 2014). A recent UK audit found that less than one third of caregivers were satisfied with their current arrangements for respite care and indicated a need for further improvement (2010). Therapeutic interventions—such as cognitive behavioral therapy—targeting barriers related to

anxiety, guilt, worry, or hypervigilant behaviors could minimize these reactions and promote the benefit of time to themselves among spousal caregivers (Quinn et al., 2014).

In this study, spousal caregivers said that change in survivors' condition was a significant contributing factor to their caregiving experiences. Spousal caregivers of survivors with improving conditions reported a great sense of relief, increased freedom, and less emotional and physical stress. Conversely, caregivers of survivors with deteriorating conditions continued to suffer negative effects of caregiving. The physical demands of caring for survivors with significant impairments could lead to back pain, sleep deprivation, and fatigue (Tseng et al., 2015), indicating that caregivers may require and benefit from respite care, as reflected in previous studies exploring the needs of family caregivers of stroke survivors (Saban & Hogan, 2012; King, Ainsworth, Ronen, & Hartke, 2010). Therefore, information and resources about the availability of respite care or other supportive programs would help caregivers gain appropriate assistance to sharing or relieve their workloads.

Spousal caregivers described barriers to continued church activities including a lack of handicapped access or suitable transportation, difficulties with getting the survivor into and out of the vehicle, or limited availability of public transportation. Participants in this study suggested that religious and spiritual practice, recognized as one of most commonly and consistently utilized coping mechanisms throughout all stages of stroke recovery, should be supported by transportation assistance and wheelchair/handicapped access to facilitate continued attendance of church services, interaction with church members, and possible support from the church or church

members. However, common barriers to public assisted transportation were also described, including issues with scheduling of paratransit services, establishing eligibility for transportation services, or lack of available routes to their destination (Ing, Vento, Nakagawa, & Linton, 2014). Participants also related challenges of private transportation, including the lack of a vehicle to accommodate the survivors' disabilities (Ing et al., 2014). Therefore, additional study is needed to identify new ways that new existing programs can more effectively serve stroke survivors and spousal caregivers.

Although focused on their current caregiver role, participants in this study highlighted the importance of maintaining hope for a better future and looking forward to the future with optimism (Coombs, 2007). Hope facilitates progression beyond present suffering, development of a new life perspective, and a more positive caring experience (Morse & Penrod, 1999; Tebb, 1994; Davis & Grant, 1994; Miller, 2000; Coombs, 2007). Hope and optimism were essential to successful navigation of adverse situations throughout stroke recovery and to sustained caregiving. Spousal caregivers in this study recognized the benefit of adopting a positive and optimistic focus that included being grateful that the survivors' condition had not deteriorated and for the caregivers' continued ability to provide care, acknowledgement and acceptance of their current situations, and re-evaluation of their expectations for the future. For the majority of participants, this transition involved realization that their original expectations regarding the survivors' recovery were idealistic, refocusing on a new life with a "different path" (Buschenfeld, Morris, & Lockwood, 2009), and subsequent adoption of more realistic expectations and corresponding adjustment of their goals (Bulley, Shiels, Wilkie, &



Salisbury, 2010; Brann, Himes, Dillow, & Weber, 2010). The process of assessing and revising their focus appeared to begin around three to six months post stroke and continued throughout the trajectory of stroke recovery. This finding suggests that healthcare professionals should consider the impact of expectations and educate spousal caregivers about the stroke recovery trajectory to encourage more realistic expectations regarding stroke survivors' recovery. Quinn et al. (2014) suggested potential strategies to promote hope and optimism including a cognitive behavioral therapy approach focused on blessings, such as what their partners could do rather than on what they could not do or accomplish, and gaining strength from religious faith. This strategy appeared to encourage continued caregiver participation in the rehabilitation process.

Caregivers also expressed concerns about living and medical expenses, such as costs related to medications, equipment, doctor visits, and other healthcare services. Participants reported continued financial stress as bills piled up and a lack of financial security about having enough money for the future because of reduced household income. Financial strain was also attributed to the perception of having to constantly fight with the insurance company, staff at the doctor's office, and the hospital regarding medical costs. One caregiver explained, "everything is a fight. Nothing gets done the first time, nothing" because "we are always in the bracket of where we made too much to get assistance but not enough to be able to afford paying the way we used to." This finding suggests a need for healthcare professionals to better inform caregivers about available financial support resources within the community.

Spousal caregivers in this study identified a process of adaptation to their new roles and settling into a new lifestyle/routine using a number of strategies that facilitated the transition, including: religious and spiritual practices, social and family support, protective buffering, prioritizing tasks and slowing down the pace, identifying new meanings within their changed relationships and making adjustments to share activities together, and striving to achieve a sense of normality and a positive outlook for the future. Many participants described this process as difficult and acknowledged the need for longitudinal support to facilitate the process during different stages of stroke recovery. Future caregiver research is needed to develop more effective strategies for helping caregivers adapt to their new role and adjust to the shift in roles and responsibilities, which represents a major adjustment from a mutually supportive and romantic husband-wife relationship to a caregiver-provider relationship.

The secondary aim of this study was to explore the relationship between qualitative and quantitative findings and develop a more thorough understanding of spousal caregivers' stress and coping experiences over time. Different methods can be used to obtain different types of information from caregivers, for example questionnaires were used to collect quantifiable data on caregiver stress and coping experiences including perceived levels of stress and coping skills. Semistructured interviews provided qualitative data about stress and coping variables and underlying reasons for caregiver perceptions. The use of multiple methods allows us measurement of overlapping, but different, aspects of caregiver experiences, thus giving us an enriched understanding of the phenomenon (Li, Marquart, & Zercher, 2000). As a result, the complete data set

indicated that although some caregivers experienced high levels of stress and low problem solving strategies, there were conditions under which this was not true. Without information from both the interviews and the survey data, different and possibly incorrect conclusions might have been reached about their experiences.

Stress occurs when individuals perceive demands in their lives that exceed their available resources (Folkman & Lazarus, 1986). Whether or not a situation is perceived as overwhelming plays a key role in determining the outcomes of stress. Participants in this study expressed physical and emotional strains that were commonly reported by spouses caring for stroke survivors in previous studies. These strains are likely related to the many aspects of life affected by stroke, including communication, physical and cognitive impairments, financial concerns, and emotional burden. This mixed-method study provided new insight into how caregivers' lives were affected and indicated that sufficient social support and resources, as well as coping strategies such as keeping a positive attitude, maintaining role changes, and seeking religious support, were critical for managing with stress,

Across interviews and quantitative measurements, caregivers who reported lower levels of stress based on their PSS scores also expressed less concern about caregiving strain with higher scores on the F-COPEs scale, which is consistent with previous research findings. The majority of previous research findings have supported an inverse relationship between stress and coping variables, however further exploration is needed to determine the meaning of higher or lower scores on both the PSS and F-COPEs instruments with respect to problem solving and behavioral strategies. Caregivers with

both high PSS and F-COPEs scores relied heavily on religious and spiritual support, although they also reported some social/family support; while caregivers with low PSS scores and high F-COPEs scores utilized more practical problem-solving strategies and other stress-reduction skills. Although the study sample was small, this was the first study to examine the relationship between caregiver stress and coping skills and the results suggest a need for further exploration in larger scale studies. Because all participants indicated that spirituality plays a significant role in reducing psychological distress and appears to improve their quality of life satisfaction, it is important to consider caregivers' spiritual needs when developing interventions.

Findings from the interviews and surveys used in this study were primarily in agreement with each other, as shown in Table 3. Concerns about caregiving stress were reflected in the PSS scale measurements and the five subscales of F-COPEs scale were also consistent with data from the interviews. However, six of 29 spousal caregivers who had low PSS scores also had high F-COPEs scores.

In addition, two caregivers who reported a low to moderate levels of stress and scored high on the F-COPEs measures were males, indicating that male spousal caregivers were capable of providing sufficient care to their loved ones (Tiegs et al., 2006). They shared similar burdens with female caregivers, but displayed some advantages in coping with the stress of caregiving. One potential reason for men's relatively reduced stress associated with providing care might be related to their instrumental approaches to solving problems and coping with stress (Tiegs et al., 2006). The male participants scored higher on the F-COPEs, indicating that they effectively

mobilized available resources and utilized strategies to overcome the difficult aspects of caregiving. This could explain why no specific stress-related themes were found in the interviews of the male participants, as their interviews were relatively short and concise with a greater focus on problem-solving approach than the interviews of their female counterparts. Tiegs et al. (2006) suggested that if the observed advantages in caregiver stress among males were indeed a result of their greater instrumental focus, incorporation of training in instrumental behaviors as part of caregiver training could be beneficial.

### **Strengths and Limitations**

Several limitations were present in this study. First, the sample may have been biased toward persons who had existing knowledge about stroke and had previously sought information. A more diverse sample is needed that includes people from different geographic areas and cultures. Second, the interviews were relatively short from baseline through one year post stroke, indicating potentially limited data. Third, as with most qualitative studies, interpretation of the transcripts may have been biased by the experiences of the researcher. To enhance the objectivity of interpretation, documentation of auditing trails for thought and decision-making processes could be of value.

This study is significant because it investigated spousal caregivers' experiences of stress and coping over an extended period of time, on average five to seven years post stroke, using a triangulated, mixed-methods approach. This is the first study to date using a quantitative and qualitative triangulation approach to investigate the stress and coping experiences of caregivers over time and the concordance or divergence of qualitative and quantitative findings. It not only provides information on caregivers of stroke survivors in

the long term, but also offers a broader understanding of their experiences and a reference for design of future intervention studies based on caregiver needs at different stages of the stroke recovery trajectory.

### **Conclusions**

As stroke survivors progress along the long-term trajectory of stroke recovery, patients and their family caregivers often experience a downward spiral of negative physical, emotional, and social effects. Although spousal caregivers experienced stress along with decreased social resources, the experiences evolved over time. Research in this area has focused primarily on the first one to two years post stroke. Longitudinal studies are critical given the progression of stroke from onset to a number of possible clinical outcomes, leaving family members with a great need for continued assistance in responding to multiple health-care issues throughout the chronic disease trajectory. By exploring their experiences over an extended period of time, this study highlights the need for ongoing psychological and medical evaluation of caregivers at different stages of stroke recovery. It also identifies some potential strategies that healthcare professionals could use to improve long-term outcomes of stroke survivors and caregivers.

### **Implications for Practice**

This study has implications for healthcare professionals who are providing care to long-term stroke survivors and their caregivers. Professionals such as clinicians, nurses, psychologists, or therapists should recognize caregivers' ongoing needs for education and practical training, and provide them with information, care guidelines, resources, and support as stroke survivors progress through different stages of the recovery. An

interdisciplinary team of healthcare professionals plays an important role in evaluating the capability of the spousal caregiver to assume and maintain the caring role and their ability to cope with the stress associated with caregiving. Providing assistance and advice about coping strategies and time management may be helpful in reducing negative outcomes associated with caregiving and improving caregivers' quality of life and psychological well-being.

### **Recommendations for Future Research**

Future intervention studies should explore: (a) the optimal timing for discharge preparation, as most patients and families indicated being overwhelmed at discharge; (b) reminding caregivers about the importance of maintaining their own health at three to six months post stroke; (c) offering socio-psychological support by incorporating respite care into discharge planning and providing information about local support groups after the stroke survivor and caregiver have settled into a new routine; (4) providing guidance three to six months post stroke and thereafter on ways to continue progress after completion of therapy; and (5) providing respite care and assistance with transportation through all stages of stroke recovery to support caregiver religious and spiritual practices, especially when there is limited transportation. Additional research is needed to corroborate these findings and evaluate interventions that may help spousal caregivers to better cope with stress at different stages of stroke recovery.

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**Appendix A**  
**Interview Questions**

Suggested Questions for Interviews/Focus Groups: (for both stroke survivors and caregivers)

1. How would you describe the process (or your journey) of recovering from a stroke?
2. What has bothered you most about having a stroke?

Probes:

- a. Were there times when you felt angry at others? At yourself? At God?
  - b. Did you ever feel depressed?
3. What aspects of your life as a couple have been most affected by the stroke?

Probes:

- a. Changes in roles?
  - b. Changes in communication?
  - c. Changes in leisure activities?
  - d. Changes in social activities?
  - e. Changes in intimacy?
4. What has helped you the most to cope with these changes?

Probes:

- a. What beliefs, practices or people have helped with your recovery?
- b. Are faith or religious beliefs important?
- c. Did the stroke change the way you felt about your self? Your worth?
- d. Are there particular coping strategies that worked well for you?
- e. Were family, friends, or others in your social network helpful?

5. Have you found any meaning in the experience of living with a stroke that you could share with others?

Probes:

- a. If so, when did you begin to feel this way?
  - b. Is there anything that is especially frightening or meaningful to you now?
6. How would you describe your degree of satisfaction (or dissatisfaction) with your life now?

Probes:

- a. Has your sense of satisfaction with your life changed over the years since your stroke?
  - b. How would you describe the changes?
7. Are there parts of your life that are more satisfying or fulfilling than others?

Probes:

- a. Personal – ability to care for yourself, ability to do what you wish
  - b. Social – ability to participate in social activities, family activities, work
  - c. Financial – ability to afford necessities, luxuries
8. What are your hopes for the future?
9. What is your source of strength and hope?

Probes:

- a. Is your faith, religion or God significant to you?
- b. If so, what religious practices are important to you?
- c. Has having a stroke made a difference in your religious practices?

- d. To whom do you turn when you need help?
  - e. What helps you most when you feel afraid or need special help?
10. Please describe the external resources (i.e., health or social service professionals, community organizations, support groups) that you consider most helpful in your adaptation.
11. Are there particular things that health professionals could have done or said that would have helped you during your recovery process?
12. Is there anything else that you would like to tell me about your recovery process?

## **Appendix B**

### **Table 3 Summary of Stress- and Coping-related Themes Over Time**



	<b>Stress-related themes/subthemes</b>	<b>Coping-related themes/subthemes</b>
<b>Baseline</b>	<ol style="list-style-type: none"> <li><b>1. Emotional stress</b> <ul style="list-style-type: none"> <li>- Changes in the survivor’s personality</li> <li>- The survivor’s unwillingness to do more for self</li> <li>- The survivor’s high demands to be done right away</li> <li>- The survivor’s perception of CG not doing enough for him/her</li> <li>- Worry/fear of recurrent strokes</li> <li>- Uncertainty of what the future will bring</li> <li>- Felt no hope about the survivor’s progress</li> </ul> </li> <li><b>2. Financial burden</b> <ul style="list-style-type: none"> <li>- Fighting with the insurance company</li> <li>- Reduced income because of the survivor’s disability</li> <li>- Household, medical cost, and kids</li> <li>- Financial insecurity when getting older</li> </ul> </li> <li><b>3. Unpreparedness</b> <ul style="list-style-type: none"> <li>- A lack of confidence in providing care</li> </ul> </li> <li><b>4. Time strain</b> <ul style="list-style-type: none"> <li>- Difficulty in keeping up with all the medical appointments, housework</li> <li>- Felt no time for self</li> </ul> </li> <li><b>5. Role strain</b></li> </ol>	<ol style="list-style-type: none"> <li><b>1. Faith in God</b> <ul style="list-style-type: none"> <li>- “We go for prayers every day”</li> <li>- “Everything is in God’s hands” and “We are trying to make it with the Lord’s help”</li> </ul> </li> <li><b>2. Be patient</b> <ul style="list-style-type: none"> <li>- Allowed extra time for ADLs and bathroom breaks on the road or wherever going out and for detailed planning on trips</li> </ul> </li> <li><b>3. Acceptance</b> <ul style="list-style-type: none"> <li>- Accept the fact there was no one else who could or wanted to cope with the situation</li> </ul> </li> <li><b>4. Changing lifestyles to the situations</b></li> <li><b>5. Good dynamic and family relationship</b> prior to stroke was helpful for the success of the caring arrangement</li> <li><b>6. Finding a balance</b> between encouraging the survivor to do more and fulfilling the caregiver role</li> <li><b>7. Hope and optimism</b> <ul style="list-style-type: none"> <li>- Hope the survivor to get better and to regain independence</li> <li>- Look forward to having lots of years to enjoy together</li> </ul> </li> <li><b>8. Compromise and prioritize tasks</b></li> </ol>

	<ul style="list-style-type: none"> <li>- Taking multiple responsibilities as to commitments to kids and elderly parents</li> </ul>	<ul style="list-style-type: none"> <li>- “My house is a mess, but I don’t care anymore. I have other things requiring my immediate attention”</li> </ul>
<b>3 month post-stroke</b>	<p><b>1. Emotional stress</b></p> <ul style="list-style-type: none"> <li>- Difficulty in dealing with the survivor’s personality changes: “I hate coming home because all that to face” and “xxx anger is frightful” and “threatened my life, he said do you want to die, one punch and I’ll knock your lights out”</li> <li>- No appreciation from the survivor who is “very self-centered and doesn’t appreciate anything you do ... it doesn’t occur to him to try to help me out in the house”</li> <li>- “I feel like I am alone in the world because I am taking care of everybody and nobody is taking care of time” and “I can’t do it all, and a lot of times, I feel resentful” and “I am the one who is suffering and why does it affect me?”</li> <li>- Frustration related to the survivor’s complaints of needs not being met immediately</li> <li>- Discouraged by the survivor not wanting to do if for self, even capable</li> <li>- “Feel like the whole world in on my shoulders”</li> <li>- Feeling overwhelmed: “there are a lot of things I can’t” and “the accumulation and the unbelievable imposition on my time, feeling overwhelmed at times”</li> </ul> <p><b>2. Time strain</b></p>	<p><b>1. Taking a break / Escape:</b> being away from responsibilities at home</p> <ul style="list-style-type: none"> <li>- Visiting family</li> <li>- Business trip</li> <li>- Getting fresh air when going to grocery stores</li> <li>- Playing golf</li> <li>- Taking vacations</li> </ul> <p><b>2. Worked out things on a daily basis</b></p> <p><b>3. Learning to be a caregiver, ADL skills</b></p> <p><b>4. Prioritize tasks</b></p> <p><b>5. Faith in God</b></p> <ul style="list-style-type: none"> <li>- A lot of prayer</li> <li>- “The whole process was really in God’s hands”</li> </ul> <p><b>6. Being grateful</b></p> <ul style="list-style-type: none"> <li>- “I know it could be worse and I thank God that I am able to what I do”</li> </ul> <p><b>7. Adjustment</b></p> <ul style="list-style-type: none"> <li>- Learn “how to adjust my rhythm and pace and schedule to be able to do the things I need to do and keep things going the way I’d like for them to be going”</li> <li>- Withdrew volunteer work</li> </ul> <p><b>8. Being patient</b></p> <p><b>9. Hope/Optimism</b></p> <ul style="list-style-type: none"> <li>- Hope the survivor to get better</li> </ul>

	<ul style="list-style-type: none"> <li>- “Feeling constantly on the go” as to keeping up with all the appointments &amp; housework</li> <li>- No time for self</li> <li>- “Everything takes longer and have to allow extra time” to accomplish</li> </ul> <p><b>3. Physical stress</b></p> <ul style="list-style-type: none"> <li>- “It is like having babies again”</li> <li>- Fatigue due to a lack of sleep</li> </ul> <p><b>4. Taking more responsibilities</b></p> <p><b>5. Financial burden</b></p> <ul style="list-style-type: none"> <li>- Hospital bills, doctor visits, physical therapy</li> <li>- Fighting with the insurance company</li> <li>- Reduced household income</li> </ul> <p><b>6. Unpreparedness upon discharge</b></p> <ul style="list-style-type: none"> <li>- Not knowing what to expect or recognize signs/symptoms of recurrent strokes</li> <li>- Medication management</li> </ul> <p><b>7. Marital relationship – never the same</b></p> <ul style="list-style-type: none"> <li>- A lack of intimacy, physical expression of love and emotional closeness – caregiver vs wife</li> </ul>	<ul style="list-style-type: none"> <li>- “I feel good, positive that it’s gonna one day, he will be able to move his left arm as he used to before and walk better”</li> </ul> <p><b>10. Social support:</b> healthcare professionals, friends, family,</p> <p><b>11. Acceptance</b></p> <ul style="list-style-type: none"> <li>- “I wish our life was like it was before but I don’t think it ever will be, but we’ll make the best of it because we love each other”</li> <li>- “You just take life as it comes”</li> </ul> <p><b>12. Trying to let the survivor do as much as possible and only jump in as needed</b></p> <ul style="list-style-type: none"> <li>- “He just doesn’t trust it enough to do what I think he needs to do”</li> </ul> <p><b>13. Suppressing vs releasing emotions</b></p> <ul style="list-style-type: none"> <li>- Cautious about speaking and trying not to discourage the survivor</li> <li>- Call someone to cry a little bit and say worse fears</li> <li>- Being honest with what’s going on</li> </ul>
<p><b>6 month post-stroke</b></p>	<p><b>1. Time strain</b></p> <ul style="list-style-type: none"> <li>- Not having “enough time between work and family obligations and seems that my house is totally out of control”</li> <li>- No time for self</li> </ul> <p><b>2. Emotional strain</b></p> <ul style="list-style-type: none"> <li>- Overwhelmed by assuming the caring role</li> <li>- Feeling more agitated and impatient: “feeling of never getting everything done and rushing in circles and running as you can all the time”</li> </ul>	<p><b>1. Taking a break/escape</b></p> <ul style="list-style-type: none"> <li>- Traveling together with the family</li> <li>- Going out to “get a different view on things”</li> <li>- Participating in the CARES study</li> <li>- Business trip</li> <li>- “I had time to myself and that’s really what I needed” or “check into a hotel overnight and just take a book or magazines and just chill out”</li> <li>- Continue working as an escape</li> </ul>

	<ul style="list-style-type: none"> <li>- Feeling of hopeless: “where had my loving family gone”</li> <li>- Struggle with the survivor’s behavioral problems: “it is never enough and it is your, the other parties’ fault that he never accepts any blame for that”</li> <li>- Lack of affection from the survivor: “I thought this was the end, you know, there is nothing in my life, everything is on my shoulders, and I really don’t want to go on with life”</li> <li>- Became depressed “because sometimes I feel that xxxx doesn’t want to do much for himself and I have to constantly remind him and then we get into a little argument” and “like I just want to give up”</li> <li>- Worry about the survivor’s health condition “each day we don’t know what’s gonna take place”</li> <li>- Felt lonely – friends started disappearing</li> <li>- Disappointment with doctors/healthcare professionals “they don’t do much unless you push hard” and reluctant to “bother busy staff” when they appeared to have “so much to do”</li> <li>- Frustration with medical staff as to billing, making appointment, access to resources, etc</li> </ul> <p><b>3. Taking multiple responsibilities</b></p> <ul style="list-style-type: none"> <li>- Handling financial and medical issues</li> <li>- Caring elderly parents, and children</li> </ul> <p><b>4. Reduced leisure activities</b> due to complex preparations including anticipating potential</p>	<ul style="list-style-type: none"> <li>- Having a break when the survivor going out trips or visiting family</li> </ul> <p><b>2. Being patient</b></p> <ul style="list-style-type: none"> <li>- Remind children that the survivor can’t help it as it’s part of his disability</li> </ul> <p><b>3. Faith in God</b></p> <ul style="list-style-type: none"> <li>- Praying to the Lord for good health and presence of mind</li> <li>- “Every day as it comes with God’s help” and “we pray and go to church” and “ask him to help us and lead us”</li> <li>- “When you do get frustrated, turn it over to that higher being that you nave, whoever it is and whatever it may be” and “I think this is just another thing through our lives that has helped me just be strengthened spiritually and to learn to cope with things”</li> </ul> <p><b>4. Being grateful /Optimism</b></p> <ul style="list-style-type: none"> <li>- “We do have a grandbaby here to give us spirit”</li> <li>- Have the faith that the survivor’s personality still be there</li> <li>- Being thankful for the survivor and self getting better</li> <li>- Looking forward and “there is gonna be a light at the end of the tunnel down the road”</li> <li>- Feeling enormous gratitude to have the survivor and giving back to other people</li> <li>- “Every day is by grace of God”</li> </ul> <p><b>5. Acceptance</b></p> <ul style="list-style-type: none"> <li>- “I mean he’ll always have the memory problem and not be able to deal with money”</li> </ul>
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	<p>needs during the road, loading and unloading stuff, parking, gasoline, etc.</p> <p><b>5. Financial strain</b></p> <ul style="list-style-type: none"> <li>- Wish had enough “financial resources to have someone come in here, on certain days and help with the physical transferring and the bathing.... When I engulfed with, it is like I am dead and can’t afford to be sick and can’t be tired”</li> </ul> <p><b>6. Physical strain</b> – caregiver’s own declining health condition</p>	<ul style="list-style-type: none"> <li>- “I am more able to accept the things that won’t change”</li> <li>- Learning that “we don’t control over anything” and accept the fact “that it’s going to be good and bad days”</li> </ul> <p><b>6. Suppressing emotions</b></p> <ul style="list-style-type: none"> <li>- Try not to show stress/concerns in front of the survivor</li> </ul> <p><b>7. Seeking professional assistance</b></p> <ul style="list-style-type: none"> <li>- Encourage the survivor to “start thinking us as a couple and partner”</li> <li>- Told the survivor to “please tell me what you want me to say and I’ll say it”</li> <li>- Taking antidepressants</li> </ul> <p><b>8. Do more for self</b></p> <ul style="list-style-type: none"> <li>- Do things for yourself and have a little time to yourself “that usually helps to get back to the point that I can be that good caregiver for him”</li> <li>- Do exercise, yoga, massage</li> </ul> <p><b>9. Being doers</b></p> <ul style="list-style-type: none"> <li>- Tired easily, “but we are not letting it keep us down from doing things”</li> <li>- “I do whatever I’ve got to do”</li> </ul> <p><b>10. Taking it one day at a time</b></p> <ul style="list-style-type: none"> <li>- “It is a daily situation, and we have to just deal with it, and try to make it through”</li> </ul>
<p><b>9 month post-stroke</b></p>	<p><b>1. Emotional stress</b></p> <ul style="list-style-type: none"> <li>- Frustrated when the survivor not tried hard enough to make progress</li> <li>- Worries about the survivor’s safety</li> </ul>	<p><b>1. Social support:</b> good network of friends, family, healthcare professionals,</p> <p><b>2. Taking a break/escape</b></p> <ul style="list-style-type: none"> <li>- Time to chill out on the way to work and home</li> </ul>

	<p><b>2. Physical stress</b></p> <ul style="list-style-type: none"> <li>- Other focused, ignoring her own needs, sacrificing for the good of others</li> <li>- Deteriorating health</li> <li>- Dealing with the survivor's declining condition</li> </ul> <p><b>3. Time strain</b></p> <ul style="list-style-type: none"> <li>- A lack of sleep, no social life, dealing with setback and regression</li> </ul> <p><b>4. Taking multiple roles</b></p> <ul style="list-style-type: none"> <li>- Big concerns as to how to juggle career, home life, and the schedules</li> </ul> <p><b>5. Other focused</b></p> <ul style="list-style-type: none"> <li>- Devoted to their spouses, ignored their own needs, and dealing with setbacks and regression</li> </ul>	<ul style="list-style-type: none"> <li>- Vacation /conference</li> <li>- Eating out at times</li> <li>- Fishing / other leisure activities</li> </ul> <p><b>3. Thinking about taking the survivor to a nursing home</b></p> <p><b>4. Lifestyle modifications</b> – trying to lose weight</p> <p><b>5. Encouraging the survivor to do more</b></p> <p><b>6. Faith in God</b></p> <ul style="list-style-type: none"> <li>- Going to church and praying</li> <li>- Reading bible</li> <li>- “God’s watching over us”</li> </ul> <p><b>7. Being grateful</b></p> <ul style="list-style-type: none"> <li>- feeling blessed</li> <li>- “I didn’t care about his limitations ... he was alive was a given, it was actually a gift”</li> <li>- “We give thanks to God everyday”</li> </ul> <p><b>8. Learning about stroke</b></p> <p><b>9. Taking it one day at a time</b></p> <p><b>10. Acceptance</b></p> <ul style="list-style-type: none"> <li>- Realizing things aren’t gonna to be the same</li> <li>- Accept that “they are just going to be the way they are”</li> <li>- Taking things as they come</li> </ul> <p><b>11. Seeking professional assistance</b></p> <ul style="list-style-type: none"> <li>- See counseling, taking antidepressants</li> </ul> <p><b>12. Doing more for self</b></p> <ul style="list-style-type: none"> <li>- “I see myself doing more for myself and as far as xxx, the things that he forgets to do, it doesn’t bother me as much anymore”</li> </ul> <p><b>13. Adjustment</b></p>
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		<ul style="list-style-type: none"> <li>- Changing job hours to accommodate the survivor needs at home</li> </ul> <p><b>14. Hope</b> – hope for better health</p>
<p><b>12 month post-stroke</b></p>	<ol style="list-style-type: none"> <li><b>1. Physical stress</b> <ul style="list-style-type: none"> <li>- Continue to be exhausted as “it is accumulative”</li> </ul> </li> <li><b>2. Emotional stress</b> <ul style="list-style-type: none"> <li>- Feeling overwhelmed, lonely, and sorry for self when looking at negatives</li> <li>- Became depressed requiring treatment</li> <li>- Suffering in silence: hiding feelings from their spouses and children; felt being strong for themselves was the only effective way to deal the day-to-day chores and other difficulties</li> <li>- Constant worries about the survivors’ safety of being left alone</li> </ul> </li> <li><b>3. Relationship changes</b> <ul style="list-style-type: none"> <li>- Moving from a mutual relationship to a caregiver relationship</li> <li>- Loss of intimacy</li> </ul> </li> <li><b>4. Taking multiple responsibilities</b> <ul style="list-style-type: none"> <li>- A nurse, therapist, a babysitter</li> </ul> </li> <li><b>5. Felt still needed guidance</b> as to how to make continuous progress after therapy</li> </ol>	<ol style="list-style-type: none"> <li><b>1. Faith in God</b> <ul style="list-style-type: none"> <li>- “I think the main thing that has kept us going over this whole year has been our belief in God and our ability to call on HIM when we needed strength”</li> <li>- Prayer</li> <li>- Going back to church</li> </ul> </li> <li><b>2. Cope with difficulties that come up</b> <ul style="list-style-type: none"> <li>- “I just do the best I can now and try to live with as best I can”</li> <li>- Take it one day at a time, solve each problem and each struggle at a time</li> </ul> </li> <li><b>3. Adjustment</b> <ul style="list-style-type: none"> <li>- Continues working part time to accommodate the survivor’s needs</li> </ul> </li> <li><b>4. Social support</b> <ul style="list-style-type: none"> <li>- Going out with friends</li> <li>- Healthcare professionals/CAReS staff</li> <li>- Church members</li> </ul> </li> <li><b>5. Being positive / Hope</b> <ul style="list-style-type: none"> <li>- “because if you look around, and you see the life of other people, you’ll see, even at your worse, things can always be worse and they can be always better”</li> <li>- Hope to keep making progress</li> <li>- “If all else fails, just laugh”</li> <li>- “There is something good and that’s the way things are”</li> </ul> </li> </ol>

		<ul style="list-style-type: none"> <li>- “We are determined to make it go and make him well”</li> <li>- Appreciate CARES program</li> <li>- “I am confident it is not the end of the world, it happened to us and we just have to deal with it”</li> <li>- “I am not afraid anymore that he might fall or slip or hurt himself” as the survivor continued to make progress over time</li> </ul> <p><b>6. Thinking about alternatives</b> for long-term care</p> <ul style="list-style-type: none"> <li>- Considering nursing home placement if unable to continue caregiving</li> <li>- Day care</li> </ul> <p><b>7. Encouraging the survivor to do more for self</b></p> <p><b>8. Remodeling the house</b> to make more accessible for the survivor</p> <p><b>9. Be patient</b></p> <p><b>10. Acceptance</b></p> <ul style="list-style-type: none"> <li>- “Take it the way it is, one day at a time”</li> <li>- “I can do nothing about it just wait and see how things come out day by day”</li> </ul> <p><b>11. Do more for self</b></p> <ul style="list-style-type: none"> <li>- Traveling</li> <li>- Enjoy the free time</li> <li>- Enjoy it so much when finally get off: pedicure, get off with family / friends, “as I don’t do it often”</li> </ul> <p><b>12. Taking a break/escape</b></p> <ul style="list-style-type: none"> <li>- Try to get out a little way from house every day to relieve stress</li> </ul> <p><b>13. Taking multiple roles/responsibilities</b></p> <ul style="list-style-type: none"> <li>- A therapist: talking to the survivor to improve his speech</li> </ul>
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		<ul style="list-style-type: none"> <li>- Trying to be well-informed as possible</li> </ul> <p><b>14.</b> When frustrated, stepping back and re-evaluate</p>
<p><b>5-7 years post-stroke</b></p>	<p><b>1. Emotional stress</b></p> <ul style="list-style-type: none"> <li>- Retrospectively “I think the low point was at the beginning. It was a fear, what were we dealing with? How far was he going to be able to come back? How much care was he going to need?”</li> <li>- The fear of uncertainty as to what’s gonna happen to the survivor</li> <li>- Spouse’s personality changes: abusive language, physical violence, and mood changes</li> <li>- Dealing with the mess associated with unnecessary spending</li> <li>- Stress about the survivor feeling being useless</li> <li>- Angry at the survivor “he was so dumb and confused, and I hate myself for that cause I can’t believe that I couldn’t see how hard he was trying and felt guilty and blamed for unrealistic expectations”</li> <li>- Angry at self as to unable to fulfill the role</li> <li>- Gotten more apart from each other as felt the spouse less listened to, irritated, and both complained, but didn’t want to hear from other</li> <li>- Felt by the survivor that their spouses were not really trying to help as “he doesn’t see this like I see it”</li> <li>- “The low point was to see him cry, to see the tears coming out of his eyes”</li> </ul>	<p><b>1. Faith in God : Religion vs non-religion</b></p> <ul style="list-style-type: none"> <li>- “My relationship with God is just asking the Lord for health, for strength, for prosperity, ... I don’t go to church to ask” and “we physically don’t go to church, it is just the spirituality is there”</li> <li>- Pray individually “we take that with us everywhere we go”</li> <li>- Common spiritual practices: nighttime ritual, singing pray, bible study, rosary, etc</li> <li>- Organizational religion along with spiritual practices was important: “it provided opportunity to talk to different people and refresh their mind” and “we could have never been able to move out that small trailer if it had it not been for people being trusting”</li> <li>- Turning worries to God and believe that “God can intervene ... HE can reach down and do things in the lives and HE can perform miracles and we have seen miracles”</li> <li>- Believe that “God will take care of you if you believe in God”</li> <li>- “It is part of God’s plan” and “it is something happens in your destiny” and caregiving is a part of who she is as “God had a plan for me to be here to take of somebody”</li> <li>- “Do the will of God”</li> </ul>

	<ul style="list-style-type: none"> <li>- “There were times when I just really want a little me, a little more time for me, I had days when there wasn’t anything, I could do but just cry out to God, literally”</li> <li>- “There were days I’d be a little resentful because I had no one to fall back, you don’t have help” and felt “I am the victim and he is the survivor”</li> </ul> <p><b>2. Still needed guidance</b> for long-term improvement after therapy</p> <p><b>3. Reduced activities</b></p> <ul style="list-style-type: none"> <li>- A lot of things changed “like it has a piece of mind and our life is surrounded by him” and “it did prevent us from going places, particularly the first 2-3 years”</li> <li>- A lack of handicapped accessibilities</li> <li>- Protecting their partner from embarrassment</li> <li>- A lack of “manly help”</li> </ul> <p><b>4. Physical stress</b></p> <ul style="list-style-type: none"> <li>- “I am not taking care of myself physically as he has to be taken care of ... I haven’t been used to going anywhere without him being with me”</li> <li>- Neglecting own needs: “my days are determined by how he was feeling and how he was reacting to things. I’ve learned his mood better and I had to learn to separate my roles as his wife to the role of caregivers”</li> <li>- “It really was a strain on my back, and I’ve been hurting”</li> </ul> <p><b>5. Taking multiple responsibilities</b></p> <p><b>6. Financial stress</b></p> <ul style="list-style-type: none"> <li>- Reduced household income</li> </ul>	<ul style="list-style-type: none"> <li>- Believe that “God brought you this far, all these years, so what makes you think HE won’t take care of you when you retire”</li> <li>- Transitioning from questioning God to believe that God would make it alright for her by realizing that “it is what sometimes HE closes a window or door to open another one”</li> </ul> <p><b>2. Social support</b></p> <ul style="list-style-type: none"> <li>- Family, friends, healthcare professionals</li> <li>- Emotional support “Some of what I want from a friend ... take my mind off things, just some fun” and someone they can “talk to”</li> <li>- Interactions with church people were one of outlets to “get out and talk” and “get some fresh air”</li> </ul> <p><b>3. Acceptance</b></p> <ul style="list-style-type: none"> <li>- Accept the fact “it’s happened, there is nothing you can do about it”</li> <li>- Learning to accept that “I am able to accept things as they are”</li> <li>- “Learning to accept what I can’t do and to say I can’t do this, ... and how to accept from other people”</li> </ul> <p><b>4. Being doers</b></p> <ul style="list-style-type: none"> <li>- “Prepare for whatever may happen and anticipate the inevitable”</li> <li>- “We believe you have to help yourself. If there is a problem, we work on it within ourselves: and “just do what I need to do and just go ahead and get it done”</li> </ul> <p><b>5. Planning ahead</b></p> <p><b>6. Having a break/Escape</b></p> <ul style="list-style-type: none"> <li>- “I leave for a while just have to have some clarity for myself”</li> </ul>
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	<ul style="list-style-type: none"> <li>- A lack of financial insecurity for the future</li> <li>- Fighting with the insurance company, staff at doctor's office, and hospital "everything is a fight. Nothing gets done the first time, nothing"</li> </ul> <p><b>7. Changes in relationship</b></p> <ul style="list-style-type: none"> <li>- Feeling trapped in an unwanted relationship "We had a good relationship as a provider and a patient, a relationship as far as a husband and wife is not there" and "inside I feel like that part of my life has gone"</li> <li>- "I am the mother and wife, but not the lover"</li> </ul> <p><b>8. Fighting for balance</b> between doing everything for their spouses and letting or wanting them to do more for themselves "I am doing things but it doesn't mean that I am feeling good, but I am pushing myself"</p> <ul style="list-style-type: none"> <li>- "I do wish sometimes he would help with something" and "trying to figure out what I should do and shouldn't do was one of the hardest things for me"</li> </ul> <p><b>9. Loss of social support</b></p> <ul style="list-style-type: none"> <li>- Friends disappeared over time</li> </ul>	<ul style="list-style-type: none"> <li>- I would love to have a week with my sisters, out of town, a cruise with sisters you know, there are times I really, really, do cherish some getting alone times"</li> <li>- Go shopping, movies, shows, once in a while to take mind off</li> <li>- Staying late at work as little escape from home</li> </ul> <p><b>7. Doing more for self</b></p> <ul style="list-style-type: none"> <li>- Pick up hobbies</li> <li>- Continue working: "I am most satisfied with my professional work"</li> <li>- "xxxxx doesn't want to participate in CAREs, but I didn't give a damn: this was for me. I needed to do something for me. It really was ... if you have somebody to talk to ... I couldn't talk to my kids because they didn't understand"</li> </ul> <p><b>8. Being strong</b></p> <ul style="list-style-type: none"> <li>- Had no other choice but being strong as "we have to be strong for the kids, so if they see me break down, they get upset. So, if you are not strong, it's a waterfall effect"</li> </ul> <p><b>9. Being patient</b></p> <ul style="list-style-type: none"> <li>- "I am getting older, I am not rushing anymore, and you've got to stop all that rushing cays there nothing now that is that important anymore"</li> <li>- Learned to be patient and taught the survivor to have patience</li> </ul> <p><b>10. Getting older changes spirituality</b></p> <ul style="list-style-type: none"> <li>- Realization of advantage of being old: "you realize your own mortality or immortality ... time becomes more precious" and "it makes you a little more aware of how precious life is"</li> </ul>
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		<ul style="list-style-type: none"> <li>- “My attitude toward people has changed ... try to make friends wherever I go, ... become more a patient and a compassionate person”</li> <li><b>11. Interdependence /Closer relationship</b></li> <li>- “I think it made us closer because we have to think more of the other person”</li> <li>- “We depend on each other more than we used to” and “the caring and love is stronger”</li> <li><b>12. Encouraging the survivor to do more for self</b></li> <li>- A transition from “seeing self as a protector” and “I am like a lioness toward him” to “I had push back and let him do more for himself as to a need to back off and let him have his own independence”</li> <li><b>13. Seeking support from healthcare professionals</b></li> <li>- Seeing grief and spiritual counselors</li> <li>- Going to support group</li> <li>- Participating in CARES study</li> <li><b>14. Hope</b></li> <li>- “Hope is something you have to have in order to keep going, you have to hold to the hope ... we are hoping to keep whatever health I do have and hope that my health holds up and hope that I can leave that job ... I pray that when I go to church that HE teaches me, that I will be allowed to live on”</li> <li>- Hope for good health, for the survivor getting better, for next generation, to see children getting married, to continue to make contributions in other people’s lives and to continue caregiving</li> <li><b>15. Feeling blessed/Optimism</b></li> <li>- “There are lots and lots of people worse than us”</li> </ul>
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		<ul style="list-style-type: none"><li>- “I thank God that he still has his mind” and cherish what they still had</li><li>- “I am not fearful at all, of what’s gonna happen to him next, ... it is like I am just about seen the worst, even yet, I know that things can always get worse, but I kind of have that attitude ... is that all it is?”</li></ul>
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### Appendix C

**Table 4. Comparison of Information from Interviews and PSS and F-COPEs Measurements**

<b>Themes</b>	<b>Face-to-face interviews</b>	<b>PSS</b>
<b>Caregiver stress</b>	<ul style="list-style-type: none"> <li>• Physical strain</li> <li>• Emotional strain</li> <li>• Financial strain</li> <li>• Changes in spousal relationship</li> <li>• Time constraints</li> </ul>	<p>To tap how unpredictable, uncontrollable, and overloaded caregivers found in their lives:</p> <ul style="list-style-type: none"> <li>• Upset because of something that happened unexpectedly;</li> <li>• felt nervous and stressed; felt confident about ability to handle problems;</li> <li>• felt things going your way;</li> <li>• Unable to control important things in the life;</li> <li>• Felt difficulties to overcome problems; felt that you were on top of things</li> </ul>
<b>Caregiver coping strategies</b>	<b>Face-to-face interviews</b>	<b>F-COPES</b>
	Social support (family/friends/healthcare professionals) Counseling/social work advocacy	Acquiring social support and Mobilizing family to acquire and accept help
	Spirituality (faith in God/Prayer/Cry to God) and church attendance	Seeking spiritual support
	Changes in spousal relationships and family structure	Family reframing
	Hope /Acceptance (caregiving is a part of who CG is and God allows thing to happen) Positive attitude	Passive appraisal

**Appendix D**

**Human Subject Protection Approval**



**Committee for the Protection of Human Subjects**

6410 Fannin Street, Suite 1100  
Houston, Texas 77030

Dr. Fang Ye  
UT-H - SN - Center On Aging

September 09, 2012

HSC-SN-12-0590 - *STROKE CAREGIVERS EXPERIENCES OF STRESS AND COPING OVER TIMEA MIXED-METHODS APPROACH*

The above named project is determined to qualify for exempt status according to 45 CFR 46.101(b)

**CATEGORY #4** : *Research, involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified directly or through identifiers linked to the subjects.*

**CHANGES:** Should you choose to make any changes to the protocol that would involve the inclusion of human subjects or identified data from humans, please submit the change via iRIS to the Committee for the Protection of Human Subjects for review.

**STUDY CLOSURES:** Upon completion of your project, submission of a study closure report is required. The study closure report should be submitted once all data has been collected and analyzed.

Should you have any questions, please contact the Office of Research Support Committees at 713-500-7943.

**Appendix E**  
**Operations Manual**

## Data Management – Transforming Data and Data Analysis

### 1. Perceived Stress Scale -10 item:

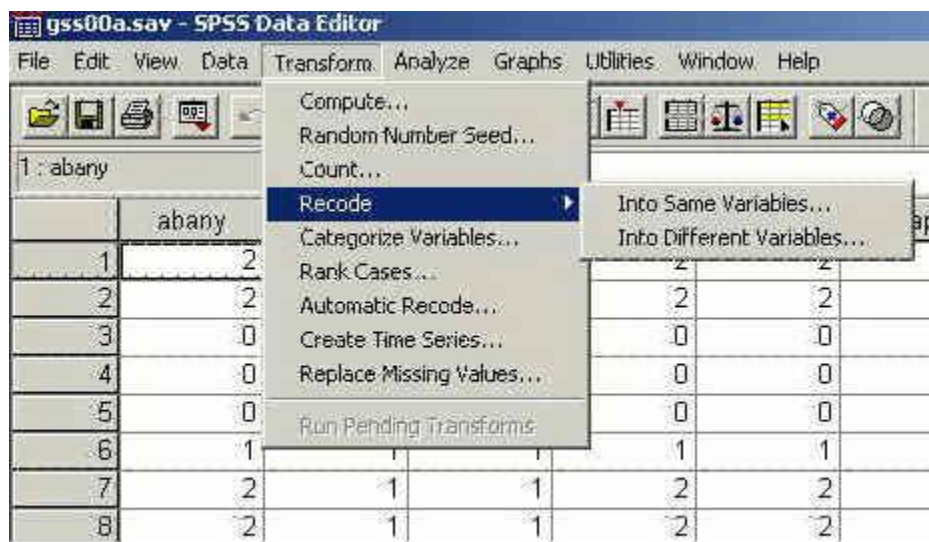
Range 0-40; higher scores are associated with higher levels of stress

Total Score	Perceived stress level
0-7	Much lower than average
8-11	Slightly lower than average
12-15	Average
16-20	Slightly higher than average
21 and over	Much higher than average

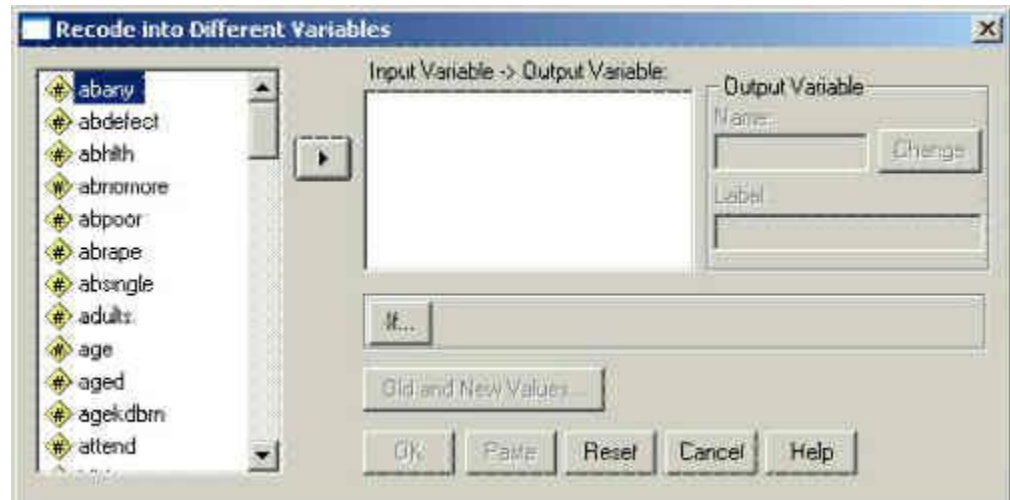
Scoring: Items 4, 5, 7, and 8 are reversed scored. All items are then summed to give the total score

Recode items 4, 5, 7, and 8 with reverse scores:

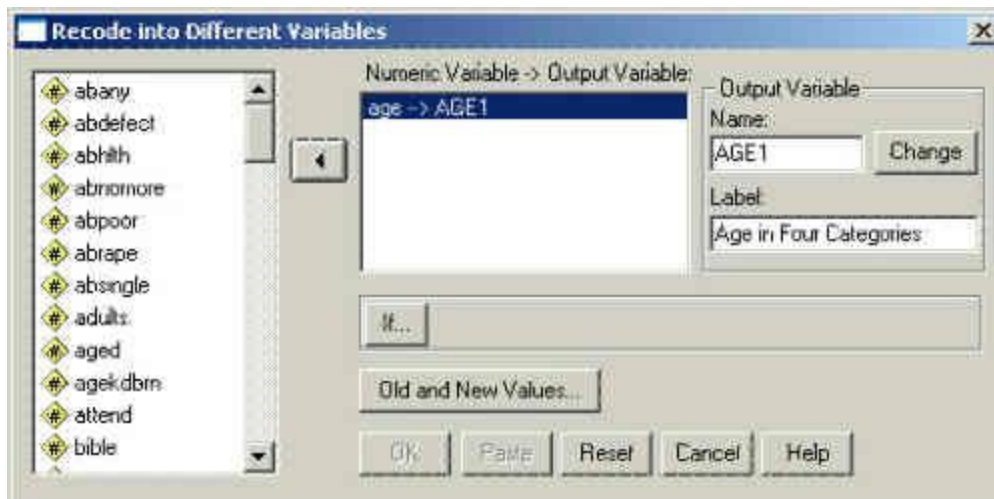
- Start SPSS for Windows and bring in the PSS stress file
- Click on “Transform” and then point the mouse at “Recode”



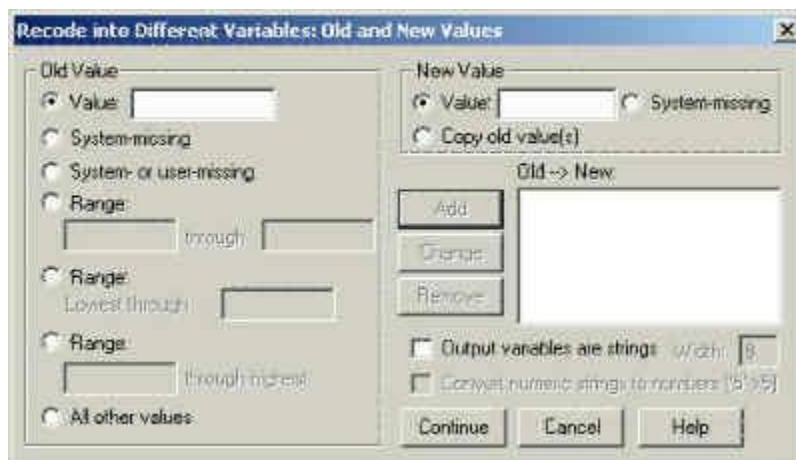
- c. Two options: “Recode into different variables” and “Recode into same variables” – choose the “Recoding into different variables” option



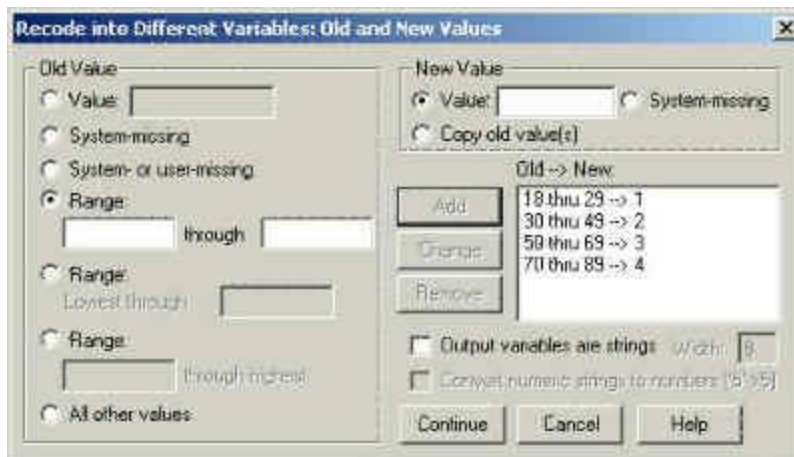
- d. Give the new variable a variable name
- e. Find “S4” in the list of variables on the left and click on it to highlight it, then click on the arrow just to the left of the big box in the middle of the window and move S4 into the list of variables to recode.
- f. Give a name to this new variable so click in the "Name" box under Output Variable and type the name "S4\_R" in this box. Or can type a variable label for this new variable in the Label box just below the Name box. Try typing "S4\_R" as the label. Click on the "Change" button to tell SPSS to make these changes.



- g. Click on the "Old and New Values" button at the bottom of the window.

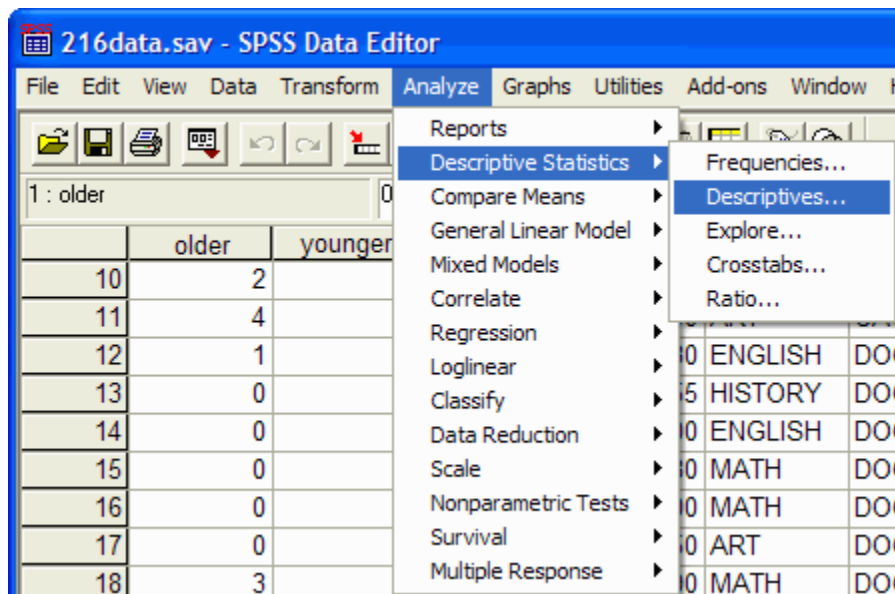


- h. Change the value into a new value by entering the value to be changed into the Old Value box and the new value into the New Value box and then clicking on Add. For example, change 18 thru 35 into value 1; As S4 is reversely coded, the true value should be recoded as:  $0 \rightarrow 4$ ;  $1 \rightarrow 3$ ;  $2 \rightarrow 2$ ;  $3 \rightarrow 1$ ;  $4 \rightarrow 0$ . Then click continue.

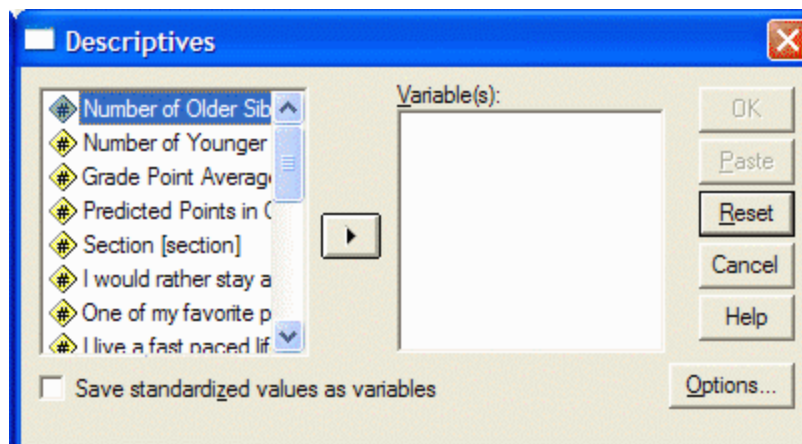


### Calculating variables:

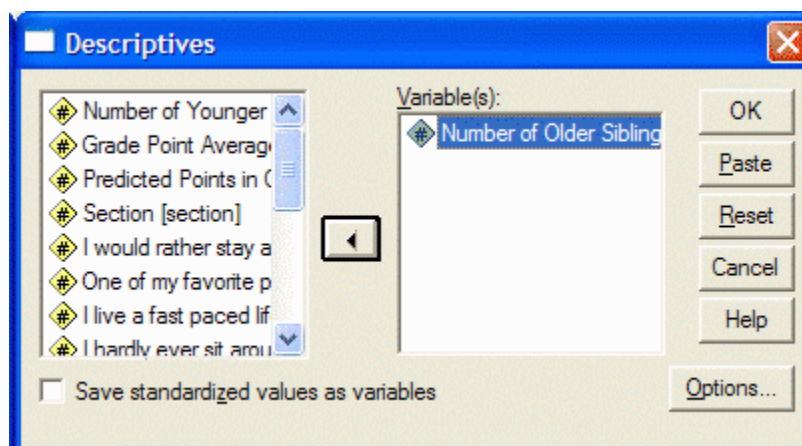
- i. Click on "Analyze", then point at "Descriptive Statistics", and then click on "Descriptives". Click on variable item to highlight it and click on the arrow to move it to the Variables box. Then click on "OK".



- j. The descriptives dialog box appears:

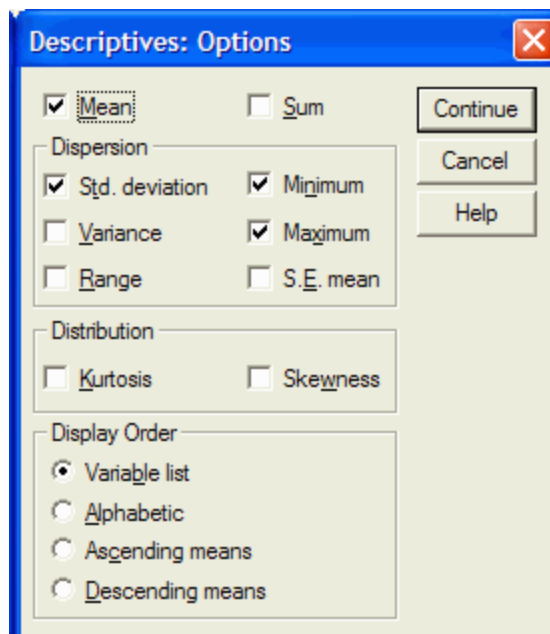


- k. Select the variable(s) to be analyzed by clicking on it in the left hand pane of the descriptives dialog box. Then click on the arrow button to move the variable into the Variables pane:



- l. Specify which statistics to be performed by clicking on the Options button.

The Options dialog box appears:



- m. Select the statistics by clicking on them (e.g. mean, standard deviation, variance, range, minimum, etc.). Then click on the Continue button. Click on the OK button in the Descriptives dialog box. The SPSS Output Viewer will appear with your results in it. The following is an example of the output:

	N	Range	Minimu	Maximu	Mean	Std.	Varianc	Skewness		Kurtosis	
	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Std. Error
Number of Older Siblings	46	4	0	4	1.26	1.255	1.575	.678	.350	-.543	.688
Valid N (listwise)	46										

## 2. **Family Crisis Oriented Personal Evaluation Scales (F-COPES) – 30 items :**

Five Subscale:

Range:

9-45, Subscale 1 –Aquiring social support (item C1, 2, 5, 8, 10, 16, 20, 25, & 29)

8-40, Subscale 2 – Reframing (Items C3, 7, 11, 13, 15, 19, 22, & 24)



4-20, Subscale 3 – Seeking spiritual support (Items C14,23,27,& 30)

4-20, Subscale 4 – Mobilizing family support (Items C4, 6, 9, & 21)

4-20, Subscale 5 – Passive appraisal (Items 12, 17, 26, & 28)

Total score: sum of all items

Range: 50-130, higher score indicates better problem solving and behavioral strategies

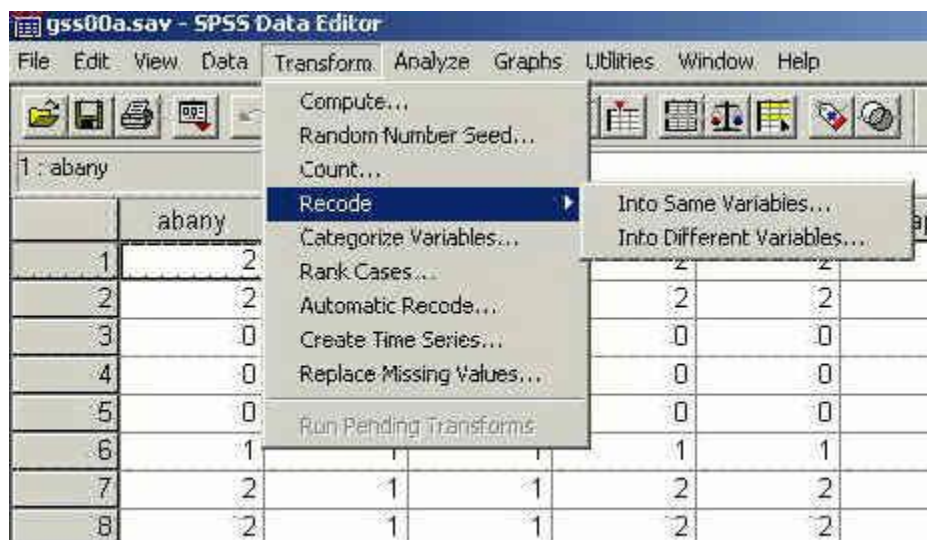
Scoring: score for each subscale is the sum of the scores of each item in subscale.

Item C18 is not used in determining the total or subscale scores.

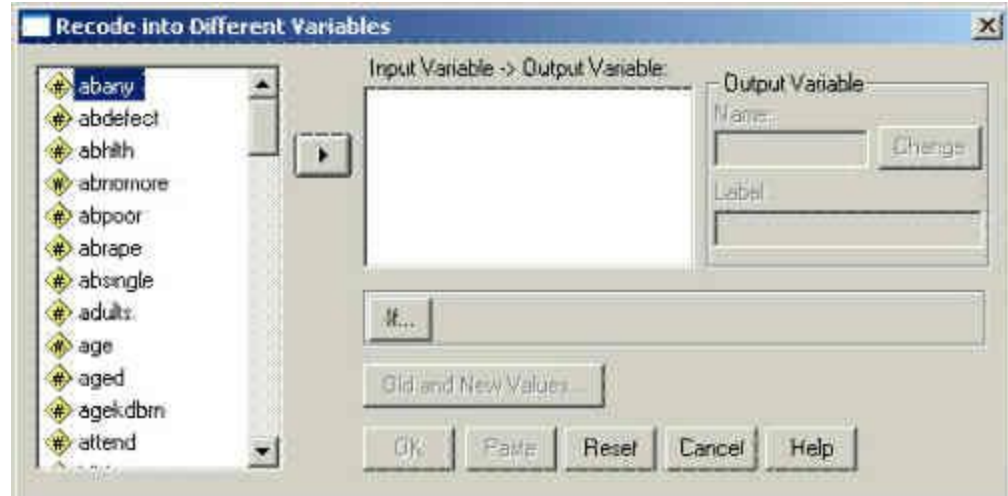
Scoring – items C12, 17, 26, & 28 are reversed scored.

Recode items 12, 17, 26 & 28 with reverse scores as same steps described as above as the PSS scale

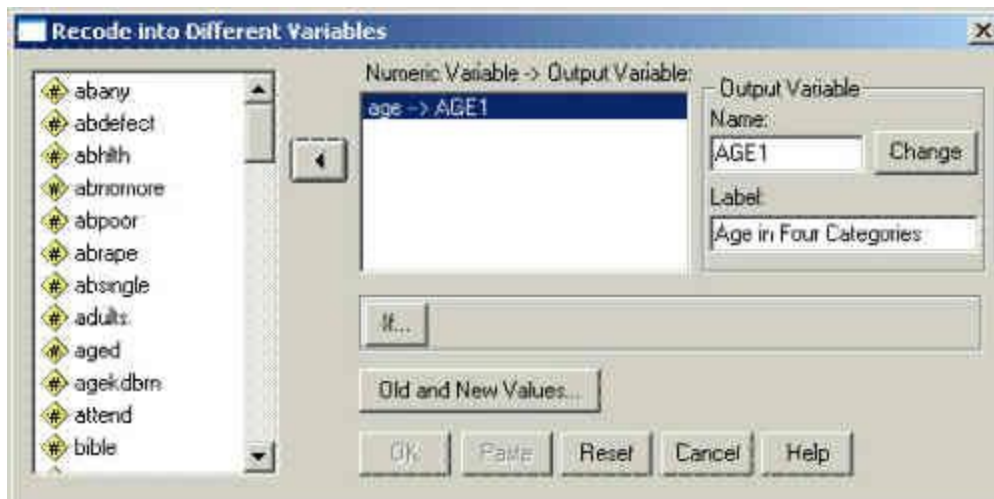
- a. Start SPSS for Windows and bring in the PSS stress file
- b. Click on “Transform” and then point the mouse at “Recode”



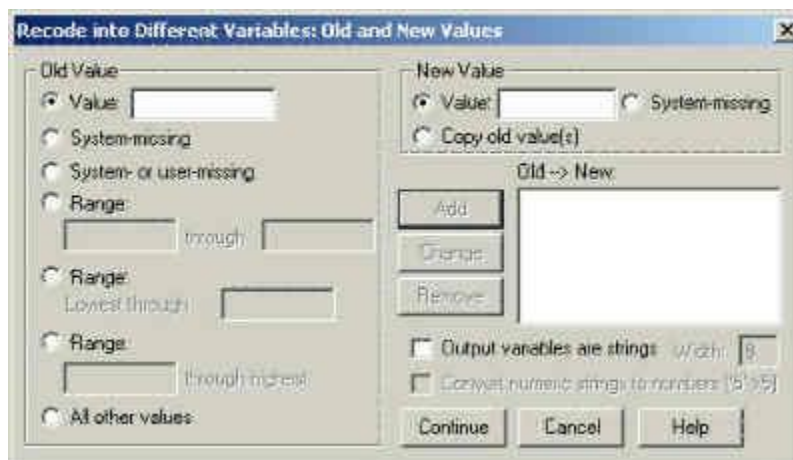
- c. Two options: “Recode into different variables” and “Recode into same variables” – choose the “Recoding into different variables” option



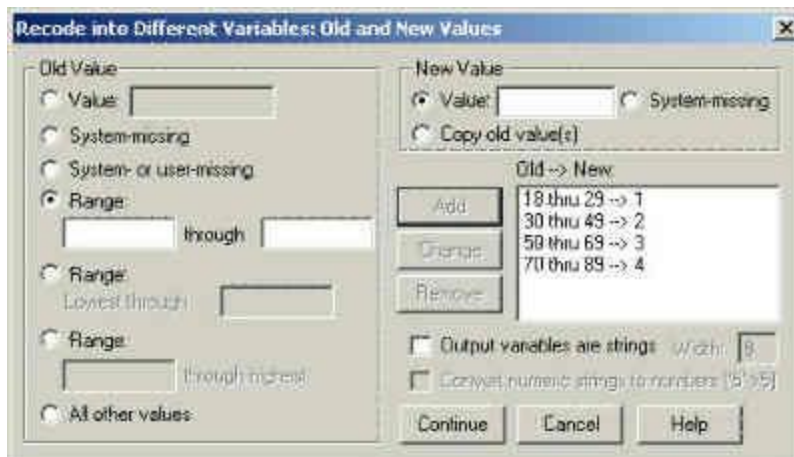
- d. Give the new variable a variable name
- e. Find "C12" in the list of variables on the left and click on it to highlight it, then click on the arrow just to the left of the big box in the middle of the window and move S4 into the list of variables to recode.
- f. Give a name to this new variable so click in the "Name" box under Output Variable and type the name "C12\_R" in this box. Or can type a variable label for this new variable in the Label box just below the Name box. Try typing "C12\_R" as the label. Click on the "Change" button to tell SPSS to make these changes.



- g. Click on the "Old and New Values" button at the bottom of the window.

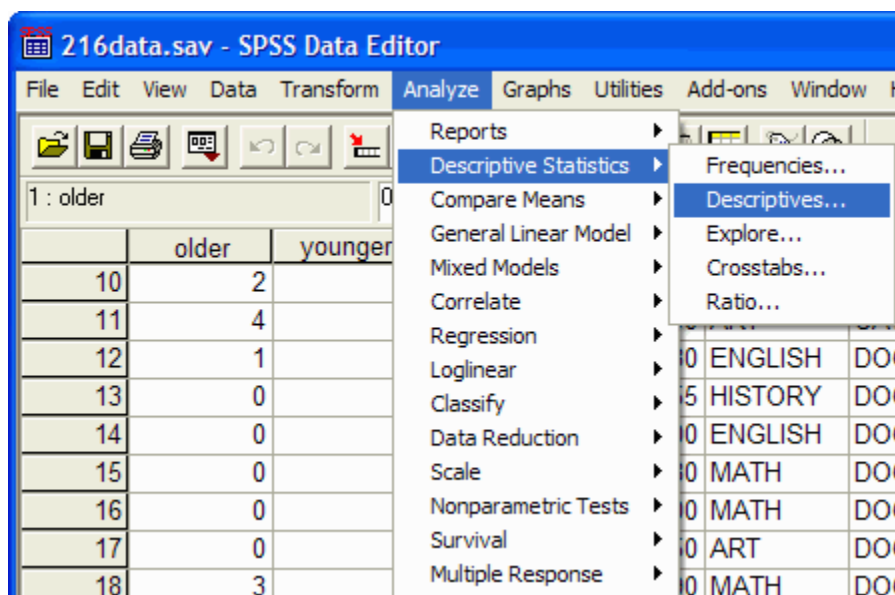


- h. Change the value into a new value by entering the value to be changed into the Old Value box and the new value into the New Value box and then clicking on Add. For example, change 18 thru 35 into value 1; As S4 is reversely coded, the true value should be recoded as: 1 → 4; 2 → 3; 3 → 2; 4 → 1, Then click continue.

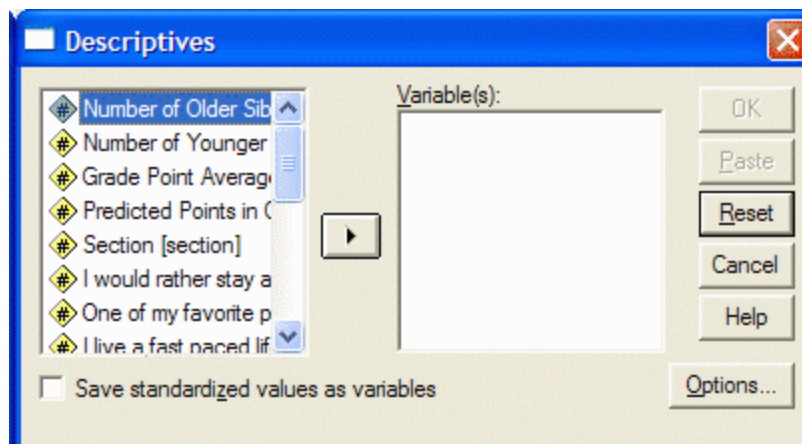


### Calculating variables:

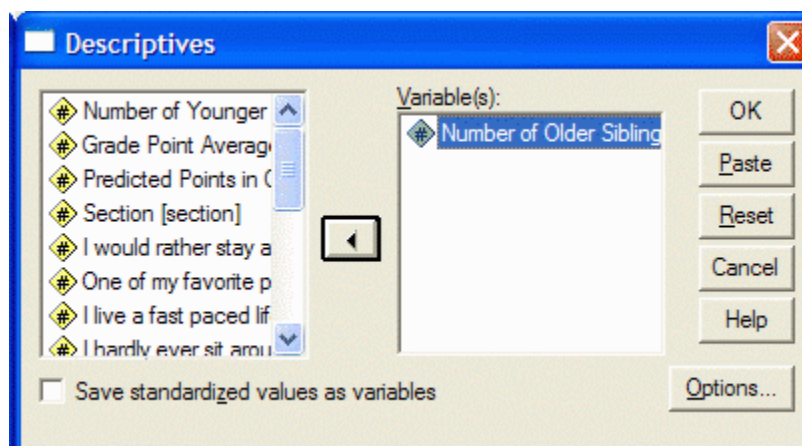
- i. Click on "Analyze", then point at "Descriptive Statistics", and then click on "Descriptives". Click on the variable item to highlight it and click on the arrow to move it to the Variables box. Then click on "OK".



- j. The descriptives dialog box appears:

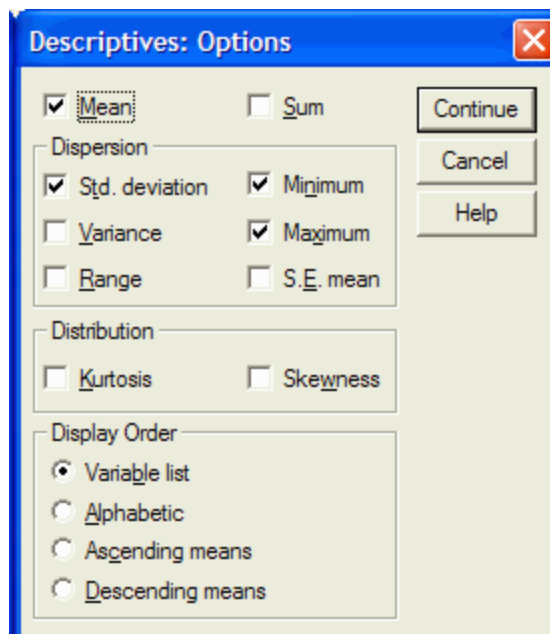


- k. Select the variable(s) to be analyzed by clicking on it in the left hand pane of the descriptives dialog box. Then click on the arrow button to move the variable into the Variables pane:



- l. Specify which statistics to be performed by clicking on the Options button.

The Options dialog box appears:



- m. Select the statistics by clicking on them (e.g. mean, standard deviation, variance, range, minimum, etc.). Then click on the Continue button. Click on the OK button in the Descriptives dialog box. The SPSS Output Viewer will appear with your results in it. The following is an example of the output:

	N	Range	Minimu	Maximu	Mean	Std.	Varianc	Skewness		Kurtosis	
	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Std. Error
Number of Older Siblings	46	4	0	4	1.26	1.255	1.575	.678	.350	-.543	.688
Valid N (listwise)	46										

### **3. Atalas. ti for Qualitative Data Management and Analysis**


- a) Creating Hermeneutic Units (HUs)
  - a. Launch Atalas. ti and choose to create a new Hermeneutic Unit option from the Welcome Wizard.
  - b. Then enter the name of the HU when prompted.

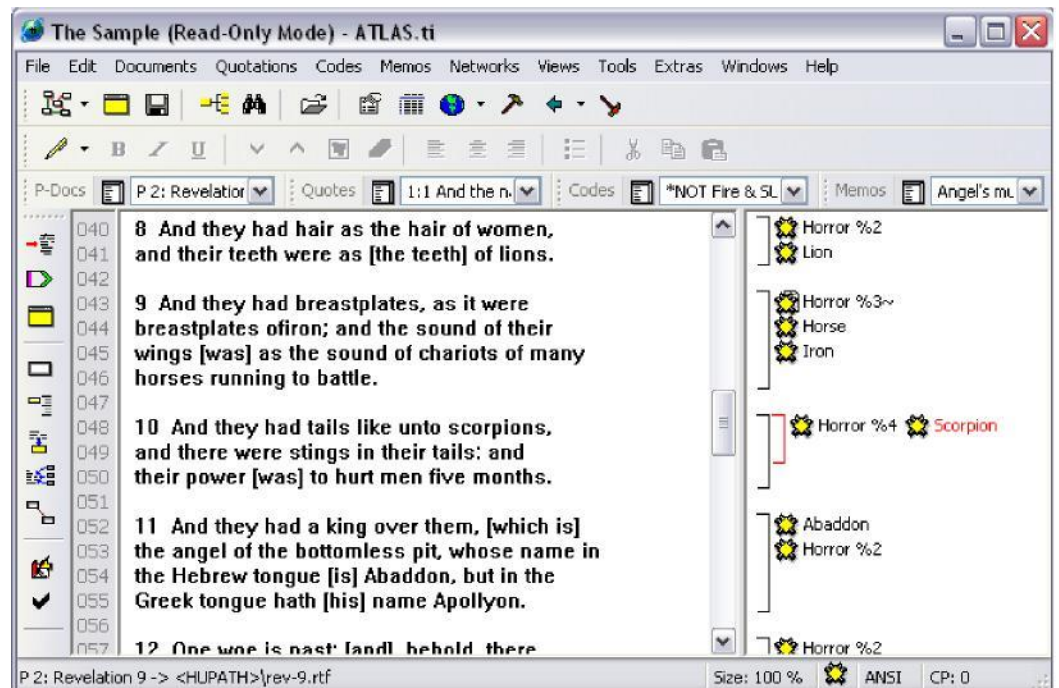
- c. From the File menu, choose save and select the location for the file to be saved.
- b) Saving HUs
- a. Under the File menu, choose save to save the project in the same location or save as to save a copy in a new location
- c) Opening HUs
- a. Select Open from the File menu or from the Welcome Wizard
  - b. Choose the Open Hermenutic Unit from Picklist option
- d) Assigning primary documents
- a. Assign/import primary the files to be analyzed by choosing Documents/Assign from the Main menu.
  - b. Select one or more files from the dialog box and click open
- e) Creating quotations
- a. Create a textual quotation, select the textual segment in the primary document
  - b. Then move the cursor into the selected are and right click on the marked region to open context menu
  - c. Then choose Create Free Quotations form the selected text's context menu
- f) Coding documents
- a. Select the segment of the text to be coded
  - b. Then select one of four types of coding techniques
    - i. Open coding – use open coding when creating a new code and associate it with an existing quotation or text segment

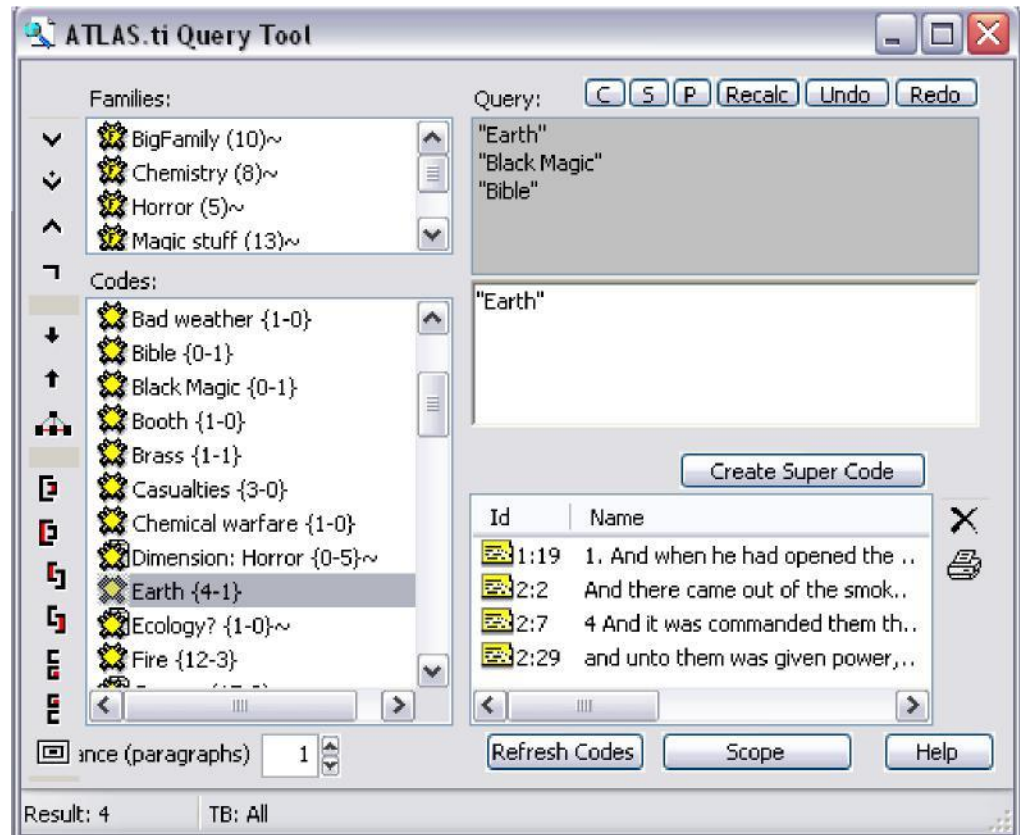
- ii. Code-by-list – use this option to assign existing codes to a quotation or selection
  - iii. In-vivo coding – use this option when selected text itself is a good name for the code
  - iv. Quick coding – use this option when applying currently selected code to the marked segment; it's a quick way to assign the same code to consecutive text
- c. Code a document using Open Coding Technique
- i. Select the text segment or quotation
  - ii. Choose Codes/Coding/Open Coding from the main menu
  - iii. Enter a name for the code and click OK
  - iv. To assign multiple codes to the selected text by separating the codes by the “|” character in the Open Coding window
    - 1. Select the text segment
    - 2. Choose Codes/Coding/Opening Coding from the main menu or the context Menu by right-clicking on the selection
    - 3. Enter the names of the codes separated by the “|” character
      - a. For example, Stress | Anxiety | emotion creates three new codes simultaneously and assign all to the selected text




## g) Query

- a. To activate the Query tool by choosing the Codes/Output/Query tool from the HU editor's main menu or just click on the Query tool button  in the main tool bar





- b. The Query tool has five main parts:
  - i. Operation tool bar – buttons located near the left margin of the window
  - ii. Code Family Pane
  - iii. Code Pane
  - iv. Query Pane
  - v. Result Pane
- c. To formulate a query, first double click on code (for example, stress and coping), the result pane will show all segments coded with stress
- d. Then double click on coping and the result pane will display segments coded with coping

- e. Click operator AND (the  button on the left margin) to apply this operator to the two operands and the result pane will display only these two segments coded with stress and coping.
- f. Saving a query using Super Codes
  - i. Click on the Super-Code button in the Query tool window
  - ii. Enter a name for the Super Code and hit return
  - iii. The new Super Code appears in the list of codes and can be used to create new queries.

#### h) Export and Import

- a. TO export to SPSS, select Extras/Export to/Spss Job from the Main Menu
- b. Open the SPSS syntax file by double-clicking on it from the directory that was saved
- c. From SPSS main menu, choose Run/All

**Appendix F**  
**Data Collection Form**

Date \_\_\_\_\_

ID# \_\_\_\_\_

**SOCIODEMOGRAPHIC INFORMATION**

**Spouse Information:**

Date of Birth: \_\_\_\_\_  
month/day/year

Date of Marriage: \_\_\_\_\_  
month/day/year

Gender: Male  Female

**Stroke Survivor Information:**

Date of Birth: \_\_\_\_\_  
month/day/year

Dominant Hand: Right  Left

Gender: Male  Female

**Ethnicity/Race**

African-American	
American Indian, Alaska Native, or Native Hawaiian	
Asian, Pacific Islander	
White, Non-Hispanic	
Hispanic, Latino	
More than two races Specify: _____	
Other	

**Ethnicity/Race**

African-American	
American Indian or Alaska Native	
Asian, Pacific Islander	
White, Non-Hispanic	
Hispanic, Latino	
More than two races Specify: _____	
Other	

**Years of Education Completed:**

Less than seventh grade	
Junior high school (9 <sup>th</sup> grade)	
Partial high school (10 <sup>th</sup> or 11 <sup>th</sup> grade)	
High school graduate (whether private preparatory, parochial, trade, or public school)	
Partial college (at least one year) or specialized training	
Standard college or university graduation	
Graduate professional training (graduate degree)	

**Years of Education Completed:**

Less than seventh grade	
Junior high school (9 <sup>th</sup> grade)	
Partial high school (10 <sup>th</sup> or 11 <sup>th</sup> grade)	
High school graduate (whether private preparatory, parochial, trade, or public school)	
Partial college (at least one year) or specialized training	
Standard college or university graduation	
Graduate professional training (graduate degree)	

**PERCEIVED STRESS SCALE**

The questions in this scale ask about your feelings and thoughts during the last week. In each case, please indicate by circling the number that best represents how often you felt or thought a certain way.

		Never	Almost Never	Sometimes	Fairly Often	Very Often
<b>1.</b>	In the last week, how often have you been upset because of something that happened unexpectedly?	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>2.</b>	In the last week, how often have you felt you were unable to control the important things in your life?	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>3.</b>	In the last week, how often have you felt nervous and “stressed?”	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>4.</b>	In the last week, how often have you felt confident about your ability to handle your personal problems?	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>5.</b>	In the last week, how often have you felt that things were going your way?	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>6.</b>	In the last week, how often have you felt that you could not cope with all the things that you had to do?	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>7.</b>	In the last week, how often have you been able to control irritations in your life?	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>8.</b>	In the last week, how often have you felt that you were on top of things?	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>9.</b>	In the last week, how often have you been angered because of things that happened that were outside of your control?	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>10.</b>	In the last week, how often have you felt difficulties piling up so high that you could not overcome them?	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>

## **FAMILY CRISIS ORIENTED PERSONAL SCALES**

### **Purpose:**

The Family Crisis Oriented Personal Evaluation Scales is designed to record effective problem-solving attitudes and behavior which families develop to respond to problem difficulties.

### **Directions:**

First read the list of "Response Choices" one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then circle number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2,3, or 4 to indicate how much you agree or disagree with the statement about your response.

Please circle a number (1,2,3,4, or 5) to match your response to each statement. Thank you.

**When we face problems or difficulties in our family, we respond by:**

		<b>Strongly Disagree</b>	<b>Moderately Disagree</b>	<b>Neither Agree Nor Disagree</b>	<b>Moderately Agree</b>	<b>Strongly Agree</b>
<b>1.</b>	Sharing our difficulties with relatives	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>2.</b>	Seeking encouragement and support from friends	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>3.</b>	Knowing we have the power to solve major problems	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>4.</b>	Seeking information and advice from persons in other families who have faced the same or similar problems	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>5.</b>	Seeking advice from relatives (grandparents, etc.)	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>6.</b>	Seeking assistance from community agencies and programs designed to help families in our situation	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>7.</b>	Knowing that we have the strength within our own family to solve our problems	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>8.</b>	Receiving gifts and favors from neighbors (e.g. food, taking in mail, ect.)	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>9.</b>	Seeking information and advice from the family doctor	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>10.</b>	Asking neighbors for favors and assistance	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>11.</b>	Facing the problems “head-on” and trying to get solution right away	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

**When we face problems or difficulties in our family, we respond by:**

		<b>Strongly Disagree</b>	<b>Moderately Disagree</b>	<b>Neither Agree Nor Disagree</b>	<b>Moderately Agree</b>	<b>Strongly Agree</b>
<b>12.</b>	Watching television	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>13.</b>	Showing that we are strong	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>14.</b>	Attending church services	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>15.</b>	Accepting stressful events as a fact of life	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>



16.	Sharing concerns with close friends	1	2	3	4	5
17.	Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18.	Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19.	Accepting that difficulties occur unexpectedly	1	2	3	4	5
20.	Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5
21.	Seeking professional counseling and help for family difficulties	1	2	3	4	5
22.	Believing we can handle our own problems	1	2	3	4	5
23.	Participating in church activities	1	2	3	4	5
24.	Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25.	Asking relatives how they feel about problems we face	1	2	3	4	5
26.	Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27.	Seeking advice from a minister	1	2	3	4	5
28.	Believing if we wait long enough, the problem will go away	1	2	3	4	5
29.	Sharing problems with neighbors	1	2	3	4	5
30.	Having faith in God	1	2	3	4	5

McCubbin, H.I., Thompson, A.I. & McCubbin, M.A. (1996). Family Assessment: Resiliency, Coping and Adaptation. Madison, Wisconsin: University of Wisconsin Publishers.

## CURRICULUM VITAE

**Fang Ye, MSN, ANP, RN**

### EDUCATION:

University of Texas Houston, Texas	2016	PhD	Nursing
University of Texas Houston, Texas	2013	Post-Master's Certificate	Nursing
University of North Dakota Grand Forks, North Dakota	2006	MSN	Nursing
University of North Dakota Grand Forks, North Dakota	2005	BSN	Nursing

### PROFESSIONAL POSITIONS:

- Houston Methodist Hospital  
Houston, Texas  
Nurse Practitioner 2013 – present
- University of Texas Health Science Center at Houston  
School of Nursing  
Houston, Texas  
Research Associate 2010 – 2013
- Trisun HealthCare  
San Antonio, Texas  
Assistant Director of Nursing 2007 – 2010
- University of North Dakota  
School of Nursing  
Grand Forks, North Dakota  
Graduate Teaching/Research Assistant 2005 – 2006
- Anhui Pulmonary and Thoracic Hospital: Hefei, Anhui, China  
Staff Nurse 1997 – 2001

## PROFESSIONAL MEMBERSHIPS

- Sigma Theta Tau International (STTI) Membership, Eta Upsilon Chapter (2006 – 2008)
- Texas Nurse Practitioner Membership (2012 – 2014)
- Houston Area Nurse Practitioner Membership (2012 – 2014)

## LICENSURE AND CERTIFICATION

- Texas State Advanced Practice Nurse, TX BON (Current – 07/2018)
- Advanced Cardiac Life Support Provider, American Heart Association (Current – 08/2017)
- Basic Life Support Provider, American Heart Association (Current – 08/2017)

## PUBLICATIONS

- Ostwald, S.K., Godwin, K., Ye, F. & Cron, S. (2012). Adverse events experienced by stroke patients during the first year post discharge. *Rehabilitation Nursing*, 38 (5), 254 - 263.

## HONORS/AWARDS/SCHOLARSHIPS

2003–2005	Dean’s List President’s Honor Roll
2004–2005	International Student Scholarship
2004-2005	Robert Campbell Foundation Scholarship
2006	Intercollegiate Academic Funding Award No. [52] & [9]
2006	Sigma Theta Tau International Eta Upsilon Chapter Outstanding Graduate Student Award
2010–2011	Good Samaritan Foundation Scholarship
2011-2013	William Randolph Hearst Scholarship for Nursing
2011-2012	Marian and Speros Martel Foundation Scholarship
2012-2013	Texas Nurse Practitioner Foundation Scholarship for Nursing
2012-2015	HealthCare & Nursing Education Foundation Scholarship for Nursing
2015-2016	Houston Methodist Hospital Scholarship