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**THE EFFECT OF INDIVIDUAL POST-STROKE ADAPTATION ON MIDDLE-
AGED LONG-TERM MARRIED COUPLES**

By

Lori Ruth Stanley

A DISSERTATION

**Submitted to Michigan State University
in partial fulfillment of the requirements
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ABSTRACT

THE EFFECT OF A CEREBROVASCULAR ACCIDENT (STROKE) ON MIDDLE-AGED COUPLES IN LONG-TERM MARRIAGES.

By

Lori Ruth Stanley

This research study examined the influence of ecosystemic factors, social constructionism, and sense of coherence on successful post-stroke adaptation. This was a qualitative research study and included eight post-stroke middle-aged couples in long term marriages of which four were female stroke survivors and four were male stroke survivors. Each participant was asked to describe their own post-stroke experiences and perceptions. Through narrative inquiry, participants were able to explore and make sense of their post-stroke process, journey to successful post-stroke adaptation, personal characteristics, and influential ecosystemic factors. Finally, it allowed participant's to appreciate the individual meaning ascribed to the stroke event and the perceived impact of the stroke on their long-term couple relationship. Exploring individual stories provided and opportunity to appreciate individual attributes and ecosystemic influences when faced with a traumatic life event. Through qualitative research analysis, three primary classes of data emerged: Ecosystemic Influences on Post-Stroke Adaptation, Sense of Coherence, and Social Constructionism. The use of grounded theory methodology was expected to contribute to the development of new theoretical concepts and ultimately, a strengths-based model to be utilized by clinicians when assisting couples following a stroke event.

Dedicated to my Mother: Alice J. Stanley and my family, whose faith and encouragement gave me the confidence to pursue and successfully complete this journey.

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During each stage of this journey it was difficult to image myself reaching this point, where all that remained was acknowledging those who in different ways contributed to my success. The past several years of my life have been primarily devoted to my dissertation. The support and encouragement from many people have made this pursuit possible. It is their friendship, prayers, and faith that are most significant and will forever remain in my heart.

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TABLE OF CONTENTS

Chapter 1	
INTRODUCTION.....	1
Rationale for Study.....	3
Importance of the Problem.....	4
Conceptual Framework.....	5
Figure 1.1 Conceptual Map.....	6
Theoretical Framework.....	7
Human and Family Ecology.....	8
Sense of Coherence.....	12
Narrative Study – Social Constructionism.....	14
Descriptions of Theoretical Map.....	16
Figure 1.2: Theoretical Map.....	17
Table 1.3: Research/Interview Questions.....	19
Chapter 2	
REVIEW OF LITERATURE.....	21
The Nature of Chronic Illness: Impact of a Stroke.....	22
Chronic Illness and Ageing.....	24
Marital Relationships and Chronic Illness.....	26
Gender Differences in Spouse-Care Providers.....	28
Spousal Care Providers and Role Flexibility.....	30
Meaning Ascribed to Illness.....	33
Sense of Coherence.....	34
Chapter 3	
METHODOLOGY.....	36
Rationale for Qualitative Methodology.....	36
Grounded Theory.....	38
Case Study.....	40
Researcher as Instrument.....	41
Research Questions and Objectives.....	41
Procedure.....	42
Sample.....	42
Sample Acquisition and Recruitment.....	43
Data Collection.....	44
Interview Process.....	44
Data Analysis.....	47
Coding Process.....	48
Table 3.1: Final Coding Frame.....	50
Trustworthiness.....	51
Validity and Generalizability.....	51
Researcher’s Role and Ethical Considerations.....	52

Chapter 4	
RESULTS AND DISCUSSION.....	54
Overview.....	54
Demographic Data.....	57
Influence of Ecosystemic Factors in Post-Stroke Adaptation.....	60
Code: Perceptions of Medical Experience.....	60
Theme: Ability to Ask Questions and Receive Answers.....	61
Theme: Involvement in Medical Care.....	64
Theme: Positive Experience in Medical Rehabilitation.....	67
Theme: Failure to Receive Tissue Plasminogen Activator.....	72
Theme: Eroding Autonomy.....	73
Code: Social Support.....	77
Theme: Family Involvement.....	78
Theme: Congregational Support.....	82
Code: Influence of Marital Relationship.....	83
Theme: Communication.....	83
Theme: Role Flexibility.....	90
Sense of Coherence.....	99
Code: Psychological/Emotional Influence.....	100
Theme: Ability to Overcome Depression.....	100
Theme: Tenacity/Perseverance.....	104
Code: Philosophical.....	106
Theme: Spiritual Beliefs.....	106
Social Constructionism.....	107
Couple 1.....	108
Couple 2.....	109
Couple 3.....	109
Couple 4.....	110
Couple 5.....	110
Couple 6.....	111
Couple 7.....	111
Couple 8.....	111
Chapter 5	
Summary and Implications.....	113
Conceptual Framework.....	114
Figure 5.1: Conceptual Map.....	116
Theoretical Foundations and Implications.....	117
Key Findings.....	117
Relational Resiliency.....	119
Marital Commitment.....	122
Contribution to Existing Literature.....	123
Ambiguous Loss.....	123
Clinical Implications.....	125
Research Implications.....	127

Limitations.....	128
Conclusion.....	129
 APPENDICES	
Appendix A: Letter to Participants.....	130
Appendix B: Informed Consent.....	131
Appendix C: Semi-Structured Interview Guide.....	133
 REFERENCES.....	 134

Chapter 1

INTRODUCTION

In the United States, a cerebrovascular accident (stroke) occurs every 53 seconds; and death from a stroke every 3.3 minutes. More specifically, 750,000 Americans per year will experience a stroke and 167,661 will die as a result (American Stroke Association, 2002). A stroke remains the third leading cause of death in the United States and the second leading cause of death in the world, contributing to an estimated 4.4 million deaths (Murray & Lopez, 1997). The annual economic cost of a stroke in the United States is approximately 49 billion USD annually; the human cost however, is immeasurable (Center for Disease Control, 2002).

A stroke is defined as a medical crisis, occurring when blood supply to the brain is interrupted by an occlusion or hemorrhage. Although a stroke occurs within the brain, it impact the entire human body contributing to extensive cognitive, physical, emotional, biopsychosocial impairment, and neurobehavioral disorders. According to the Global Burden of Disease Project (Murray & Lopez, 1997), a stroke is the leading cause of serious long-term adult disability resulting in partial or total loss of functional independence.

An unexpected loss of functional ability in addition to complex perceptual changes, is a significant challenge to a stroke survivor's sense of identity and self-concept (MacMillan, Hart, Martelli, & Zasler, 2002). Limitations of autonomy and social functioning can render a self-concept based on physical aptitude and mastery, untenable.

In addition to the loss of functional capacity, a stroke usually decreases the survivor's ability to effectively maintain preexisting familial relationships and social

roles (Fields, Cordel, & Bowman, 1983), which can have deleterious consequences for the survivor's perception of self competence and agency (Glass & Maddox, 1992).

Previous research suggests that the emotional impact of post-stroke losses and caregiving pressures constitutes a psychosocial crisis for the entire family (Palmer & Glass, 2003; Cohen, Harbin, Collis, & Greenberger, 1986). Although some physiological symptoms can be detected, by nature a stroke occurs without warning providing no time for post-stroke adjustment. Depending on the extent of post-stroke disability, families are forced to make significant adaptations both as a unit and as individual family members. Family members, most often the survivor's spouse, must immediately assume the role of caregiver, managing and supporting the vast consequences commonly associated with a stroke. Furthermore, the survivor and his or her family are ill equipped and unprepared for the multifaceted health care system, which requires immediate adaptation and participation. Previously healthy and active individuals are suddenly disabled, often losing a portion or all functional, emotional, physical, and cognitive abilities (Kelly & Winograd, 1985).

Due to the significant reduction in health care coverage and other cost control measures, survivors can be discharged from an acute medical care setting within 1 to 2 weeks following a stroke (Schmidt, Guo, & Scheer, 2002) at which time, some stroke survivors are transferred to a rehabilitation setting. Typically before the survivor is medically stable, the survivor's family must decide if they are able and willing to provided home health care or begin the difficult and painful process of selecting a long-term care facility. According to Anderson, Linton, and Stewart-Wynn (1995), after stroke survivors are released from medical care, 80% return home, necessitating full or partial

dependence on family for emotional, physical, and psychological assistance (National Stroke Association, 1999). Post-stroke dependence is due primarily to functional limitations including the inability to perform activities of daily living (ADL's), emotional, and cognitive incapacitation. From 1970 to the early 1990s, the number of non-institutionalized stroke survivors increased from 1.5 million to 2.4 million and continues to rise annually (ASA, 2002).

Rationale for Study

This research project examined the influence of ecosystemic factors, social constructionism, and sense of coherence on post-stroke adaptation and relational impact. This study was both unique and significant as it explored participant's sense of coherence (SOC) and environment influences to determine what factors facilitated or hindered participant's post-stroke process in relation to adaptation. Finally, it allowed participant's to appreciate the meaning ascribed to the stroke event and consider the impact on their long-term couple relationship.

Medical outcome studies have traditionally focused on biological parameters of disease; however, there is a growing interest in systemic factors that contribute to individual outcomes and adaptation. Identifying influential ecosystemic factors may provide clinicians the opportunity to appreciate and delineate the reason why some individuals are able to successfully adapt when faced with an illness while others are not. For purposes of this research study, adaptation is defined as a multifaceted concept which includes several specific indicators including the following: acceptance of disability, perception of and psychological and social functioning.

Importance of Problem

When a stroke occurs in middle-age and in the context of a long-term marital relationship, previously established patterns within the marital dyad must be re-defined, reorganized, and renegotiated. For the purposes of this research study, a long-term marriage is defined as in excess of 10 years and middle-age, over 50 years old. Some changes can be made with relative ease while others are more difficult or require greater adaptive resources.

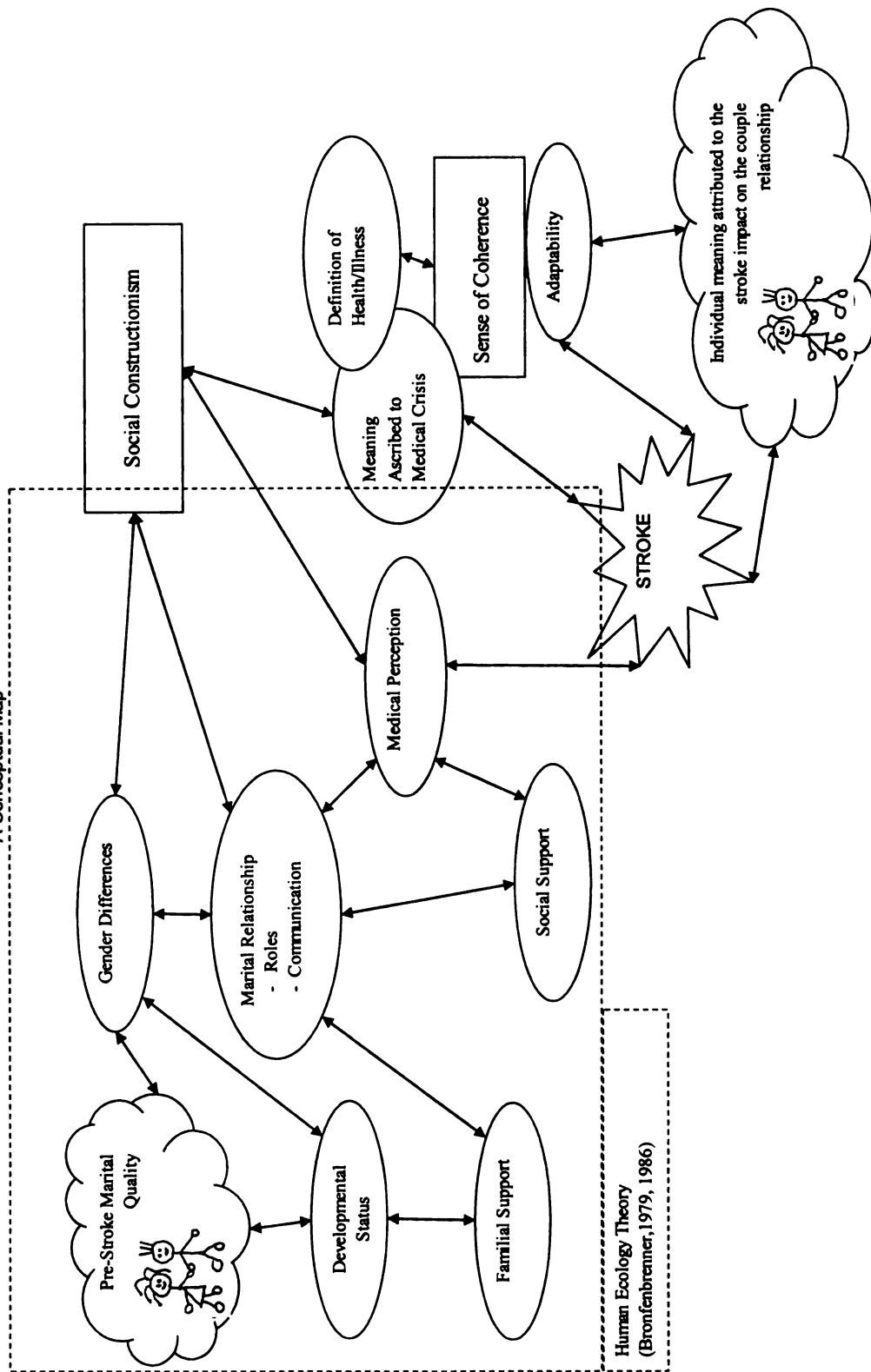
Post-stroke adaptation and biopsychosocial impact vary appreciably depending on the nature and extent of the stroke and pre-stroke factors including pre-morbid health status, comorbidity, pre-stroke personality, meaning ascribed to the stroke event, social support, and pre-stroke family dynamics (Burman & Margolin, 1992). The degree of adjustment within the marital dyad may be more difficult in middle-age long-term partners as they are more likely to have established traditional gender roles.

A stroke within a marital relationship creates a significant amount of stress on the couple dyad. In a long-term marriage, a spouse is typically the survivor's closest family member, and the person the survivor often relies on for physical care, social interaction, emotional support, and financial assistance. The spouse's reaction following their husband or wife's stroke is directly linked to the survivor's personal perception of his or her disability, self-concept, and self-esteem (Helgeson, 1993; Lawton, Rovine, Moss, Kleban, & Glicksman, 1989). The subjective exploration of successful post-stroke adaptation is expected to provide valuable insights necessary to the development of grounded theory.

Conceptual Framework

The conceptual map (See Figure 1.1) depicts a visual representation of this study. When post-stroke consequences disable one partner in a long-term marriage, the marriage system as a whole may be at risk of becoming less functional. However, specific ecological correlates reciprocally interact and influence the stroke survivor and his or her spouse's post-stroke process. The concepts proposed by Bronfenbrenner's human ecological theory (1979, 1992) are significant to this study and will be discussed in the theoretical perspective section in greater detail. The conceptual map illustrates the significance of the couple's pre-stroke marital relationship, which will likely influence their experience of both the stroke itself and the capacity for the couple to successfully navigate the consequences of the stroke on their relationship. The conceptual map identifies various ecosystemic considerations that possibly impact the ability of a marital dyad to successfully adapt following a stroke. Circles are used to represent these environments. This conceptualization also includes sense of coherence as a possible mediating factor such as comprehensibility, manageability, and meaningfulness in relation to the stroke survivor's and spousal care provider's perception of influential personal resources contributing to individual recovery processes. Finally, Social Constructionism asserts that people make meaning of their experiences and act in accordance to their constructed realities through the process of mutually co-editing their stories. This map illustrates that the stroke and entire recovery process entails individual processes by which each individual makes meaning of this experience, ultimately culminating in a joint story about the impact of the stroke on the couple relationship.

Figure 1.1
Ecosystemic Influences on Successful Individual Post Stroke Adaptation
A Conceptual Map



Theoretical Framework

Examining post-stroke adaptation was accomplished in the context of three major theoretical perspectives and through the development of a separate, yet unified, theory which integrated components of each. Human Ecological Theory, (Bronfenbrenner, 1979, 1986), Social Constructionism (Gergen & Gergen, 1984), and Sense of Coherence (SOC) (Antonovsky, 1987) provided an appropriate multi-framework useful to explore participant's post-stroke adaptation and coping process and the meaning ascribed to the impact of the stroke on their couple relationship. Each theory provided a lens through which influential ecosystemic factors, individual coping processes, and individual meanings ascribed could be explored.

Bronfenbrenner's model of human ecology (1979, 1986) is central to this study and provided a relevant theoretical framework to explore systemic influences on the reciprocal interaction of individuals within multiple environments. This study focused on the personal stories of both the stroke survivor and his or her spouse, while incorporating the ecological context and narrative meanings ascribed. Social constructionism provided a theoretical background to explore individual post-stroke adaptation processes and meanings ascribed to the stroke event. The third theoretical approach relative to this study was the adaptive theory, Sense of Coherence (SOC) (Antonovsky, 1987). Post-stroke adjustment and adaptation is influenced by many factors including personality resources, coping ability, and meaning ascribed to disability.

Human and Family Ecological Theory

Examining the impact of a stroke on middle-age couples in long-term marriages, from an ecological perspective revealed unique relationships between individual post-

stroke adaptation and influential ecosystemic environments. These factors included perception of medical experience, social support, and pre-existing marital constructs.

The composition of an individual's ecosystem is determined by the interaction of systems, subsystems, and individual roles. A stroke survivor is influenced by several interacting environmental systems, which include nuclear, and extended family members, medical/health care environment, and social environment. The stroke survivor's marital relationship is part of several interacting systems, including family, health care systems, social support, and medical environment. Environmental influences have a positive and/or negative impact, which may hinder or facilitate individual successful post-stroke adaptation.

Bronfenbrenner (1977) emphasized the need to examine interactions between people and the changing environment in which they live to understand human development. The human ecological theory focuses on human-environmental interaction within a network of systems, subsystems, and supra systems. Ecosystems are the primary concept in human ecology and the basic element of human-environmental interaction and analysis. According to Bronfenbrenner (1979), individuals function within four primary interconnected environmental systems, conceptualized in order of proximity to the individual, and it is within these environments that individuals are constantly interacting and evolving. Bronfenbrenner's (1979) theory of human development illustrates reciprocal interactions between several environmental systems and human beings within these systems. Over the course of one's life span, people and their environments mutually accommodate constant change and growth.

Bronfenbrenner (1979) defines these systems as follows:

Microsystem - the immediate environment including direct interaction between individuals and the changing environments in which they exist. A couple's microsystem includes the marital relationship, immediate family members, peer relationships, and occupational environments.

Macrosystem - A macrosystem relates to broad influences that affect all other systems including cultural definitions and sociological ideological values that affect the way in which individuals interact in other systems. Social norms influence how meaning is ascribed to post-stroke disability and how individuals make sense of their experience.

Mesosystem - A mesosystem includes all environmental systems in which the developing person interacts including work, educational environments, community and social environments such as church and support groups. It is important to consider the mesosystemic environment, as post-stroke consequences do not affect only one area of a couple's life. The process of operating in different settings is not mutually exclusive as environmental influences are reciprocal and operate in both directions. Although the family is the primary context in which human development occurs, there are other settings in which development process can occur.

Exosystem - The exosystem does not directly involve the family but can affect or be affected by the family. Individuals significant to the developing person are involved in these systems (e.g., social networks or occupational environments). It connects several support systems however the individual is not a direct participant. For example, an indirect connection may be evident if managed care insurance providing stroke rehabilitation also allowed psychological services. Therapeutic counseling would

significantly increase the professional psychosocial support a couple may receive immediately following a stroke. The healthcare system (e.g., hospital/rehabilitation environment) is an applicable exosystem in this research project. Both the medical and rehabilitation settings played an important role in each participant's post-stroke adaptation process.

For purposes of exploring the influence of different environmental systems in human development over a period of time, later work by Bronfenbrenner (1986) included the chronosystem.

Chronosystem - Life transitions are the primary concepts within the chronosystem. Expected and non-expected transitions occur over the course an individual's lifetime. Normative transitions are expected transitions that occur over the course of normal development including marriage, childbirth, and retirement; non-normative transitions include divorce, moving, unexpected family medical crisis, and death. These transitions occur over the course of an individual's lifetime and can inspire developmental changes.

Bronfenbrenner's (1979) conceptualization of environmental influence on individual development is a practical paradigm for this study. It is strengthened by including integral concepts of the Process-Person-Context Model (Bronfenbrenner, 1992). Specifically, this model recognizes the reciprocal effect of environmental and personal characteristics working together to produce a more substantial effect on human development than either does by itself.

Bronfenbrenner (1992) defines the two primary concepts of this model as follows:

1. The design permits assessment not only of developmental outcomes but also

of the effectiveness of the processes producing these outcomes (p. 199).

2. The design reveals how both developmental outcomes and processes vary as a joint function of the characteristics of the person and of the environment, thus permitting the detection of synergistic effects (p.200).

Although stroke survivors interact and develop in a variety of microsystems, the marital relationship is one of the most influential contexts regarding post-stroke adaptation and directly influences the stroke survivors overall outcome. The marital structure is inevitably affected following a stroke event as each member attempts to cope with the changes among and between themselves (Minuchin & Nichols, 1993).

Sense of Coherence

The influence of SOC as a personality factor explicating the differences in individual coping and adaptation ability following an unexpected medical crisis has received increased attention in psychological and medical related disciplines and may provide an expansion to existing family systems theory. SOC is a mediating or decisive factor that contributes to an individual's ability to effectively adaptation in a medical crisis and provided a useful framework to examine the relationship between SOC and post-stroke adaptation within the context of long-term marital dyad.

According to Antonovsky (1979, 1987), SOC is a symbolic and prevailing personality factor directly linked to an individual's ability to adapt following a disabling medical crisis. It represents one's perception of manageability and control over life and provides insight into individual differences in coping and adaptation. The three reciprocally interacting components of SOC are identified as contributors to individuals perception: comprehensibility, manageability, and meaningfulness. Each contributes to

an individual's general perception of their world and perceived ability to successfully cope when faced with a crisis. Comprehensibility refers to the degree to which the stressor is to be organized and predictable. Manageability is the perception that the demands of the stressor are manageable and that the personal resources necessary to control the stress is available. Meaningfulness refers to the perception that the stressor is understandable and individual is motivated to the An individual's SOC facilitates the ability to cope and adjust while maintaining psychosocial and physical health. When faced with a medical crisis, those with higher levels of SOC were found to use more constructive means of coping with stress by perceiving it to be controllable, understandable, and were motivated to adapt.

Post-stroke consequences typically include partial or total dependence, physical limitations, and a significant adjustment period for both stroke survivors and his or her spouse (Crewe & Kraus, 1988, 1990; Marinelli & Dell, 1977; McCubbin, Hamilton, & Patterson, 1982). Although, it is common for survivors and caregivers to experience stress, anger, and depression, empirical and clinical data have demonstrated that the degree of psychological affect varies considerably among individuals faced with a similar diagnosis (Kulchycky, & Goodwin, 1988; Goldberger & Breznitz, 1982; Freedman, Kaplan, & Sadock, 1975). Researchers have expressed a growing interest in the psychological and social factors that influence an individual's ability to cope both physically and psychologically (Antonovsky, 1987; Dohrenwend & Dohrenwend, 1981; Garrity & Marx, 1985; Holyroyd & Lazarus, 1982).

According to Antonovsky (1987) and Sagy (1990), the degree of marital crisis following a stroke is predicated on the couple's ability to cope with multiple unexpected

or adverse demands inherent in post-stroke adjustment (Maturana & Varela, 1992). Lavee, McCubbin, and Olson (1987), assert that higher levels of SOC within a marital dyad, enhances a couple's marital perception, enthusiasm, and the ability to successfully work through post-stroke emotional issues. SOC is not a mutually exclusive factor but a shared experience that directly affects the ability of a couple to successfully or unsuccessfully adapt or adjust following a stroke. For example, if a stroke survivor has a strong SOC, his or her spouse is typically less anxious and consequently able to cope more effectively (Antonvosky & Souramin, 1988; Baider & Kaplan – De-Nour, 1988; Kelly & Lambert, 1992).

The ability to successfully adapt following a stroke is linked to both individual personality factors and a supportive spousal relationship, which is more likely to be found in long-term marriages. Charny (1986) suggests that individual partner's brings specific assets and limitations into a marital relationship and couples adjust in ways that take advantage of each other's strengths and weaknesses. This adjustment allows married individuals to function effectively together or separately, demonstrating the influence of personal and ecosystemic factors on adjustment. Several recent studies (Rena, Moshe, & Abraham, 1996; Feigin, 1998; Nillson, Axelsson, Gustafon, Lundman, & Norberg, 2001) explored the differences among post-stroke couples and their ability to adapt within the context of marriage. The results revealed a positive correlation between SOC and adaptation to disability regardless of the degree and extent of disability. Individual SOC was empirically linked to successful post-stroke adaptation and had a significant role throughout all stages of disability (Antonovsky, 1987).

Narrative Study - Social Constructionism

Respect and value of individual perceptions and meanings constructed through personal experiences is a primary tenet of narrative inquiry. Employing a narrative stance empowered participants to become “experts” of their personal post-stroke processes and experiences (White & Epston, 1990). Social constructionism recognizes the tendency and value of individuals to story their life experiences based on their perception and construction of reality (Moules, 2000). The social constructionist approach suggests that individuals actively participate and interact within their social-cultural environment. These environments include assumptions, “taken for granted” rules, and beliefs about what it means to be disabled or unwell. It is within this framework of shared definitions that stroke survivors and care-giving spouses interact and behave accordingly. Fundamental beliefs and knowledge about a stroke is a collective socio-cultural construct of the survivor and caregiver (Atwood, 1992). The meaning ascribed to post-stroke consequences is based on a couple’s collective contextual or cultural experiences (Gergen & Davis, 1985) and perception of reality constructed from personal experiences and close relationships (Franz & White, 1985). It is the con-constructed definition of health and illness that directly affects and governs the way in which couples structure and organize following a stroke.

The social systems of the survivor and caregiver influence their belief systems, lifestyle, and experiences relating to health and disability. The social constructionism model allowed the researcher to focus on participating couple’s perception of illness and the impact of the stroke on their couple relationship. By storying individual experiences, participating couples identified individually and collectively beliefs about the stroke

event, post-stroke experiences, the affect on family, and what changes are desired in response to the stroke.

In this sense, narrative processes can be understood as an effort to face negative life outcomes and to cope with the impact of change and loss. Researchers agree that in order for a couple to make sense of a stroke experience, events must be organized in a way that demonstrates chronological dimension (Bruner, 1990; Mishler, 1986). Narrative stories carry implications for the well being of the stroke survivor and his or her spouse, helping to elucidate a variety of potential outcomes. In doing so, the couple can reflect and create desired or anticipated future events. In effect, a survivor and his or her spouse become historians of the “self” and as a couple, developing an internally consistent interpretation of the life cycle so that past, present, and future are experienced as congruent. The assumption is that such processes work to preserve a sense of coherence and continuity in identity and self, which are seen as critical determinants of mental health (Antonovsky, 1987; Basch, 1976; Cohler, 1982).

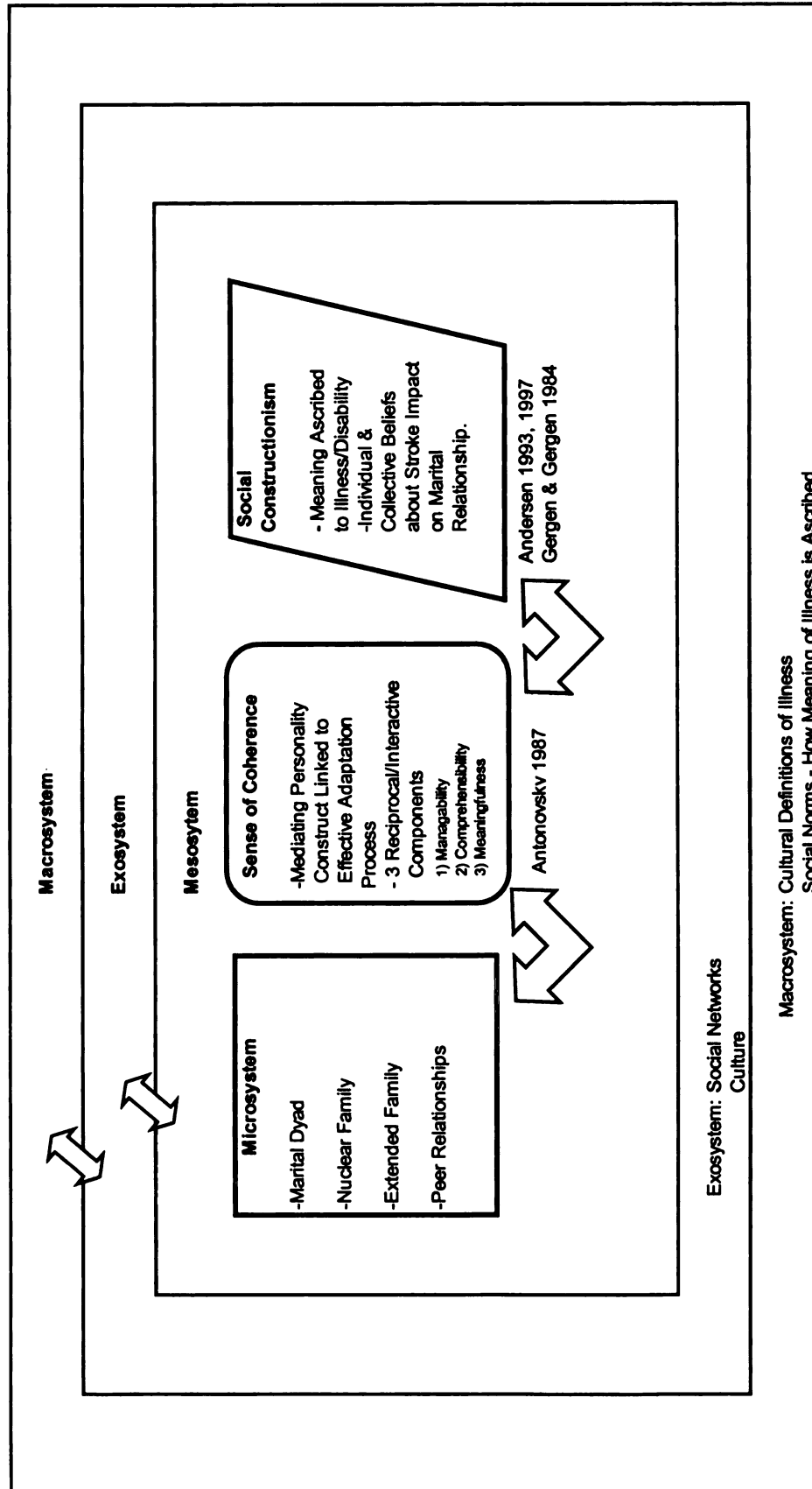
Description of Theoretical Map

Figure 1.2 is an illustrative representation of the theoretical concepts that guided this research study. Ecosystemic environments relative to participating post-stroke couples and outlined by Bronfenbrenners' human ecology theory (1979, 1986) are depicted by the outer sectors of the map. The concept of individual successful post-stroke adaptation is reflected within each system.

Sense of coherence (SOC) is relevant to personal characteristics of each individual participant and the way in which their experiences and perceptions are processed. Successful adaptation, represented in proximity to stroke survivor and his or her spousal caregiver, reflects the meaning attributed to the impact of the stroke on their couple relationship. Specific ecosystemic influences contributed to individual post-stroke self-narratives.

The process of social constructionism occurs within the context of individual experiences and contributes to the meanings ascribed to the stroke event. It is these meanings that inform each participant's current and future beliefs and consequently, their behavior (White & Epston, 1990). Separately and conjointly, stroke survivors and spousal caregivers choose different parts of their experiences from the past and present, as well as future expectations and connect them in a manner that allows them to create self-narratives (Gergen, 1985).

Figure 1.2
Ecosystemic Influences on
Post-Stroke Adaptation Process



Ecosystem
Bronfenbrenner, (1979, 1986, 1992)

Three primary research questions were developed based upon the on the theoretical and conceptual maps. Research and corresponding interview questions are represented in Table 1.3. The research questions explored in this study were as follows:

Human Ecological Theory

- 1. How do aspects of the ecosystem influence adaptation involving each member in post-stroke couples?*
 - 1a. What is most/least helpful in the medical system in regard to promoting adaptation?*
 - 1b. What types of social support are most/least helpful to post-stroke adaptation?*
 - 1c. How does the marital relationship itself, influence adaptability?*

Adaptive Theory – Sense of Coherence

- 2. How does sense of coherence (SOC) influence individual members of long-term marriages post- stroke adaptation?*

Social Constructionism

- 3. How does each member of the couple make meaning of the impact on their couple relationship?*

Table 1.3 Research/Interview Questions

Research Questions:

Human Ecological Theory

How do aspects of the ecosystem influence adaptation involving each member in post-stroke couples?

1a. What is most/least helpful in the medical system in regard to promoting adaptation?

1b. What types of social support were most/least helpful to post-stroke adaptation?

1c. How does the marital relationship itself, influenced adaptability?

Sense of Coherence

2. How does sense of coherence (SOC) influence individual members of long- term marriages post-stroke adaptation?

Social Constructionism

3. How does each member of the couple make meaning of the impact on their couple relationship?

Interview Questions:

Tell me about your medical experience relating to the stroke?

- What did you believe was most helpful? Why?
- What did you believe was not helpful? Why?

What types of social support did you utilize in your recovery

What type was integral to your recovery?

- How were these types of support most helpful?
- What about this support do you feel made it so helpful?
- How were these types of social support was not as helpful?
- What about this support do you feel made them not as helpful?

How do you think the marital relationship itself influenced your successful adaptation?

What type of impact did the relationship have on role flexibility?

- How did the two of you communicate prior to the stroke?
- What is it about the way the two of you interact that has helped you following the stroke?
- Is there anything about the way the two of you interact that made it difficult to interact?

What are the things about you as an individual that you help adapt?

What is your general outlook on life?

- How do you get personal strength?

Tell me about what impact you feel the stroke had on your present relationship?

In Chapter One, the theoretical and conceptual maps are explicated, setting forth the specific areas under study. Chapter Two defines the theoretical framework and relevant literature review related to post-stroke adaptation in middle-aged, long-term married couples.

Chapter 2

REVIEW OF CRITICAL LITERATURE

The majority of empirical research pertaining to cerebrovascular disease (stroke) has focused on the physiological and psychological consequences of the stroke survivor. Comparatively fewer studies have explored the influence of ecological and personal factors when investigating the post-stroke impact and subsequent adaptation process of middle-age couples in long-term marriages. Examining a long-term marital dyad may provide important insight in to those at risk for experiencing adverse outcomes when faced with an unexpected crisis (Carter & Carter, 1994; Primomo, Yates, & Woods, 1990).

The existing literature suggests that several factors influence adaptation within a marital dyad following an unexpected medical crisis or chronic illness. These factors include: nature and extent of the medical crisis, developmental stage the couple, role flexibility, and social support. The ecosystemic factors that influence adaptation following a chronic illness include: access to healthcare, medical perception, and the quality of the pre-stroke marital relationship. Some of these factors will be examined by the design of sampling (e.g. nature of the illness, gender, developmental stage). Other factors will be accounted for in the theoretical and conceptual frameworks and research questions (e.g. marital relationship, meaning ascribed to illness, (SOC), and access to healthcare). The following literature review will explore scholarship in each of the following areas.

The Nature of Chronic Illness: Impact of a Stroke

In order to appreciate the deleterious impact of a cerebrovascular accident, it is necessary to understand basic neurological causation and post-stroke consequences. There are several different types of strokes however; a cerebral infarction or cerebral ischemia is the most common type of stroke, accounting for approximately 80% of all strokes. When a cerebral ischemia occurs, blood vessels in or around the brain become blocked. A blockage can originate in an artery of the brain or elsewhere in the body, often the heart. When the blockage or clot breaks off it can travel to the brain, until it lodges in a blood vessel (ASA, 2002). These "traveling clots" are called emboli. Strokes caused by emboli from the heart are often seen in people with an irregular heartbeat (arterial fibrillation), as well as those following a heart attack or heart surgery. The degree and type of post-stroke disability depends of the extent of damage and where the stroke occurred (Periard & Ames, 1993).

Paralysis is a common post-stroke consequence affecting the side of the body opposite to the damaged brain region. For example, damage to the right cerebral hemisphere results in paralysis on the left side of the body (left hemiplegia), while left cerebral hemisphere damage results in paralysis of the right side of the body (right hemiplegia). Survivors with left cerebral damage may also experience speech and language problems; respond with more caution and uncertainty, and in a disorganized manner. Survivors with right cerebral damage tend to have language function problems that can include excessive talking, impaired speech, decreased attention span, and visual-spatial perceptual deficits. Visual-spatial deficits affect the ability to accurately judge

depth, distance, size, rate of movement, and relation of parts to the whole (Fowler & Fordyce, 1972).

A stroke is often associated with pre-existing systemic factors such as age, access to proper medical care, premorbid health, smoking, obesity, and perception of health and illness. Depending on the severity of the stroke and the access to professional occupational, speech, and physical therapy, a stroke survivor may be able to regain some semblance of pre-stroke functions (Henderson, 1984). Post-stroke adjustment is generally defined and measured by the degree of consequential disability in a number of areas. Those who have experienced a stroke are at a greater risk of having a subsequent stroke, which is often a major concern for both the survivor and their support system and the reason it is imperative that stroke symptoms are recognized. Controlling the underlying cause of a stroke directly influences the level of recovery and decreases the potential for future strokes.

Stroke survivors are often left with residual chronic disabilities and psychosocial impairments affecting a wide variety of aspects of their daily life (Rau, 1991). Post-stroke functional disability occurs in approximately ninety-percent of stroke survivors and can present a significant challenge to pre-existing family dynamics (Periard & Ames, 1993; Sacco, Wolf, Kannel, & McNamara, 1982). Survivors with severe post-stroke disabilities usually necessitate high levels of attention and care. For example, post-stroke paralysis or equilibrium difficulty may require assistance with ambulation and with other activities of daily living (ADL's) (e.g., bathing, dressing, preparing meals, taking medication). In addition, survivor's suffering from post-stroke confusion, memory problems, or impaired vision may require constant supervision for reasons of personal safety.

Due to physical and/or cognitive disabilities, post-stroke consequences for the survivor can include role loss, relocation to care setting, and increased dependency. Moreover, a stroke often disrupts the survivor's ability to communicate effectively, either temporarily or permanently, causing interaction with friends and family to be difficult (Rau, 1991).

Chronic Illness and Ageing

Due to the increasing prevalence of stroke and the rapidly aging population at risk for stroke, the number of spouse caregivers is expected to increase dramatically. Accordingly, if one member in a long-term marital relationship is faced with a chronic disease or disability, the spouse will likely become the primary care provider, responsible for providing both physical and emotional support.

Chronic illness is a major concern for aging adults and is more likely to occur in older adults than any other age group (Corbin & Strauss, 1984). According to McDaniel, Hepworth, and Doherty, (1992), 45% of adults over the age of 65 were limited due to a chronic medical condition or disability. Although a stroke seldom occurs before the age of 45, after 45, the risk for experiencing a stroke doubles (Life Extension Foundation, 2002). In middle-age and elderly populations, a stroke is a leading cause of disability.

Due to caregiver burdens, a stroke that occurs in middle-age may be more detrimental than during other developmental stages. Caring for a chronically disabled or ill spouse is particularly challenging in later-life when illness threatens the mortality of a long-term relationship. Marital relationships may be at higher risk for failure depending on factors such as the age, physical health, and socioeconomic status. A spouse,

particularly those in long-term marriages, who must relinquish their previous duties and responsibilities, may experience feelings of guilt and sadness due to the shift in roles.

In elderly survivors, post-stroke adaptation has been related to the level of pre-stroke function. Less physical limitations pre-stroke were associated with better physical outcome and a lower risk of medically necessitated institutionalization (Colantonio, Kasl, Ostfeld, & Berkman, 1996). In one study lower levels of functional recovery were reported by younger stroke survivors with significant post-stroke disability in comparison to older stroke survivor's that had actively participated in post-stroke rehabilitation programs (Ferrucci, Bandinelli, Guralnik, Lamponi, Bertini, Falchini, & Baroni, 1993). According to researchers, these results may have been due to the older survivor's coping mechanisms and compensatory tactics (Ferrucci, et al., (1993). Wyller (1998) suggests that in older stroke survivors, the presence of a supportive social network was a salient factor in increased feelings of well-being and in predicting successful post-stroke outcomes.

The psychological reaction to chronic illness or chronic disability, such as a stroke, varies among individuals and partially depends on the stroke survivor's particular stage of development. Each developmental stage has specific stressors aside from those imposed by an unexpected medical crisis or chronic illness. If a stroke is experienced during middle-age, the survivor's spouse is most likely to become the primary caregiver (Freese, 1990). In a long-term marriage, the spousal caregiver assumes the role of providing care while attempting to maintain the integrity of the family and couple relationship (Harke & King, 2002). Experiencing a stroke during this time can include significant interpersonal consequences for the survivor's spouse who may be in the

process of re-evaluating his or her personal life accomplishments and future personal goals. A survivor's spouse may perceive post-stroke disability or restrictions as an obligation or threat to his or her own future.

In middle-age, a person is more likely to have established a career, be involved in a committed relationship, and are often providing support and guidance to their own children as they begin to leave the family and become independent (Marinelli & Orto, 1978). While in good health, middle-aged couples often begin to prepare for retirement as life long dreams appear to be within reach (Roessler & Bolton, 1978). In middle-age, adults are typically aware of the potential for chronic illness or disability however; their life scripts do not typically plan for its occurrence until old age.

Post-stroke disability suffered in middle-age often impedes further occupational growth and necessitate early retirement. This can have a significant impact on the survivor's identity, self-esteem, and economic well-being of the entire family system (Raderstorf, Hein, & Jensen, 1984). Also during this time, adults begin to assume responsibility for their own parents who may be increasingly dependent which can add to existing financial and emotional stress.

Marital Relationships and Chronic Illness

Past and present research consistently demonstrates a positive correlation between marital status, health, and immunity against chronic illness. Carrere, Gottman, and Ochs, (1996) report that a supportive caring spouse is directly linked to healthier immune functioning in their spouse and increased protection against chronic medical conditions in his or her partner. In a study of cardiac patients, researchers, Coyne, Rohrbaugh, Shoham, Sonnega, Nicklas, and Cranford, (2001) demonstrate that the level of marital quality is a

significant predictor of survival following congestive heart failure. Moreover, marital quality is directly associated with decreased requests for pain medication and re-hospitalization, increased compliance with prescribed medical regimens, and improved post surgical outcomes (Kulik & Mahler, 1989). In the same study, patients that perceived negative reactions from their partners, exhibited higher levels of pain related behavior (Schwartz, Slater, & Birchler, 1996).

Furthermore, research documents that individuals who are unmarried have higher mortality rates (Berkman & Syme, 1976), less chance of surviving if diagnosed with a chronic medical condition (Gordon & Rosenthal, 1995) and less adherence to prescribed medical regimens (Goodwin et al., 1987). Additionally, Weissman (1987) determined that unmarried individuals have a significantly higher rate of major depression than those who are married. However, simply being married does not guarantee protection from a chronic illness or disability.

Married couples with lower levels of marital satisfaction have demonstrated compromised immune systems, higher rates of general health problems, and a higher rate of negative health outcomes (Greene & Griffin, 1998). Researchers believe that conflictual and negative marital relationships outweigh the benefits reported by individuals with high levels of marital satisfaction.

Researchers propose that post-stroke marital quality and family adaptation is directly correlated to the level of post-stroke disability, emotional changes, and the level of cognitive impairment (Brocklehurst, Morris, Andrews, Richards, & Laycock, 1981). According to Dennis, O'Rourke, Lewis, Sharpe, and Warlow, (1998), the more dependant the survivor, the more likely a caregiver will experience depression. Data

confirms that post-stroke behavioral changes rather than physical impairment contributes to caregivers' reported stress and depression (Anderson et al. 1995). Furthermore, providing care for survivors with high levels of depression or anxiety was found to be particularly stressful for spousal caregivers (Addington, Hall, Lay, Altmann, & McCarthy, 1998).

Gender Differences in Spouse-Care Providers

In 1997, researchers reported that over 2 million Americans provide care to a disabled or elderly person (Neal, Ingersoll, & Starrells, 1997). According to demographic data, caregivers are most often married, middle-aged, and female. Due to the history of gender socialization, it is not surprising that women are more likely to offer to provide care and accept care-giving roles. Approximately half of these women are employed, 35% are over the age of 65, and of those older than 65 many have their own personal chronic medical problems (McCauley, 1994). Gender differences in spousal-care-giving significantly affect the nature and extent of care (Brok, 1992; Gwyther, 1990; Vinokur, 1990).

In one study involving postoperative cardiac patients, women reportably provided more conducive recovery environments, due to the fact that it is women who are typically responsible for the family's general health care and therefore, were likely to be more familiar with care-giving (Badger, 1990). In contrast, men were more likely to solicit care-giving and housekeeping assistance from others while their wives were recovering or became disabled. According to Young and Kahana (1989), male caregivers were more focused on home repair projects, household chores, and provision of medically related transportation, while female caregivers reportably focused on household activities

including cooking, cleaning, laundry, and shopping. Other similar studies determined that the duration of the chronic illness or disability resulted in lower adjustment levels for women whereas, the decreased ability to effectively perform regular responsibilities and activities of daily living resulted in lower adjustment levels in men (Foxall, Eckber, & Griffith, 1986). Women also displayed less enthusiasm to care-giving and in their attempts to manage multiple roles, report feelings of guilt and inadequacy (McCauley, 1994). Male spouse-care providers reported lower levels of depression (Cohen, Luchins, Eisdorfer, Paveza, Grogory, 1990) and were less likely to express feelings of anxiety or fear in an effort to avoid exacerbating their spouse's distress level and concerns (Worby & Babineau, 1974).

In the majority of studies focused on gender and caregiving, researchers purport that women versus men, reported higher stress levels (Cassileth, Lusk, & Strouse, 1985), depression (Lieber, Plumb, Gerstenzang, & Holland, 1976), lower levels of marital satisfaction (DesRosier, Catazaro, & Piller, 1992), increased mood fluctuations and elevated levels of ensuing mental health problems (Young & Kahana, 1989). Moreover, researchers assert that women reported higher rates of subjective burden, feelings of social isolation, perceived loss of companionship, conflicting and overwhelming role changes, and perceived demanding or insensitive survivor behavior (Parks & Novielli, 2000).

Spousal Care Providers and Role Flexibility

Experiencing a stroke is understandably a traumatic event for the stroke survivor; however, researchers believe that the survivor's spouse experiences comparable psychological distress. Previous research suggests that spouses of chronically ill patients have equal or higher levels of stress and anxiety with wives of male patients being the highest (Oberst & Scott, 1988). In a long-term marital relationship, a survivor's spouse is typically the closest family member and as a result plays a significant role in care taking and post-stroke adjustment (Glass, Matchar, Belyea, & Feussner, 1993; Evans, Bishop, & Haselkorn, 1991).

Schumacher (1995) proposed that a role change in one family member elicits reciprocal changes with other family members. For example, if a survivor requires post-stroke care a family member, most likely a spouse will assume the role of caregiver (Hartke & King, 2002; Schumacher, 1995). Within the marital dyad, chronic disability often demands immediate renegotiation or the assumption of different roles. Spousal-caregivers must assume not only their own responsibilities but also those of the stroke survivor. A spouse's ability to effectively cope with the demands of care-giving is linked with the extent and nature of role strain necessitated by the survivor's post-stroke functional limitations (Beach, 1993). As a chronic illness continues or during periods of exacerbation, role demands may increase and force the caregiver to discontinue participation in other activities.

The role of a caregiver is complicated and challenging with competing responsibilities to assume. The ability of a couple to effectively adapt following a stroke has been directly linked to the degree of role changes required (Beach, 1993). Frequently,

a caregiver's life takes on a new focus and change in structure from the previous lifestyle (Schumacher, 1995). The willingness and ability of a spouse to provide supportive care for the stroke survivor has a direct impact on whether a survivor is able to return home rather than remaining in a medical institution (Anderson et. al. 1995; Draper, Poulos, Cole, Poulos, & Ehrlich, 1992). The caregiver commitment may be emotionally and physically difficult for the survivor's spouse as post-stroke consequences often necessitate comprehensive and long-term care. A spouse-caregiver may attempt to care for the survivor to the detriment of his or her own health. Caregiver depression can render spousal care providers incapable of providing requisite medical care, consequently decreasing the quality of life for both partners while the presence of a spouse may ensure higher quality of care for the survivor, it does not necessarily correspond with the caregivers well-being (Parmelee, 1983).

In studies of breast cancer patients, spouses typically serve as the primary caregiver (Manne, 1994) and were relied upon by the survivor for emotional and tangible assistance including management of medication, transportation assistance, and provision of companionship (Barker & Lemle, 1984; Primomo, Yates, & Woods, 1990).

The marital relationship is inescapably altered due to the shift in roles, responsibilities, emotional balance, and complementarity. Shifting from an intimate marital relationship to a caregiving and care receiving relationship is a significant challenge. If the marital relationship is further compromised by the survivor's inability to attend to personal activities of daily living and self-care, marital boundaries require redefinition. For example, changes in sexual intimacy between couples as a result of

chronic illness may necessitate partners to redefine the relationship from lovers to companions.

Couples who were sexually active prior to a stroke are likely to continue to be interested in sex, however may not be able to engage in sexual activities without physical and emotional renegotiation (Brocklehurst, et al., 1981; Williams, 1993). Post-stroke weakness or paralysis, required medication regimen, inability to effectively communicate, and loss of sensation or body awareness can interfere in a couple's sexual relationship. Additionally, continence is a principal measure of dependence and elucidates the severity of post-stroke disability (Brittain, Peet, & Castleden 1998). If a stroke survivor is rendered incontinent, his or her spouse will likely become responsible for basic hygiene, changing, dressing, and toileting further compromising the previous roles as husband and wife. Survivors often feel frustrated and humiliated, resulting in reduction of self-esteem and furthering the restoration of their pre-stroke sexual life. It is not uncommon for sexual desire to drastically decrease due to the energy expended during care taking and during the survivor's attempts to acclimate to daily activities (Hart, 1986). Resuming a sexual relationship after a stroke may require renegotiation and consideration of alternative techniques.

In an effort to regain control or compensate for loss, survivors may react angrily or feel resentful towards his or her caregiver. Fortunately, this struggle can be used as a catalyst for change, personal growth, and can foster closeness in the marital and family system as shifts in roles, power and responsibilities arise. Ascribing new definitions and meanings to relationship-adjustments can be mutually created in the context of marital communication.

Meaning Ascribed to Illness

Theories on stress, coping, and adaptation to an illness or chronic medical condition suggest that the subjective appraisal and interpretation of the implications has a significant impact on coping responses and outcomes. As a couple begins to appraise the post-stroke consequences and examine the resultant imposed restrictions, they may have to re-negotiate and re-define their personal identities that have been shaped over the course of their life time both separately and together (Campbell, 1986). Within a long-term marital relationship, couple's form personal definitions, identities, and expectations of their relationship (Schultz, Thompkins, & Rau, 1988). Marital patterns are unconsciously defined and shaped over long periods of time and only become problematic when challenged by a major event or crisis. For example, in a long-term marriage, post-stroke consequences often necessitate the redefinition and renegotiation of established patterns and interpersonal behaviors, compelling the couple to construct a mutually acceptable meaning of the stroke.

The ecological environment in which the couple interacts reciprocally affects the definition or meaning ascribed to an illness. Social culture and social networks are formed and defined by both marital and individual experiences. The meaning ascribed to illness is shared and negotiated in everyday interactions and it is deeply embedded in the social environment (Atwood, 1996). The social culture and the social networks shape and are shaped by the individual's experiences.

In past research, the extent of post-stroke disability was purported to be the determining factor in a survivor's ability to adjust (Sagy, 1990). However, there is increasing empirical evidence suggesting that adjustment to disability is multifaceted and

incorporates not only the physical repercussions but also personal and family changes (Antonovsky, 1987). Accordingly, current literature on disability and health outcomes suggests an emergent need to explore psychological and social factors that distinguish individual differences in the ability to cope when faced with a disability. There is a growing interest in elucidating the formidable influence of the (SOC) and an individual's ability to adapt when faced with a disability by perceiving it as manageable and consequential (Trieschmann, 1980).

Sense of Coherence

Returning home following a stroke is likely to generate stress and anxiety. A wide range of issues influence emotional and physical coping however, it is believed that internal psychological resources account for individual differences in the ability to effectively coping with faced with a chronic disability. The psychological resources include: individual personality, personal history, meaning ascribed to disability, pre-stroke level of family cohesiveness, and social factors (Thompson, Sobolew-Shubin, Graham, & Janigian, 1989). Antonovsky (1987), asserts that an individual's sense of coherence (SOC) is psychological and consequently a social factor that intercedes between personality and health outcome. An individual's (SOC) suggests the way in which the world is perceived and shapes unique coping styles when faced with complex and challenging situations (Badura, 1985; Cella, et al., 1988). With in the (SOC) framework, elucidation of subjective differences in coping and adapting to a medical crisis will be explored. Examining the (SOC) of spousal caregivers may aid clinicians is identifying and supporting specific variables that correlate to successful post-stroke adaptation in middle-age married couples.

Chapter Three explicates the logistics and outlines the qualitative methodology utilized in this research study. It also provides a detailed account of the data collection and analysis.

Chapter 3

METHODOLOGY

Rationale for Qualitative Methodology

Qualitative research is an interactive and transformational process involving close contact and interaction with the researcher, research participants, and the data.(Sword, 1999). Although, quantitative research provides an understanding of general trends and information, qualitative methods provide a more specific and greater understanding of a phenomenon (Gerhart, Ratliff, & Lyle, 2001). Qualitative research affords the researcher in-depth descriptions and explanations to the process of events in a contextual setting (Miles & Huberman, 1994.)

Although the participating post-stroke couples may have had similar post-stroke experiences, the individual stories captured the most meaningful aspects for each couple and revealed the unique characteristics across stories. These stories may become an anchoring source for stroke survivors, spousal caregivers, and their families as a whole (White & Epston, 1990). The use of qualitative methodology potentially enhances understanding of specific ecosystemic factors that can contribute to the couples' construction of meaning around the stroke and the impact ascribed to their couple relationship. It could also provide an opportunity to make sense of the post-stroke process individually and in the context of their marital relationship (Alldred, 1998).

According to Van Manen (1997), individual experiences, processes, perceptions, assumptions, and meaning ascribed to specific events are the primary emphasis of a qualitative research study. By not condensing human experience, interactions, and themes into quantifiable and testable data, the intrinsic value of human-relational phenomenon

increases the intrinsic value of human-relational phenomenon. Furthermore, it allows the value and significance of subjective meanings and the reciprocal flow of human experiences, fundamental in family system studies to be appreciated (Gilgun, 1992; White & Epston, 1990). Utilizing a qualitative research approach allowed the researcher to examine, identify, and understand, the individual post-stroke perceptions and experiences of middle-age couples in long-term marriages without reducing the process to scientific inquiry or empiricism (Miles & Huberman, 1994) or reducing these experiences to quantifiable “truths” (Schnitzer, 1993). Ecosystemic factors were also identified and examined to determine how these systems facilitated or impeded successful post-stroke adaptation. Further, this research will examine how these systems specifically contributed to the couples’ sense of successful post-stroke adaptation concerning the couple relationships themselves (Marshall & Rossman, 1995.)

Growing interest and research in the field of marriage and family theory has increased the preference and utilization of qualitative research methodology (Doherty, Boss, LaRossa, Schumm, & Steinmetz, 1993; Sprenkle & Moon, 1996). Fundamental beliefs and knowledge about a stroke event is a collective socio-cultural construct of the survivor and caregiver (Atwood, 1992). Individual post-stroke experiences and stories will be examined, in particular, meanings and themes reflecting social contextualization of ideas and individual perceptions (Newfield, Sells, Smith, Newfield, & Newfield, 1996).

The post-stroke meaning ascribed by participants was based on participating couple’s collective contextual or cultural experiences (Gergen & Davis, 1985) and perception of reality constructed from personal experiences and close relationships (Franz

& White, 1985). By storying individual experiences and perceptions collectively and individually, couples identified their separate beliefs regarding the impact of a stroke, the affect on their couple relationship, and the desired changes in response to the stroke.

Employing grounded theory methodology to collect and analyze subjective data from post-stroke couple's was expected to generate emergent themes and patterns essential to theoretical development (Strauss & Corbin, 1990; Glaser & Strauss, 1967).

Grounded Theory

Grounded theory methodology narrows the disparity between qualitative and empirical research and is considered to be of equal value (Glaser & Strauss, 1967). According to Sprenkle and Moon (1996, p. 66), Grounded theory was developed for the purpose of closing "the embarrassing gap between theory and empirical research." Grounded theory is a qualitative research method, in which theory is developed by blending interpretations of phenomena and conceptions from these interpretations with existing theory and research (Glaser & Strauss, 1967). Moreover, it is considered more reliable in research studies where multiple methods are used to collect and analyze data (Lincoln & Guba, 1985). Data is collected from a number of sources, including direct observation, recorded interviews, field notes, and audio taping (Strauss & Corbin, 1990). As data is collected and analyzed, it is compared and modified against relative empirical findings using an empirical iterative approach (Strauss & Corbin, 1990). In grounded theory, collecting and analyzing data is a continuous and closely linked process throughout the entire research endeavor (Strauss & Corbin, 1990). As data is collected and analyzed, it is constantly coded, re-coded, compared, reintegrated, and evaluated for interrelationships. Consequently, researchers are able to detect and report emerging

patterns at the onset of data collection. As themes and patterns emerge, data is separated into categories by meaning and interpretation, which leads to theoretical development (Hoshmand, 1989).

Narrative stories of a particular phenomenon are static interpretations from an individual's subjective perception. These stories are also a relative explanation based on individual assumptions and contextual influence. During the data collection and analysis process, similarities and differences among participants were examined and categorized accordingly. Features and relationships of each category were then compared with other emerging patterns until theoretical saturation was reached and three primary classes of data emerged (Strauss & Corbin, 1990). Theoretical saturation occurred when data collected failed to generate new information (Strauss & Corbin, 1990).

Grounded theory research focuses on conceptual relationships inferred through assimilation and relevance rather than specific description and evidence as proof (Glaser, 1978). Grounded theory provided the most effective means to gather and analyze complex phenomena and was expected to contribute to the global understanding of individual post-stroke experiences and its influence on reality construction (Patton, 1990). As data were collected, analyzed, and substantively categorized, more specific and directive research questions were generated.

Successful post-stroke adaptation is a function of family system concepts that relate to all couple relationships including, pre-marital quality, individual perceptions and experiences, communication skills, and trust. In addition, successful adaptation will reflect other issues relating to sense of coherence (SOC), and social constructionism both individually and collectively.

Language is considered to be a primary source for interpreting and comprehending the way in which individuals construct reality and ascribe meaning in their lives. As such, language is best understood when examined in the environment where it naturally occurs (Newfield, et al., 1996). Attending to the language of long-term married partners in their natural environment provided insight into the personality dispositions and sense of coherence (SOC) of both spouses. Language analysis provided valuable insight into the construction of familial themes and patterns. Through language, including appreciative interview questions, the researcher co-creates meaning, metaphors, and the direction of stories.

Case Study

As interest in qualitative research methods has increased, so has the use of case study research (Merriam, 1988; Moon, 1991). Case study research is well suited for a comprehensive analysis of small, criteria based sample (Anderson, 1990; Hamel, 1992; Miles & Huberman, 1994; Moon, 1991). It offers the researcher flexibility to focus on generalizations, rather than testing specific hypothesis or confirming statistical evidence (Firestone, 1993; Lincoln & Guba, 1990; Yin, 1989).

Researchers can examine multiple cases and explore commonalities or differences in themes while learning more and generating hypothesis about a specific case. Case study methodology includes both formal and informal case studies. For the purposes of this research study, an informal case research approach was appropriate. Informal case study research is often used in studies with a small sample size, providing the researcher greater contact with each participant and increasing the likelihood of discovering unique and relative information (Sprenkle & Moon, 1996).

Researcher as Instrument

In a grounded research study, the researcher is the primary instrument, both collecting and analyzing relevant data. Grounded theory provided a methodological means to analyze verbal representations while providing theoretical value to the exploration of subjective phenomena.

Social constructionism and narrative theories support a non-judgmental and co-created position. Through personal semi-structured interviews the researcher will collaborate with participants and co-created implications, descriptions, and focus individual stories. Listening to the stories of post-stroke couples allows the researcher to glean information that may increase understanding and normalize other post-stroke couple's experiences and generate ideas for effective interventions and treatment strategies.

Interview Questions and Objectives

One purpose of conducting a qualitative research study is to examine a phenomenon that is considered unique or novel, allowing the researcher to distinguish significant factors and generate hypothesis for future theoretical development. In this research study, the post-stroke adaptation process of middle-aged long-term marriage couples was explored. More specifically, couples in which one partner suffered a stroke within the past 7 year period. Additionally, specific ecosystemic factors were examined to determine if there was a connection between these factors and the couple's ability to successfully adapt following the stroke event.

According to Marshall and Rossman (1995), formulating relative research questions while remaining open to new concepts is a challenge. In grounded theory,

research questions begin broadly, allowing for general responses and providing the researcher with the “bigger picture” (Fetterman, 1989). An explorative approach was utilized to obtain each participant’s subjective post-stroke experiences for the purpose of understanding their unique experiences and to generate a hypothesis for future research (Marshall & Rossman, 1995). Interview questions remained flexible throughout participant interviews and became more specific and concentrated as unique concepts began to emerge (Taylor & Bogdan, 1984). The specific research questions were guided by theoretical frameworks and existing literature regarding adaptation in long-term married couples faced with an unexpected medical crisis (described in Chapter Two). The purpose of the interview questions was to guide participants to tell their story. Figure 1.3 is an illustrative representation of the research questions that guided this study and the corresponding interview questions. In addition to the use of a semi-structured interview generated directed guided by specific research questions a narrative method was used. This method was loosely guided by a set of interview questions that were used to elicit couple’s stories about their own post-stroke experiences and perceptions. In order to construe meaning of the couple’s experience, an interpretive mode of inquiry was utilized.

Procedure

Sample

In qualitative research, the goal is not to select a large or random sample, rather one that will provide data that is both rich and comprehensive (Fetterman, 1989). Sample selection is dictated by explicit criteria and directed by the research questions and the researchers suppositions (Goetz & LeCompte, 1984). Although specific sample sizes are

not mandated, a sample must be sufficient to reach data saturation (Marshall & Rossman, 1995).

Due to detailed and in-depth data expected from each participant, a small and purposeful sample met this criterion (Newfield, et. al., 1996). The participating sample included 8 post-stroke couples, of which 50% were female stroke survivors and 50% were male stroke survivors. Additional inclusion criterion was as follows:

- a. Participants are 50 and older (middle-age)
- b. Participants have been married for no less than 10 years.
- c. Participants have no children living at home.
- d. The stroke survivor was married to the same spouse at the time the stroke occurred and at the time this study is conducted.
- e. Survivor suffered a stroke with in the past 7 years.
- f. The survivor experienced only one stroke.
- g. Each couple reported successful adaptation following the stroke event.

Sample Acquisition and Recruitment

Participants were recruited from a stroke support group sponsored by a medical rehabilitation hospital in a large mid-west city. This rehabilitation facility has a large contingency of stroke survivors and a long running support group designed for stroke survivors, his or her spouse or significant other. The purpose of the support group is to provide support to post-stroke couples and facilitate adjustment and adaptation following a stroke.

The stroke group coordinator was initially contacted as a means of informing members about the study and to invite participation. Permission was granted by the coordinator and a description of the study and participation criterion was posted in a

monthly newsletter generated by the rehabilitation facility. If a couple was interested in participating and met the inclusion criteria, they were asked to provide their names and contact information which was then forwarded to the researcher by the group coordinator.

Data Collection

Interview Process

In qualitative research, personal interviews are considered an effective means for collecting in-depth subjective information (Kerlinger, 1986). Conducting a personal interview allowed the researcher to clarify participant's response and further probe for rich and comprehensive data. Prior to scheduling personal interviews, participants were contacted by telephone to verify participation eligibility and confirm their interest in the research study.

Before each interview commenced, participants were asked to read and sign a consent form that provided a written comprehensive description of the research objectives and interview process. Participants were also asked for permission to record the interview via a tape recorder provided by the researcher. Additionally, they were encouraged to ask questions or express concerns in an effort to avoid any negative psychological consequences in terms of participation (Boss, Dahl, & Kaplan, 1996).

Participants were informed that the objective of an in-depth interview was to collect descriptive data regarding individual perceptions, experiences, and meaning ascribed to the stroke event, examine the systemic influences that informed their narratives regarding their successful post-stroke adaptation, and to consider the meaning they ascribed to the stroke impact on their couple relationship. Additionally, obtaining a detailed history of each partner's post-stroke feelings, experiences, attitudes, and perceptions provided an opportunity for the researcher to personally understand each participant's experience. Interviewing each

partner separately was expected to increase the likelihood of freedom of expression and allow the researchers to detect individual disparities and similarities.

In an effort to address the research questions, the interview focused on meanings ascribed to the stroke, sequence of events, relationships, and feelings. The average length each interview was 2.5 hours and was essentially divided into three parts. Participants were interviewed in their homes at a pre-arranged date and time. Initially, couples were interviewed together while preliminary demographic data was collected. The stroke survivor and his or her spouse were then interviewed separately and encouraged to explore their personal perceptions and meaning regarding ecosystemic influences, social support, marital influences, individual attributes, and the impact of the stroke on their marital relationship.

An interview guide was utilized to aid the researcher (Miles & Huberman, 1994) and to insure general consistency and structure throughout interviews, while allowing the informants to tell their stories from a personal perspective. Semi-structured interviews allowed for unanticipated changes in direction, flexibility, and adjustment of interview questions as necessitated by the individual participant. Stories developed as the researcher asked specific questions, placed the individual and story in context, and insured anonymity of the informant's story.

The first portion of the interview included specific interview questions related to environmental factors that they felt contributed to their successful adaptation process. Each participant was also asked to describe their couple relationships prior to the stroke event, during the acute phase following the stroke, and at the present time. They were asked to consider any personal characteristics that contributed to their individual ability to adapt and what role their marital relationship played in their successful adaptation.

They were also asked to describe the type of social support they found to be helpful or unhelpful. Finally, participants were asked to consider the impact of the stroke event on their current couple relationship. This portion of the interview relied heavily on each partner's construction of his or her personal narratives with the researcher guiding the progression of the interview.

An open-ended interview was conducted with each couple both conjointly and individually. Minimal prompts and open-ended questions were employed as needed. The researcher also documented and kept field notes to recall specific and noteworthy details of each interview and to document non-verbal behavior that might have been overlooked while listening to each recorded interviews. At the conclusion of the interview, a summary sheet was completed to note specific and emerging themes or patterns among participants. The summary sheet provided information useful in the construction of initial premises to be explored in subsequent interviews.

In an effort to triangulate data, thus increasing reliability, (Newfield, et al., 1996), participants were asked to create ecomaps illustrating their primary environmental systems. The researcher explained the process and purpose of completing the ecomap and provided a general overview using open ended semi-structured questions and prompts as necessary to insure the inclusion of relevant systems. These systems included nuclear and extended family networks, friendships, social support, religion, and work. The majority of the participants completed this exercise with little prompting. The researcher drew the circles and directional arrows representing relevant systems as described by each participant. Each informant was asked to describe and explore the specific influences in each system that either facilitated or hindered successful their post-stroke adaptation

process. Primary environmental systems that emerged within participants' shared experiences were used to categorize data into codes and from participant's shared experiences within each system themes were developed.

Data Analysis

The purpose of this study was to identify ecosystemic and social influences that contributed to successful post-stroke adaptation in middle-aged long-term marriages. In a qualitative research study, data analysis is a continuous process that begins with the initial participant contact and continues through the entire data collection and coding process (Miles & Huberman, 1994). The data from the tape-recorded interviews was transcribed verbatim and analyzed through grounded theory methodology (Glaser & Strauss, 1967; Miles & Huberman, 1994; Strauss & Corbin, 1990.)

To become familiar with the data, the researcher reviewed participant interview transcripts, eocmaps, and field notes repeatedly over the course of several weeks (Miles & Huberman, 1994). After completing participant interviews and through constant comparison of the interview transcriptions, the researcher determined that the data had become saturated and the data collection process was complete at that point.

One of the primary benefits of recording participant interviews was that it allowed the researcher to listen as many times as necessary to capture the themes, patterns, and meanings of each participant's story. This method of data collection insured accurate representation of the participant's motives, beliefs, attitudes, and knowledge source of the post- stroke phenomena (Cicourel, 1987). In grounded theory research, a constant comparative approach is used to identify concepts and categorize data to provide a structured framework for organizing data. This method of analysis is systematic but

allows for both flexibility and adjustment. Throughout the coding process, descriptive and pattern coding were employed by the researcher (Miles & Huberman, 1994.)

Coding Process

In qualitative research, coding provides a means to organize and integrate data while simultaneously interpreting meanings. Miles and Huberman (1994), described codes as the identification and compartmentalization of conceptual and descriptive data assimilated throughout a research study. Data coding insures accuracy and efficiency throughout the data collection process and expedites data analysis. The coding process began with broad concepts and patterns conceptualized by the researcher throughout the interview process. Miles and Huberman (1994) suggest that looking for themes across multiple cases clarifies and defines emerging patterns.

Constant comparative methods (Marshall & Rossman, 1995) in addition to domain analysis and componential analysis (Fetterman, 1989) during the entire data collection process resulted in the emergence of specific categories and themes. Following each interview, data was reviewed, organized, and integrated into existing data and eventually separated into three main classes of data, corresponding to each research question. The salient themes are displayed in Table 3.1 and in narrative form in Chapter 4.

As data was analyzed, it was separated into different classes differentiated by different colored highlight markers. Data from each class was copied to three different computer files, separated by primary data classifications. As open coding began, each file was printed and analyzed using a line-by-line descriptive approach (Strauss & Corbin, 1990). Concepts from both the ecomaps and field notes were similarly coded and

compared. The ecomaps and narratives were coded likewise and comparisons were made between the two in order to generate a comprehensive and unduplicated list of categories. Based on the literature review, predetermined categories were established and guided the research process. Other categories also emerged throughout the study (Altheide, 1987). Following categorization and coding, relevant data was printed under a corresponding heading in a computer file. These filed categories were used for the next stage of coding which identified patterns that emerged under each code. These patterns eventually revealed relevant themes that emerged from the data. Cross-case patterns were identified and assembled as informal data displays for the purpose of keeping the data organized. The themes were then added to the computer files under the appropriate corresponding codes. The final coding frame was assembled as a chart to assist with the narrative discussion of the result and to allow for a comprehensive presentation of the data. Table 3.1 represents the final coding frame and emergent themes from each code.

Table 3.1
Final Coding Frame

Class	Code	Theme
Ecosystemic Influence on Post-Stroke Adaptation	Perception of Medical Experience	Ability to Ask Questions and Receive Information Involvement in Medical Care Positive Experience in Medical Rehabilitation Failure to Receive Tissue Plasminogen Activator (tPA) Eroding Autonomy
	Aspects of Social Support	Family Involvement Congregational Support
Sense of Coherence	Psychological and Emotional Influence	Ability to Overcome Depression Related to Post-stroke Disability Tenacity/Perseverance
	Philosophical	Spiritual Belief
Social Constructionism	Successful Post-Stroke Adaptation	Individual Perception of Stroke Experience on their Couple Relationship

Trustworthiness

As with any research study, establishing trusting relationships with participants through honesty and respect is essential. Due to the anticipated small sample size, confidentiality was a significant issue. Use of pseudonyms and altering demographic information in addition to advising informants that they may withdraw at any time during this study, may have provided informants the incentive and privacy needed to participate.

It was imperative that individuals participating in research studies are protected from undue risk or exposure to harm. In accordance with university policy, appropriate documentation was submitted to the University Committee on Research Involving Human Subjects (UCRIHS) and standards such as strict confidentiality were upheld throughout the data collection and analysis (see Appendix D).

Validity and Generalizability

The validity of a qualitative research is contingent upon the thoroughness and expertise of the researcher. Collecting data from multiple sources to understand a specific phenomenon increases the likelihood of accumulating corresponding and accurate data (Patton, 1990). The validity of qualitative research is also increased and strengthened by triangulation (Miles & Huberman, 1994). Triangulation is a process that is used to further support research validity by consulting multiple sources or repeating interviews with one source (Fetterman, 1989). This occurred through observation, reading the interview transcripts multiple times to insure descriptions and perceptions are accurately captured, personally transcribing the interview, multiple coding, directly quoting informants, and use of eco-maps (Alldred, 1998). Becoming very familiar with the data is a type of “soaking” or data saturation, which also increases research validity.

Furthermore, the validity of reported finding in qualitative research is improved to the extent that the findings are not influenced or distorted by researcher interpretation (Hare-Mustin, 1994).

Researcher's Role and Ethical Considerations

A qualitative researcher becomes the primary research instrument when he or she acknowledges that an objective or disinterested researcher is non-existent (Boss, et al., 1996). Grounded theory research methods are both interpersonal and personal as in-depth exploration is required when examining a specific phenomenon as well as the need to explore the fundamental components within the participant's natural environment. Due to the subjective nature of story telling, it is suggested that the researcher assure participants that the data collected will be kept confidential and their identity will remain anonymous.

In grounded research, it is important that the researcher clearly and explicitly explain the participant's right to withdraw from the study at any time without consequence while also respecting the personal nature of the research environment, usually the participant's home, and role of the researcher as an unfamiliar entity (Gilgun, 1992; Olson & Sprenkle, 1976). It is important that researchers remain self-aware, empathic, flexible, and reflexive while reflecting on the specific content and process of the participant's story (Gale, 1996). Attention to researcher reflexivity is essential to maintaining reliability in qualitative research. Researchers inevitably interpret data through personal suppositions and predetermined assumptions. Due to a personal awareness of care-taking tendencies, it was important that during the participant interviews, the researcher did not interject either empathetically or sympathetically or ask

superfluous questions that may have lead participants away from the specific research questions.

The findings and salient themes of the participating couple's responses are detailed in Chapter Four.

Chapter 4

RESULTS AND DISCUSSION

Overview

In Chapter 4, results from this research study are integrated with existing scholarship. Research conclusions, clinical implications, and recommendations for future research are found in Chapter 5.

The primary objective of this research study was to explore the influence of ecosystemic factors, social constructionism, and sense of coherence on successful individual post-stroke adaptation and the impact on middle-age long-term marriage partners. Specifically, this study examined the factors that each participant considered to be helpful or unhelpful in his or her ecosystemic environment, the influence of individual sense of coherence in relation to post-stroke adaptation, and finally, the meaning ascribed to the stroke event on their long-term couple relationship.

Through narrative inquiry, participants were encouraged to explore and story their personal post-stroke processes and ascribe meaning to their experience. This project allowed long-term married couples to appreciate and examine their individual perceptions regarding the impact of the stroke on their couple relationship. Furthermore, a narrative approach provided participants the opportunity to make sense and story their post-stroke process within the context of their personal experiences and perceptions.

In a qualitative research study, the parameters and specific focus of data collection are pre-determined by the researcher prior to the onset of data compilation. The structure of a research design is based on the researcher's preference and research goals. For example, the degree to which participants are required to adhere to the specific

content of a research questions, is directly linked to the level of control desired by the researcher (Miles & Hubermann, 1994). Adhering to a tightly structured research design characteristically produces data that is manageable, straightforward, and more easily analyzed. However, a tight design may preclude the formation of rich and significant data related to an individual's post-stroke experience, process, and perception and in direct contrast with the primary tenet of qualitative research, which seeks obtain data that is rich, comprehensive, and reflects social contextualization (Fetterman, 1989). In comparison, a loosely structured research design is likely to produce a surfeit of data and may guide the researcher to additional insights. However, a less structured design could potentially produce an excess of superfluous information, ultimately complicating data coding and final analysis.

In an effort to maintain both balance and flexibility, a semi-structured interview was conducted and based upon the research questions and conceptual maps. A semi-structured interview approach allowed for unanticipated changes in direction and adjustment of interview questions as necessitated by the individual participant. Broad questions were initially posed; providing participants the freedom to elaborate to the extent necessary to appreciate their post-stroke experiences and create personal meaning. The interview relied heavily on the each partner's construction of their individual narratives with the researcher guiding the interview progression as needed with minimal prompts and open-ended questions. As the interview progressed, more specific and directive prompts were used to insure that specific areas of inquiry were addressed. Additionally, depending on the nature and extent of the survivor's cognitive impairment, additional clarification and interview direction was offered.

Within this chapter, basic demographic data regarding the research participants will be described and salient themes from each interview will be presented. As indicated in Chapter 3, interview questions were formulated in direct relation to the research questions set forth in Chapter 1.

Demographic Data

This chapter will provide a basic demographic depiction of the research participants and set forth the salient themes of each interview. The research sample was solicited and recruited from an established post-stroke support group located in a large mid-west metropolitan area. Participants that were interested and fulfilled the inclusion criteria were asked to provide their name and contact information to the group coordinator with the agreement that this information would be forwarded via e-mail, directly to the researcher. Due to the nature and sensitivity of this topic, the research was designed to recruit and select sample participants from a renowned rehabilitation program for treatment of stroke survivors. Consequently, anonymity and confidentiality was a relevant concern. In deference to participant's confidentiality, specific names have been replaced with pseudonyms and other identifying demographic information altered or left out.

The selected sample was comprised of eight married couples; four (50%) couples consisted of male stroke survivors and four (50%) female stroke survivors, together with their spouses. One member of each couple had experienced a major stroke event within the past seven years (1998 – 2005). The initial inclusion criteria required a post-stroke period less than five years. However, this specific criterion was modified to attain gender equality; the post-stroke period was increased to 7 years. Participants were Caucasian with the majority middle to upper socioeconomic status. The participants ranged in age from 50 to 70, ($M = 61$). The male stroke survivor ranged in age from 50 – 66, ($M = 62$), and female stroke survivors ranged from 58 – 65, ($M = 62$). The post-stroke period was ($M = 4.6$) years.

The majority of stroke survivors were at home at the time the stroke occurred and immediately pursued emergency medical care. All stroke survivors were hospitalized for a period of time in varying lengths based upon the severity of the stroke. The average inpatient hospitalization period was approximately two weeks. Subsequent to being discharged from an acute care facility, each stroke survivor was admitted a rehabilitation hospital re-known for post-stroke psychosocial care. Furthermore, each stroke survivor's spouse was directly involved and played an integral role in both the medical and rehabilitation system.

For the purpose of coding, a semi-structured interview, guided by specific research questions, was conducted with each participant. In addition to the recorded interview, ecomaps were created to depict the primary systems in which participants were embedded including extended family, social, religious, occupational, and recreational networks. Each interview was transcribed verbatim and analyzed conjointly with individual ecomaps for the purpose of strengthening the research process through triangulation (Miles & Huberman, 1994).

Each class of data is presented sequentially in terms of the principal themes that developed, followed by a brief description. A pictorial synthesis has also been included in Table 1, Chapter 3. The codes and themes identified within each major data classification are listed in Table (1). Direct quotes are included to exemplify the relevancy of participants' responses that contributed to the development of each data classification. Due to the relatively small sample size and homogeneity of the recruitment source, confidentiality was a cogent concern. Responses that could be linked to specific participants were collapsed with similar responses, conveying the main theme while

maintaining anonymity. Furthermore, to preserve the confidentiality of participants stories, all references to specific genders will appear as a bi-gender reference, for example, “he” is referenced as “he/she” and “her” as “her/him.”

Through recurrent analysis, three major data classes emerged. The initial data class was defined as, the Ecosystemic Influence on Post-Stroke Adaptation. Within this primary data class, the three prominent codes were identified. The specific codes are as follows: Perception of Medical Experience, Aspects of Social Support, and Influence of Marital Relationship in regard to post-stroke adaptation. Data analysis will focus on individual and couple interactions in relation to these codes.

Influence of Ecosystemic Factors in Post-Stroke Adaptation

Human and family ecology served as the underlying background and guiding framework for this research study and provided an effective method in which to explore external ecosystemic influences on successful post-stroke adaptation. Bronfenbrenner's theory of human development suggests that individuals operate, reciprocally, within several distinct, yet interconnected, environments making it impossible to separate any part from the whole. It was these interactions that influenced post-stroke adaptation and the perceived impact on specific couple relationships.

The first research question asked: *How do aspects of the ecosystem influence adaptation for each partner?* This interview question provided a means to explore and identify influential ecosystemic factors within various environments. The specific ecosystemic influences were the primary interest within this class. The primary environmental systems identified were used to categorize data into specific codes and through participant's shared experiences within each system, subsequent themes were developed.

Code: Perception of Medical Experience

Empirical evidence demonstrates that providing medical information to patients, significantly increases patients understanding, perception of control, and future prognostic expectations (Brody, Miller, Lerman, Smith, & Caputo, 1989). A patients' perception of medical care and quality of life has been consistently linked to physicians' ability to offer and provide relative medical information. The following themes were identified as influential ecosystemic factors that facilitated or impeded individual post-stroke adaptation.

Themes:

- 1) Ability to Ask Questions and Receive Answers
- 2) Involvement in Medical Care
- 3) Positive Experience in Medical Rehabilitation

Theme: Ability to Ask Questions and Receive Answers:

Due to the ambiguous and unpredictable post-stroke prognosis, all participants reported extremely high levels of stress, fear, and sadness, particularly during the period immediately following the stroke. The diagnosis or occurrence of a serious or life threatening illness is considered to be a significant and feared threat to any family system (Holmes & Rahe, 1967). The lack of concrete information in addition to the indeterminate outcome was a major source of stress for a number of participants and other family members.

The ability to ask questions and receive information from attending medical staff emerged as a common theme that contributed to each participant's perception of their medical experience. One spouse stated, "I always asked lots of questions and read a lot. The doctors were respectful to me and I felt like I was included in the care program the majority of the time." Another stated, "I had so much more confidence in him/her medical care after having a lengthy conversation with the neurologist. I felt like he was really listening and took my concerns seriously. That made me feel so much better and so much less anxious."

Several participants' referenced conversations with their treating physicians, immediately following the stroke, and recalled that when the doctor took time to talk directly to them, rather than simply "checking vitals", their anxiety levels reportedly

decreased. Rather than the conventional “diagnose and refer”, a common managed care approach, taking time to meet with family members and answer questions provided an opportunity for medical personnel to discover familial resources and other information and may help them to normalize what the family is experiencing. Several participants recounted that although the emotional and mental stress was “enormous” he/she felt more encouraged and optimistic after the doctor spent time with the survivor’s family answering questions and listening to concerns “I asked the doctor a million questions as soon as he came in the door. He explained things, and even if he came in really early in the morning he always woke me up and would tell me what was going to happen today.” Other participants expressed appreciation for the nursing staff as the nurses kept them “updated” on the medical care of the survivor particularly when diagnostic testing was ordered. “I felt like I could ask the nurses questions and could usually get a straightforward answer depending on the nurse.” Another stated, “I think I trusted the nursing staff as much as the doctor.” Regular updates on the survivor’s medical status from the medical staff were mentioned several times as a stress reducer and increased overall confidence in the care provided. “I felt so much better about being able to leave the hospital for short periods of time knowing the nurses had my cell phone number and would call if anything happened.”

On the other hand, several spouses and survivors had different experiences regarding communication with the medical staff. “It was horrible. They do not know what to do for a stroke,” another stated, “They are just horrid and basically all they do is run some tests until you come out of there.” One spousal caregiver that expressed discontent during the initial hospitalization period explained that due to the

overwhelming experience, he/she did not know “where to begin” asking the medical staffing for information, and felt that his/her presence was not “considered” by the treating doctors. Other unhelpful factors identified by participants, specifically within the hospital environment, included, the manner in which the medical staff spoke in front of the stroke survivor who later reported that they were able to hear conversation but were unable to reciprocate. For example, one spouse stated, “I was very angry when the doctors would say to me that there was nothing that they were going to be able to do anymore” a survivor also reported a similar experience explaining that he/she had so many questions “but the doctor would not even take the time to try and talk to me.”

The manner in which the medical staff addressed participants was also identified as an influential variable. Participants agreed that they felt more comfortable and perceived the doctor as more “trustworthy” when the information and discussion was conveyed to them as a couple. Participants could recall specific occasions when the doctor or other medical staff would maintain eye contact and speak directly to the survivor’s spouse. When this occurred, survivor’s reported they felt left out and frightened. During the initial hospitalization period, the majority of participating stroke survivor’s experienced post-stroke paralysis to varying degrees and were unable to speak. Aphasia refers to speech and language impairment, which is a frequent post-stroke characteristic, making communication difficult or impossible. Stroke survivors are often left with aphasia, however, cognitive skills, receptive language ability, reasoning capabilities, and other intellectual functions remain intact.

Communication impairment as a post-stroke consequence can have devastating effects on the stroke survivor and his or her spouse. Rollin (1987) concluded that

dysphasic survivors reported diminished self-concept, increased loneliness, and feelings of isolation. During the initial hospitalization period, it is not uncommon for survivors to be heavily medicated. Regardless of the survivor's condition, couples agreed that they felt more comfortable and preferred the doctor treated them as a couple rather than speaking directly to the spouse. A spouse recalled that even though, the specific details immediately following the stroke were difficult to recall, one specific conversation "out of a million" remained indelible. When the treating physician was present, he would often hold the survivor's hand while speaking to them as a couple, making eye contact with both of them. He/she explained:

"...like we were both included and important which was so valuable. I always felt much better when the doctor spoke to both of us. It made me feel like I was not the only person making the decisions carrying all of the pressure during those times."

Depending on the level of aphasia, communication can be frustrating for both the stroke survivor and his or her family members. Aphasia is a language and speaking impairment common to stroke survivors typically more pronounced in left hemispheric strokes. While cognitive abilities remain intact but aphasia creates significant language processing problems where the survivor is unable to verbalize the desired words or is unable to process the words coming in.

Theme: Involvement in Medical Care

During the in-patient period, decision-making is typically afforded exclusively to the treating medical staff and family responsibilities become survival and concern about future medical treatment. As the medical system becomes the governing body, the roles,

rules, and behavior specific to that family are often overlooked. The medical staff's concern and attention is centered on the survivor's care, rather than individual identities and the couple or family system. It is not uncommon for couples in long-term marriage to develop specific roles, boundaries, and values through both tacit and explicit agreements over time, which define their individual couple system. A sudden or acute illness presents a significant challenge to the previously developed relationship.

Previous research has purported the significance of family involvement in post-stroke function recovery. Kriegsman, Van Eijk, Pennis, Deeg, and Boek, (1997), assert that the availability of a spouse or partner, regardless of the quality or quantity of support, increases overall functional capacity and mobility (Baker, 1993). Conversely, lower functional outcomes have been associated with a lack of a spousal support or involvement of a close family member, following a stroke (Dombovy, Sandok, & Basford, 1986).

During the initial hospitalization period, the majority of both stroke survivors and spousal caregivers describe feeling "excluded and separated" from treatment decisions and medical care while others reported feeling "off balance" and/or "out of control". This feeling was more prevalent when spouses were not provided with regular medical updates and explanations for medical changes. As the survivor's medical condition began to stabilize, participants identified that forming a collaborative relationship and being able to contribute to his or her care was a significant factor and influenced their overall initial medical experience.

The majority of spouses expressed a strong desire to be involved in the survivor's care and described a heightened appreciation for the attending medical staff when they

were allowed to contribute. For example, one participant stated, “Being able to help take care of him or her made me feel like I was actually doing something rather than just sitting around watching everything.” Due to the longevity of their marital relationship, several participants also felt more capable of providing the personal care, as they were aware of the survivor’s personal preferences. For example, one participant appreciated being involved, she stated, “The nursing staff doesn’t even know him/her. They would ask me what he liked and did not like and I could tell them. I don’t know if he/she knew what was going on, but I felt better.”

Several participants directly participated in the survivor’s personal care, tending to activities such as bathing, grooming, and dressing. Among the participants that assisted with care, several reported feelings of empowerment and some sense of control in a situation that felt “totally” out of control. One spouse stated, “I was an advocate and made sure that the nurses knew exactly what the medications were for and made sure that we counted all of the pills and the nurses did not appear to mind my presence or involvement.” One survivor reported, “When the medical staff allowed our family to assist the nursing staff, in particular with in personal care (e.g., bathing, toileting, feeding), my anxiety level went down.” “I did it all. Depending on the nursing staff, I wanted to help, some of them really appreciated that I was there.” In regard to the uncertain post-stroke prognosis, one participant stated, “I wanted to know what I was going to have to do and I wanted them to tell me and show how to take care of him or her when we went home.” Providing direct care appeared to be an opportunity for spouses to maintain a sense of intimacy. One participant stated, “I felt that being involved in his/her daily care was a key for him/her feeling less scared.” Several spouses reported that it was

due to their long-term relationship with the survivor, they were able to convey his/her likes and dislikes to the medical staff.

Theme: Positive Medical Rehabilitation Experience

The continuum of stroke care typically includes transition from an acute medical facility to a specialized stroke rehabilitation program. According to stroke experts, immediate rehabilitation with a specific emphasis on mobilization provides the best opportunity for survivors to regain functional capacity (Evans, Bishop, Matlock, Stranahan, Smith, & Halar, 1987). Early rehabilitation prevents secondary problems as joint stiffness, decubitus ulcers, and pneumonia due to being in a supine position for a long period of time. Several stroke survivors began rehabilitation while in the hospital. When deemed “medically stable”, the stroke survivor was discharged from an acute medical setting and admitted to an inpatient rehabilitation program. Admission to this rehabilitation program required a full commitment and active involvement from both the stroke survivor and his or her spouse. In addition, all stroke survivors were expected to return home at the end of the program. Each stroke survivor indicated that his or her goal was to be as functionally independent and productive as possible.

According to rehabilitation experts, the majority of a stroke survivor’s functional gains are attributed to spontaneous recovery within the first 30 days (Sandin, Cifu, & Noll, 1997). Subsequent functional gains and overall rehabilitation success depends on several factors including when the stroke survivor begins a stroke specific rehabilitation program, the extent of the brain injury, the survivor's attitude and motivation, the rehabilitation team's skill, and personal support from family and friends (Smith & Clark, 1995). Due to the varying and complex rehabilitation needs of each survivor, progress

and recovery differed. Participating stroke survivors with the least disability benefited the most. However, even seemingly minor progress in those with more severe disabilities, made the difference between returning home and being institutionalized (Evans, et al., 1987).

Upon admission to the rehabilitation program, each couple and other family members collaborated with the designated stroke rehabilitation team, and together developed an individualized treatment plan to reach identified goals. The family and medical collaboration continued throughout the rehabilitation process. The rehabilitation program operated on a team approach including the stroke survivor, his/her spouse, partnered with a comprehensive team of physical therapists, occupational therapists, speech-language pathologists, rehab psychologists (behavioral medicine), nursing staff, case managers, recreation therapists, and physiatrists. Participants described it as an active and learning experience in which they both participated in goal setting, therapy, and education. According to several spouses, previous physical skills and abilities were lost new skills were needed.

Initially, each stroke survivor underwent series of diagnostic tests to determine their individual level of functioning. The rehabilitation program included strengthening and conditioning exercise, training in self-care and daily living skills, ambulation and mobility, retraining in speech, language, and swallowing, monitoring medications, and cognitive perceptual training. Participants were involved regularly in three main types of therapy; 1) physical therapy, intended to restore physical functioning (e.g., walking, range of motion), 2) occupational therapy, assists survivors to relearn skills necessary for everyday living (e.g., dressing, activities of daily living), and 3) speech language

pathology, teaches alternative ways to recall lost memory and effective communication techniques.

According to one survivor, “Right away when you begin rehab. You’re into occupational therapy and physical therapy, every therapy that there is, and you are tired but when you are in therapy you don’t have time to think about what has been lost only what you might get back.” Another survivor stated, “Therapy was helpful. I couldn’t walk when I first started therapy and now I can walk and I can drive and I can do almost anything.” Another participant reported, “Once we got to the rehabilitation center, he/she (survivor) began to work as hard as possible to become independent and it was his/her work ethic that made him keep on trying to do better.” Although, in this case, a full recovery was not expected, he/she was encouraged by other patient’s progress also in the rehabilitation program. “I knew that he/she wasn’t going to be the person that I always knew but I could see other people that were walking and were driving and I thought that he/she was going to get to that point and it’s a long road.”

One participant recalled, “I was amazed when they got him/her up and walking while he was still in the hospital. They continued to try to get him moving after only one week and then on to rehab. It was great there.” Another spouse stated, “My vision with him/her was that I am the caretaker and I am going to kick him/her in the butt and do everything that he/she has to do to get him/her better and on his/her own.”

A number of survivors described an overwhelming fear of becoming a burden on their family members. Several survivors recalled that while they felt very motivated on the “inside” it was extremely frustrating to when they were not able to “make my body do what I was telling it to do.” Participant’s noted that seeing even a small gain in movement

of ability was celebrated. According to one survivor, "I'll never forget one of my initial therapy sessions. I was instructed to pick up a marble and place it on a board with indentations for each marble. It is unbelievable how you can think you can do it and you can't." Furthermore, he explained, "The thing that saved me, was that every day you do it, you do it a little bit better, just a little bit better and the therapist would congratulate me. I thought, hey alright, I did it one more time." One spouse stated, "I wanted him/her to come home but with having some type of dignity in front of the family was crucial." He/she indicated that encouraging independence would help increase his/her self-esteem and likely be a motivator for future efforts towards autonomy. Another spouse indicated, "I needed him to work and if that meant that he/she was going to be crying while he/she was working, then that is what had to happen." Survivor's and his or her spouse were occasionally at odds with the rehabilitation process. For example, "He/she said I'm just not going to do this anymore, and I said, well, yes you are." Another participant asserted, "Even when he/she wanted to give up, we worked and worked and worked. He/she just wanted to give up and I fought him the whole way and assumed control and said, you are going to fight this." Several spouses remembered feeling as though they were constantly encouraging the survivor to participate. Specifically, one spouse remembered, "I pushed and pushed and pushed."

It was not uncommon for supporting spouses to report feelings of frustration and guilt while participating in the rehabilitation program. The majority of spouses felt that the rehabilitation program was the best, and for some the "only" opportunity for the survivor to regain as much independence as was possible. Several spouses reported feeling "pushy or demanding" in their efforts to motivate the survivor. One spouse

recalled, “I felt like I turned into the nasty spouse which was hard on both of us.”

Another states, “I would not let him/her rest, I was always “nicely” suggesting and encouraging him/her to do just a little bit more, try just a little bit harder.”

The primary goal of a rehabilitation program was to provide stroke survivors with the support necessary to achieve a functional level, which would allow them to return to independent living at home. A stroke survivor’s ability to reach a specific level of functional capacity is a decisive factor in whether they will be able to return home or be placed in a long-term care facility. According to the majority of stroke survivor’s their will to recover, their desire for independence, and spousal support was essential for successful rehabilitation.

A caring and able spouse or partner can be one of the most important positive factors in rehabilitation. Family members' knowledge also helps a lot. According to Black, Soltis, and Fartlett, (1999), it is important that family members understand what the stroke survivor has been through and how disabilities can affect the survivor. Prior to admission to the rehabilitation program, the survivor’s spouse was required to make a full commitment and be actively involved in the rehabilitation process. Again, the length of time spent in the inpatient rehabilitation setting depended upon nature and extent of post-stroke disability. All of the survivor’s spouse, both male and female, commended the rehabilitation program and felt fortunate to have had the opportunity and access to the therapeutic resources. The majority of the survivors considered the rehabilitation process to be a positive experience, with one survivor reporting that regardless of the opportunity, it was difficult to get and stay motivated.

During the initial hospitalization period, perceptions of medical care and treatment varied to some degree, however, both and spouses expressed overall satisfaction with the rehabilitation program and felt that they had benefited from their participation. The majority of participants stated felt more comfortable when they were admitted to the rehabilitation program and described the medical staff as being more supportive and friendly. One spouse recalled, "I never felt comfortable until we began the rehabilitation program." Several spouses indicated that the encouragement from the staff and the intensity of the program increased feelings of optimism and decreased feelings of helplessness.

Themes:

- 1) Failure to Receive Tissue Plasminogen Activator (tPA)
- 2) Eroding Autonomy

Theme: Failure to Receive Tissue Plasminogen Activator (tPA)

In 1996 the U.S. Food and Drug Administration (FDA) approved the use of Tissue Plasminogen Activator or tPA a thrombolytic genetically engineered blood clot dissolver used to prevent permanent heart damage or brain damage immediately following a heart attack or stroke. tPA has been shown to be very effective in treating ischemic strokes caused by blood clots that obstruct the flow of blood to the brain and account for approximately 80% of all strokes. tPA can dissolve blood clots and restore blood flow to the brain significantly reducing the permanent effects of a stroke, but must be administered within the first three hours after the onset of symptoms (ASA, 2002). According to the American Heart Association [AHA] (2005), the more quickly tPA or other appropriate treatment is administered, the better the chances for recovery.

Seeking immediate medical attention following the onset of stroke symptoms is critical to identify the specific type of stroke and to determine if the stroke patient is a viable candidate for tPA (AHA, 2005). While all participating stroke survivors sought and received immediate medical attention, the majority did not receive tPA. Failure to receive or be considered for tPA, was identified as a common “unhelpful” factor that significantly influenced participant’s immediate medical experience and long-term comprehensive medical perception. Several spouses stated, “I wish that he/she could have got that new drug to see if that would’ve helped him/her so he/she wouldn’t have been so severely disabled.” Another spouse indicated, “We requested tPA when we got there, and they said no they weren’t going to do that, so that was something that he/she and I both totally regret that we weren’t more aggressive.” The stroke survivor(s) that did receive tPA credit the administration of the drug to their level of recovery.

Many stroke survivors believe that the failure to receive tPA increased the lengthiness of their recovery process. One survivor stated, “I could have been mowing my lawn by now if I had gotten that medication, I can’t remember the name of that drug, but I heard that people who get that right away are better than the rest of us..

Theme: Eroding Autonomy

During the onset of hospitalization, the pervading tone of the medical staff led a number of participants to describe their medical experience as “poor” or “negative.” Several stroke survivors recalled that they had been treated with little respect and/or regard towards their personal autonomy. For me, it was not so much what hospital staff did, but how they did it. They acted like I wasn’t even in the room,” reported one

survivor while another survivor expressed a similar reaction, “....it was like I was invisible.”

Spousal caregivers also described feeling frustrated and resentful when they perceived a lack of control, “It was maddening. That was one thing that really pissed me off. I would not ever know what was going on. Medical staff would just breeze in and without saying a word, whisk him/her away.” His/her doctor would just come in and not even look at me when he was in the room.” Both stroke survivor’s and spouses reported that it was not uncommon for the medical staff to address the survivor’s spouse directly with little or no eye with the survivor. For example, one spouse recalled, “On occasion the doctor would only address me rather than him/her but I didn’t want to call attention to this or point it out when they were talking to me.”

As indicated previously, stroke survivors commonly suffer from aphasia, a speech and language impairment that prevents or impairs ones ability to communicate verbally or non-verbally. While the majority of participating stroke survivors initially experienced aphasia, their ability to comprehend and process language remained intact. One survivor described his/her feelings when the doctor would address his/her spouse rather than speaking to both of them, “I’m the one that had the stroke and I wanted to talk to the doctor and he wouldn’t even look at me, he would just talk to my husband/wife.” Another stroke survivor recalled similar feelings of frustration, “I was scared to death and felt even more scared when no one would talk to me. I felt terribly excluded.” It was not uncommon for stroke survivors to experience fear and helplessness when they were not included in conversations between the medical staff and his or her family members. For example, “I felt helpless and discounted.” According to one spouse, “When the doctor

would not look at him/her (stroke survivor), I worried it was because he/she was not going to make it.” Another spouse explained, “When he/she (stroke survivor) was right there, and they would act like he/she wasn’t in the room times I would get very angry about it.”

Several survivors felt particularly frustrated when medical staff would discuss their prognosis with others, “As if I didn’t have a damn thing to say about it.....like I wasn’t even involved.” Several other participants indicated that when receiving results from a specific diagnostic test or information regarding future the medical staff rarely made an effort to include them in the conversation directly or indirectly. As such, participants described medical staff as “less trustworthy” than when they felt included in care decisions. One couple specifically recalled a situation when the treating physician spoke directly to the survivor’s spouse, in the presence of the survivor, the spouse indicated that the stroke survivor’s would not likely survive due to post-stroke complications. He/she spouse described feeling, “It was surreal, here I was listening to this doctor telling me my husband/wife would probably not make it and he/she was lying right there. I knew he/she could figure out what the doctor was saying. It was indescribable. The stroke survivor also vividly remembered the conversation and described the experience as “maddening.”

A majority of participants believed that the level of post-stroke aphasia was directly related to whether the survivor was included in discussions between family members and medical personnel. A number of participants also noted that in the presence of other family members, the medical staff was more likely to address them, excluding the actual stroke survivors, particularly in cases where severe post-stroke aphasia had

occurred. At the time of the participant interviews, both the stroke survivor and his or her spouse pointed out that even when aphasia had occurred, the survivor was aware and understood the majority of discussions between medical staff and family members.

This partial relationship between the treating physician and stroke survivor was associated not only with increased anxiety, reported by the survivor and his or her spouse, but also with depression during the initial hospitalization period. One survivor expressed a concern common to the majority of survivors, “When the doctor spoke with my husband/wife, I never felt so alone and scared. I felt trapped inside of myself.” Several more survivors indicated that the inability to communicate with the treating doctor was very frustrating and they felt that the doctor should have included them in all discussions. It was not uncommon for spousal caregivers express feelings of anxiety and frustration when the medical staff focused solely on them rather than on their husband or wife, who were the actual patient. Feeling frustrated with the medical staff because of this was a common sentiment expressed among spouses ... “I didn’t like it when they treated him/her like they did not even know what was going on. I knew that he/she could hear them talking. I wish I could have said something at the time.”

Several participants believed that the survivors were excluded from conversations with treating medical staff due to the general discomfort of addressing a patient who does not exhibit any outward signs of comprehension. One spouse acknowledged, “The initial treating doctor would completely ignore him/her (stroke survivor) and only speak to me.” In another case, the stroke survivor was in fact included in several conversations with his/her treating physician, however, it was the way” in which he/she was included that caused him/her to experience frustration. “Sometimes my doctor would actually look me

in the eyes when he was in the room, but the damn doctor would then speak in a very loud, slow voice, “I had a stroke it doesn’t make me retarded!”

Code: Social Support

Research has increasingly recognized social support as a significant post-stroke determinant (Berkman & Syme, 1976). Numerous research studies have established a direct connection between social support and level of recovered functional outcome following a stroke (Evans & Northwood, 1983; Friedland & McColl, 1987; Stephens, Kinney, Norris, & Ritchie, 1987). Sources of social support include marital relationships, family members, friends, and community support, and are invaluable to post-stroke recovery. Clark and Smith (1999) found that stroke survivors from higher functioning supportive families not only function at a higher level, requiring less caregiver assistance, but also are more likely to become re-involved in social activities. The degree of social participation and integration varied among individual stroke survivors and was significantly influenced by specific post-stroke outcome and functional abilities.

Several research studies have demonstrated that stroke survivor’s who report higher levels of social support and social interactions experience lower level of depressions (Elliot, et al., 1992). Furthermore, emotional and informational support from close friends or peers has been associated with decreased caregiver stress, increased self-confidence, and higher levels of personal perception reported by stroke survivors (Stewart, Dodle, Hart, Langille, & MacPherson, 1998). Researchers purport that nature and severity of the stroke event is actually less significant in post-stroke recovery than the presence of social support perceived to be “emotionally supportive” and “empathetic”

(Glass & Maddox, 1992) and is linked to increased levels of post-stroke recovery (Evans & Northwood, 1983) implying the importance of subjective perception.

A sudden and unexpected medical crisis or disability not only disrupts social, emotional, and personal relationships for the survivor, but his or her spouse, and/or other family members are often similarly affected. It was not uncommon for contact with friends and extended family to decrease for both the stroke survivor and spousal caretakers following the stroke event due to medical limitations, physical disability, and self-consciousness about these changes. Post-stroke physical and emotional changes initially led to decreased self-esteem and increased self-consciousness in several stroke survivors. The majority of stroke survivors believed that the reduction in social interaction was predominantly related to their fear of rejection from close friends and former associates while spousal care takers related their reduction in social involvement to physical and emotional exhaustion.

One stroke survivor reflected, “The neighbors were supportive. Some were and some weren’t. You know, it’s funnybut some neighbors withdrew from me it seems like. I think they withdrew because they didn’t understand. I don’t blame them. I don’t quite understand the stroke either.”

Theme: Family Involvement

Although the degree and type of social support varied among participants, it was a common theme throughout each individual story. Participant’s reported that in addition to both immediate and extended family support, social support had a significant post-stroke impact. One participant stated, “That is just what we do when someone needs

something.” Another stated, “It was not a question of “if” people would “pitch in”, it was when and how much do we need.

Empirical research of stroke survivors has established a direct connection between social support and post-stroke functional abilities (Evans & Northwood, 1983; Friedland & McColl, 1987; Stephens, et al., 1987). Support from close relationships including, family members, close friends, and the community were considered “invaluable” to both stroke survivors and spousal caregivers in post-stroke recovery. From a family systems perspective, when a medical crisis occurs within the nuclear family, it is anticipated that the family will be reciprocally influenced by the extended family system of which they are members (Becvar & Becvar, 2003). All participants reported some level of family support. Support included assistance with the survivors’ daily needs, house cleaning, and cooking. As previously indicated, the majority of strokes occurred within the stroke survivor’s home. Consequently, immediate post-stroke support was provided by the survivor’s nuclear family. However, shortly thereafter, participant’s reported that social support, other than nuclear or extended family, was a constant presence. One participant stated, “That is just what we do when someone needs something.”

Past research suggests that the stroke survivor and his or her family is vulnerable to psychosocial problems following a stroke and continued familial support was important subsequent to acute medical care and discharge from a rehabilitation program.. As previously indicated, the majority of strokes occurred within the stroke survivor’s home. Immediate post-stroke support was typically provided by the survivor’s nuclear family and extended family. Many participants reported that their children were present

immediately following the stroke, and several spouses identified their family support as “as a blessing” due to the overwhelming nature of a stroke experience. One spouse recalled, “Everybody was just unbelievably supportive, our kids would stay at the hospital allowing me to worry less about what was going on at the hospital and do what I needed to do at home.”

Each spouse spent a significant time with the survivor during the initial hospitalization period, several spending the night. Spouses reported that social support during his time period was critical. Family members would “take turns” staying at the hospital, providing an opportunity for spousal caregivers to leave the hospital setting to go home and attend to personal and family matters. Each participant described social support that was helpful and contributed to varying degrees to individual post-stroke adaptation. Participant’s family involvement ranged from bringing food to relieving tension and the monotony of the hospital environment. One spouse fondly recalled, “My kids would bring me food, they would bring fun stuff up there like Chinese. I didn’t even want to leave the room to go eat because that was usually the times that there were shift changes.” Another spouse stated, “I was used to seeing my sisters but didn’t want to leave him/her at the hospital. Instead they came to me. It made me feel less disconnected.” Family support described by participants varied depending on the specific needs of each individual. “Our family spent some time just encouraging and supporting us and helping me straighten out around the house.” Several spouses indicated that they “could not have done it” without assistance from family members. Social support continued for the majority of participants following their discharge from the rehabilitation program.

Other research demonstrated that empathy, as an element of emotional support, was linked to the level of post-stroke recovery. Furthermore, other research found that overall progress following a stroke was greater for stroke survivors that reported higher level of emotional support attained regardless of the nature and severity of the stroke (Glass & Maddox, 1992). Clark and Smith (1999) found stroke survivors from higher functioning families function at a higher level, requiring less caregiver assistance, and are more likely to become re-involved in social activities. Satisfaction with social relationships has been directly linked to stroke survivor's general health status. Conversely, stroke dissatisfaction with social relationships is reportedly foretelling of poor health suggesting the importance of the recipients subjective impression.

A direct link between stroke survivors perceived satisfaction with social relationships and overall health status has been established. Social support has also been shown to be an effective and significant factor for family caregivers. Mant, Carter, Wade, and Winner, (2000) demonstrated that families who received stroke support from an organized and affiliated Stroke Association, described an increase in both social activity and self reported health. The degree of social participation and integration varied among individual stroke survivors and was significantly influenced by their specific post-stroke functional abilities. Several participants that described higher level of social support described increased social involvement and interaction

Previous research studies found that stroke survivor's who report higher levels of support and social interactions experienced lower level of depressions (Elliott, Herrick, Witty, Godshall, & Spruell, 1992). Several participants described close friends as a source of constant and continuing helpful support. One survivor recalled initially feeling

very supported and less depressed as a result. She noted the importance of “Two long friends that were always there for me.” Several spouses indicated they became more aware of the importance of being supportive to others in times of “crisis” and suggested they would be supportive under similar circumstances.

Theme: Congregational Support

Another type of social support considered to have a significant influence on individual participants was support provided by individual religious congregations. Several participants identified congregational support as a reciprocal and influential ecosystemic factor that facilitated their individual successful post-stroke adaptation process. Support ranged from providing transportation, meal preparation, and home care. Several participants, both stroke survivors and spousal caregivers indicated that simply knowing that the entire congregation was praying for them provided a significant source of comfort, “Knowing that that the entire congregation was praying and very emotionally supportive and compassionate.” Another spousal caregiver reported that the congregational members from her church also visited stroke survivors during the initial hospitalization period. “They sat with us and held our hands and we all prayed together for the strength to get through this.”

Several participants reported that their pastor/minister/priest came to both the hospital and the rehabilitation center to offer support. One spouse recalled that her pastor’s presence contributed to her own personal strength in making a crucial decision, “The doctors wanted me to decide about a surgical procedure that could have killed him, but they also told me it might be the only way to save his life and I remember being really overwhelmed. My pastor prayed with me about and it made me feel stronger.”

Congregational support for some, continued beyond the initial hospitalization period. For example, parishioners made home visits, offered verbal and spiritual support, prepared meals, assisted with ADL's, provided respite care, which allowed care providers the opportunity to return to work. Several spousal caregivers reported that in order to maintain health insurance, it was necessary for him/her to return to work rather than providing requisite medical care. In one case, individual members of the congregation signed up for "shifts" and were taught salient medical care by the spousal caregiver. One spousal caregiver recalled:

"The members from my church were amazing. It relieved so much stress....I never could have concentrated on my job if I had to constantly worry about whether he was getting proper care. At first it felt like a 'Catch 22'...about the insurance vs caring for him, but after I didn't have to worry about his care, it was a lot easier than I thought."

Another stroke survivor, working together with parishioners, constructed a wheel chair ramp which provided access to church for not only the survivor, but also for other physically challenged parishioners. "It was good for all of us, they got a ramp for other people in wheelchairs, and I was able to contribute to something that I was good at."

Code: Influence of Marital Relationship

Theme: Communication

Current research suggests that couples faced with an unexpected and unpredictable chronic illness, are likely to experience significant obstacles in marital communication (Rolland, 1994). Moreover, found that when confronted with the unpredictable post-stroke physical, emotional, and behavioral disabilities, couple's

reported increased tension, decreased cohesiveness and exacerbation of pre-marital problems.

The sudden onset of a stroke leaves the stroke survivor and his or her family unprepared for the devastating post-stroke implications. Depending on the nature and extent of post-stroke consequences, previously established roles, life- scripts, and personal self-image become unbalanced. Consequently, long established communication patterns, developed and shaped over time within a family system, are significantly challenged. In long-term relationships, successful adaptation is predicated on effective communication within the marital dyad system. Effective communication is a relative term and specific to each individual couple.

Researchers assert that effective marital communication correlates positively with healthier adjustment to illness and marital satisfaction (Gotcher, 1992). According to Barbato and Perse (1992), in long-term marriages, couples that are able to convey personal feelings or successfully resolve conflicts reported higher levels of marital satisfaction and thus were more likely to effectively manage conflict, requisite role and responsibility changes, and communicate emotionally salient issues (Vess, Moreland, & Schwebel, 1985). Couples that have developed effective communication patterns prior to the onset of a medical crisis are more likely to experience healthier post-stroke adjustment and marital satisfaction. For example, several spouses felt that there was little notable change in their communication patterns. "We could always talk. Now it just takes a little longer but we both still try."

Aphasia is a communicative impairment that usually occurs immediately following a stroke event and renders the stroke survivor completely incommunicative.

Although a stroke survivor may be unable to communicate, their receptive ability and reasoning capabilities often remain intact. Aphasic survivors may eventually regain some level of communication function through intense speech and language therapy; however, they rarely regain their level of pre-stroke articulation and communication skills.

The inability to communicate was described by a majority of participants as extremely “frustrating” and contributed to feelings of depression for both survivors and spousal caregivers, within in the first two years following the stroke event. Several stroke survivors described feeling frustrated and angry with their inability to communicate with their husband or wife. “It drove me crazy! I had so much to say but could not even begin to convey my thoughts. I just shut-up and refused to talk for a while.” A stroke survivor’s inability to effectively communicate can lead to the development of unhealthy interactional patterns within the marital dyad. Avoiding discussions or unconsciously creating distance within pre-existing family relationships may occur in a survivor’s effort to detach from overwhelming feelings. According to Rollin (1987), aphasic survivors demonstrate diminished self-concept, loneliness, and increased feelings of isolation. One spouse recalled that, “That aphasia, or whatever it’s called, was the worse thing. I had no idea what he/she wanted or how he/she was feeling about anything. I was so glad that part got better.” Other stroke survivors reflected, “I think that was the worst part for us. I really just wanted to shut down but I really like how we use to just sit and catch-up with each other and I did not want to lose that part of our marriage.” Manne, Taylor, Doughert, and Kemeny (1997), reported that ineffective or lack of communication, can advance mutual feelings of loneliness, anxiety, and depression. Communicative deficits are less obvious than the physical and emotional

limitations, however, pre-stroke marital balance is easily disrupted as the lack of communication or communicative impairments can easily be misinterpreted or misunderstood. Three spousal expressed similar experiences, “I would have no idea what he/she was trying to say or what he/she wanted. I would usually have to guess and that made him/her so mad because it was usually the wrong thing.”

Participants, mainly stroke survivor’s, reported that communication impairment following the stroke was a prime contributor to post-stroke depression. Stroke survivor’s and spousal caregivers reportedly experienced profound sadness, heightened levels of anxiety, loneliness, and frustration, particularly in cases where the survivor experienced post-stroke aphasia. One survivor explained that he or she still experiences frustration, regarding the inability to effectively communicate, “It changed because I am not able to express myself as well. I used to be very articulate and sometimes I am not able to express that feeling as well so I tend to get a little louder and I hate myself for that.” Another stroke survivor stated, “I interact differently. After the stroke, my kids don’t come and talk to me.”

Binder (1984) found that aphasic stroke survivors often experienced feelings of inadequacy and a sense of loss in regard to their personal and family relationships. A majority of stroke survivors explained that shortly after they had returned home following rehabilitation, they became more aware of the repressions of not being able to effectively communicate. “You just want to stay inside of yourself. There were actually people around but I felt really lonely and alone” recalled one survivor, another stated, “I thought I would be so glad to get home but when it was just the two of us, the fact that we could not even have a normal conversation made me feel crappy about myself.”

Consistent with the literature, several stroke survivors expressed frustration in response to their difficulty communicating with their families and in particular, their spouse. Several survivors spoke about communication difficulties in reference to their perceived reaction of their spouse. One survivor remarked, “He/she feels bad a lot of the time because we don’t talk anymore. It’s just too frustrating for me,” while another survivor reflected that the type of communication was more problematic, “I said bad things...I don’t know why I did it but I was mean sometimes. We communicated much better before the stroke.” Several others described feeling “helpless and frustrated” regarding the inability to communicate and in accepting this as a long-term condition. “We always talked things out as a couple, now I had no idea what he/she thought about things. I had to make all the decisions,” explained one spouse. A majority of spouses expressed similar sentiments, “After the stroke there were huge communication problems and still are especially when it is a hard day” and/or the reaction of another spouse, “In the beginning, right after the stroke, if I had a problem I would not feel comfortable bringing it up because it seemed so frustrating for both us. It just felt like too much work.”

There were differences in participant’s post-stroke emotion and feelings regarding their personal abilities. Varying post-stroke lengths of time had elapsed for each couple (1 – 7 years) as such, communication deficits were not as severe or noticeable, according to participants. The majority of participants, including both stroke survivors and spousal caregivers, explained that eventually they were able to adjust and compensate as necessary to accommodate the survivor’s communication difficulties. “I knew what he/she was trying to say even when they couldn’t get all the words out or get all the

words right,” recalled one spouse. Another spouse explained, “Due to the cognitive impairment following the stroke, communication was very difficult. After the stroke, he/she had difficulty for the first 2-3 years it very frustrating at first, but now we are able to communicate a lot better than right after the stroke.” One spouse recalled, “It was just amazing to me how he could say something and it was not necessarily the word but it was the tone and I would know what he was getting at and I thought this is what being married for such a long time does to you. It was just fantastic.” In regard to current communication issues, stroke survivors, in general, indicated that while they still felt frustrated with residual post-stroke communication problems, they were not as self-conscious as in the past, more comfortable with their limitations, and likely to initiate conversations and less likely to avoid social interactions.

Although communication patterns had changed, one spouse explained, “After the stroke, the “survivor” seemed to be more aware of my feelings and will ask me how I am feeling. He/she notices when I have a bad day and will say, are you sad?” Other spouses mentioned that although the depth and frequency of pre-stroke conversations had dramatically changed, there was still an “emotional closeness.” In a very poignant statement, one spouse indicated, “Even though I do miss having emotional discussions I have learned to deal with it. But you know what, I think he/she actually loves me more than h/she did before and I think that I love him/her more now than before the stroke.” One spouse indicated, “Prior to the stroke we could always talk about everything and now we may communicate less but it is still meaningful.” Several other participants expressed similar sentiments including, “Maybe we don’t talk as much as we used to....but I know he/she loves me no matter what.”

In contrast several spousal caregivers's explained that they were more concerned that their marital relationship was too fragile as was the survivor and feared that expressing their personal concern may have caused additional distress. For example, two spousal caregivers recalled their reluctance to discuss the increased stress they felt from the increased roles and responsibilities, "I was so stressed out but he/she was the last person I was going to vent to. He/she felt so bad about being a burden, how could I have complained to them?" Another spouse expressed similar sentiments, "When his/her whole life was turned upside down, the last thing they needed was to hear me complain about a little extra work that I had to do." Others found solace in friends or confided in other family members, "I talked to my brother/sister everyday and poured my heart out. I think that was what made the initial situation more tolerable" and "My friend became my sole source of support, at least initially, they would listen for hours and just let me vent."

Rolland (1994) suggests that a couple facing chronic disability can alleviate constant conflict when both partners are free to express themselves emotionally and initiate discussions when the need arises. Communication perceived as compassionate and understanding by marital partners lowered emotional reactivity and reported stress levels (Pistrang & Barker, 1995). While communication was described as "difficult" by the majority of participants, in particular communication immediately following and within the first year of the stroke event, many reported that they were eventually able to return to a "functional" level of communication, "At first, I missed talking about everything with him/her and thought.....well this is just going to have to be the way it is.

But now, we can talk even better than before,” One survivor explained:

“That was the best part about getting better; getting better meant we could spend more time together just talking. I felt like we have been away from each other for a really long time and then it was just like catching up. It really motivated me to try my hardest in speech therapy.”

Theme: Role Flexibility

According to research on family health care, approximately 80% of stroke survivors return home to be cared by family members (Han & Haley, 1999). In the current research study, all stroke survivors were able to return to their homes following their discharge from the medical and rehabilitation settings.

In a long-term marriage, changes in primary roles and identities are often the result of a major medical crisis. According to Lyons (1991), an unexpected chronic illness or medical crisis with an indeterminable prognosis has greater impact on pre-existing relationships. The degree of influence on the relationship is contingent upon the degree and complexity of the relational reorganizing required (Lyons, 1991; Burman & Margolin, 1992).

When a stroke occurs within a long-term marital relationship, the survivor’s spouse is expected to become the primary caregiver. Without warning, unprepared spouses must assume and manage a multitude of personal, emotional, behavioral, and physical changes in their long-term partners. Several spouses reflected, “I had no time to prepare....one day you are a husband/wife taking care of your own thing...and next thing you know, your whole world is turned up upside down.” The degree of difficulty to regain some semblance of pre-stroke relationship balance was described by one

participant as, “For me it was very difficult at first. He/she couldn’t do anything at first. I had to take care of him/her and the house while still trying to work to support us. I was really afraid of not being able to do it all...I was afraid I would fail us.” In addition to the innumerable responsibilities of providing post-stroke care, spousal caregivers must attend to their own personal identity while simultaneously redefining their personal long standing marital and social roles.

A number of survivors described the difficulty of feeling and becoming totally dependent and relying on others for “everything.” Other participants talked about similar experiences regarding the immediate need to renegotiate established roles. For example, one spouse recalled, “We really struggled initially with who was going to do what. We both felt very frustrated.” Two survivors described the first several months after returning home as “unbearable.” According to one, “I was so used to working with my hands and keeping busy. It was hell having nothing to do. I was bored and always in a bad mood.” Another survivor recalled that relying on his/her spouse for personal assistance was more difficult than asking for assistance with a household task, “He/she had to help me into and out of the shower. He/she washed my hair and got me dressed. I always felt like such a burden but he/she never complained.” While post-stroke adjustment was described by participants as difficult one spousal care provider described:

“The change in our roles after his/her stroke felt overwhelming at times. But, I don’t begrudge anything that I had to do and I felt good about helping. I know he/she would have done the same for me.”

A stroke that occurs within a long-term marital relationship can create a significant challenge to established roles and relationship patterns previously guiding

the couple system. Tacit agreements regarding boundaries, sanctions, roles, and responsibilities developed and maintained over the course of the relationship are threatened. The meaning ascribed to these changes has a direct impact on the stroke survivor's ability to ultimately adapt to the post-stroke consequences and their ability to make the necessary personal adjustments. The reaction of the spousal caregiver and importance attributed to the stroke survivor's needs directly influences the survivor's personal perception of his or her disability, self-concept, and self-esteem (Helgeson, 1993; Lawton, et al., 1989).

As indicated by (Rodgers & Calder, 1990), successful emotional adjustment is more likely to occur in mutually empathic and caring marital partners. Furthermore, Dombovy, Sandok, and Basford, (1986) suggest that support provided by a caring, competent spouse is one of the primary factors in functional recovery. The availability of resources and perception of the spousal care provider had a direct influence on the couples overall coping success. Within a marital relationship, stroke recovery is a collaborative process requiring both the reconstruction and renegotiation of roles and identities. The ability of the stroke survivor and his or her spouse to accept changes in established roles and responsibilities can minimize the relational disruption caused by the stroke. One couple similarly described the period of time immediately after the survivor returned home, "We could always get through things. We just accepted things were going to be different and did not stress over the little things." A spouse's ability to adapt and adjust to the care providing role is critical to the overall adjustment of the stroke survivor. One stroke survivor expressed:

"I felt so bad at first that he/she had to do everything for me but when he/she felt

stressed we would talk about it and I think we both felt better. We never let it get to a boiling point. We have both always been patient people and never really had too many big fights during our marriage.”

The ability of a spousal caregiver to effectively adjust and cope with the often inordinate post-stroke demands, is partially based on the level of caregiving responsibilities (Beach, 1993). The requisite role adjustment and renegotiation, as described by participants, varied and but was primarily dictated the degree of post-stroke limitations and level of pre-stroke complementarity. To varying degrees, all participating survivor’ described reliance on his or her spouse for basic physical care (ADL’s), emotional, social, and financial management or assistance. Whereas, spousal caregivers described taking on additional responsibilities including cooking, driving, assistance with ADLs, and financial management.

“Frustrating” and “difficult” was commonly expressed by participants in regard to the adjustment in marital roles and responsibilities. In reference to this issue, a number of participants, both survivor’s and their spouse, expressed similar reactions. For example one participant explained:

“I had no idea about when to bring our cars in for service or how to change the furnace filters and he/she was always good at remembering everyone’s birthdays, anniversaries, you name it! I had to be reminded when it was our own anniversary let alone my aunt so and so. I know he/she felt bad about not keeping up with all of that so I tried my best but I know he/she was disappointed.”

Another stated, “I liked to cook a little before the stroke but I really had to learn how afterwards.”.....“Not working outside of the house was terrible. I felt like I was being lazy just sitting around and I felt that he/she thought I could have done more”... “I used to spend a lot of time with friends. After the stroke, I felt guilty even going out for a few hours.”

In addition to the being described as frustrating and difficult, spousal caregiving, spousal care was also expressed as “indispensable.” A majority of survivor’s expressed similar sentiments of one, “I would not be here today if it weren’t for him/her” and “I don’t know what I would have done. I can’t even think about it.” Whereas, the majority of spousal care providers expressed similar sentiments of one, “I cannot imagine not being there and totally taking care of him/her myself.

A stroke that occurs within a long-term marital relationship can create significant challenges to established roles and relationship patterns that previously guided the couple system. Tacit agreements regarding boundaries, sanctions, roles, and responsibilities that are developed and maintained over the course of the relationship are threatened. The meaning ascribed to these changes has a direct impact on the stroke survivor’s ability to ultimately adapt to the post-stroke consequences and their ability to make the necessary personal adjustments. The reaction of the spousal caregiver and importance attributed to the stroke survivor’s needs directly influences the survivor’s personal perception of his or her disability, self-concept, and self-esteem (Helgeson, 1993; Lawton, et al., 1989). Several survivors explained that their perception of the post-stroke burden and responsibilities

that their spouses had assumed was as equally painful as the stroke event. One survivor recalled, "I felt so bad for him/her. It made me feel worthless and at first, I wished I had died instead of becoming such problem for everyone." However, other survivors perceived their spouses to be more caring and tender after the stroke. "You know, I think that this (stroke) brought us closer together. We worked it out and I feel more in love that ever," another explained, "I never felt like I was a burden. My husband/wife was always supportive and never acted like I was a pain or like I was a pain in the butt."

Marriages once described as "egalitarian" experienced difficulty during the adjustment period immediately following the stroke. A majority of male participants worked outside of the home and managed the majority of the household income while female participants were primarily responsible for raising the couple's children and managing the overall household. Initially, the inability to perform previous activities or take an equal part in previously shared responsibilities was a significant factor in both male and female participants. In particular, a number of survivor's expressed sadness and/or frustration when required to relinquish his/her primary role due to their post-stroke functional limitations, "This was a pretty traditional marriage. I mean I brought home the bacon and he/she didn't really work. I worked and he/she stayed at home. I was the breadwinner before the stroke." A predominance of male survivors expressed regret and frustration at having to relinquish their long-term established careers required by the stroke. The majority of stroke survivors were employed either full time or part and/or retired but active. Each believed that they were going to eventually return to some semblance of their previous positions or be able to resume pre-stroke household

responsibilities (mowing the lawn etc.). Returning to work following their stroke recovery was a motivating factor for most survivors. “I just kept thinking about what it would be like when I got back to work. Everything was going to be so much better” explained one survivor. Unfortunately, due to post-stroke limitations, very few survivors were able to return to work and eventually faced involuntarily retirement.

Several spousal caregivers also expressed concern about the change in employment. For example, “When will I ever be able to retire because I carry our health insurance and we certainly depend on that insurance?” Another spouse recalled initially feeling angry that he/she was “forced” to continue working rather than being able to decrease hours to part time, “Before the stroke, we had planned on me cutting back my hours to part time. After the stroke, I needed to work all I could because we lost one salary and for the health insurance benefits. I couldn’t help thinking “Why isn’t he/she covered himself/herself?” One participant explained, “I worked outside the home but after the stroke, I had to give up my job because I felt like I could not leave him/her all day long.” Another participant expressed a similar experience, “I broke down. He/she slept all day while I worked full time. I was up for hours at night making sure he/she was all right. I was so exhausted all the time. It was just like being on the go all the time, all the time and that was horrible.”

Becoming responsible for household tasks appeared to have a greater impact on male spousal care providers. Several male spouses indicated that, prior to their wives stroke, they were not aware of the extent of household responsibilities until they were required to “take over.” For example one spouse indicated, “Anything she would have done for me, I do now” and “There isn’t time to sit down and read a

book.” Whereas, financial management was identified as a major role adjustment for both stroke participating survivors and spousal care providers. It was described as difficult for male participants that had previously managed the couple’s finances to “relinquish” this role and more difficult for female participants to “assume” the financial management role if they had previously had been uninvolved prior to the stroke event. For instance, several male participants expressed feeling a loss of control related to the relinquishment of former responsibilities, “I always took care of our money. We shared every aspect of it but I used to keep track of it and manage it.” Another stated, “I think I actually resented him/her when it came to managing our money. I was a jerk at first and would question him/her on certain things. I think that was just my way of thinking I was still in control.” A few female participants also expressed frustration about assuming the financial responsibilities. For example, one participants explained, “That was a big adjustment for me when I had to take over the finances. I didn’t even know where the checkbook was kept let alone how to pay the bills.” “I felt like I was making a mess out of his/her system. Frankly, I really did not care about it in the beginning. There was so much else to do than enter receipts, debits, and just keeping track of what we spent,” explained another. “In the past,” explained on spouse, “I was very independent. He/she provided for us very well and he/she always handed over the money. He/she paid all of the bills. I had my own checking account with my money that I made at work and tried not to live on that money. That was a big adjustment for me when I had to take over the finances.”

According to participants, stroke survivors and spousal caregivers, some role and responsibility adjustments within the marriage were made with relative ease, while others were not. For example, one spousal caregiver stated:

“Things like the finances, I did them when I was single so I knew how to do it, I just hadn’t done it our marriage because he/she had offered. At first we kind of did it together and after I understood his/her way of doing them, we were fine...no problems. He/she was so organized, it was a lot easier than I had ever imagined. We worked on them together so I never really felt alone.”

Several participants explained that their marital roles did not change significantly following the stroke, for example, “Our roles really did not change that much. After the stroke, I helped with all of the things that he/she used to do. He/she really wanted to be able to get back to do things without my help,” another participant indicated that the post-stroke changes “It was a little bit overwhelming for me but I really did not want any outside help. I ended up doing everything myself,” “It was sometimes difficult, but manageable” explained one participant. Another explained, “We had to renegotiate our roles because before he/she would never have done household chores and now h/she does them all. It’s nice to come home and not have to worry about the house anymore. I can go to work and when I get home our time together is our time together.” Two female participants described the transition in responsibilities for other responsibilities including outdoor work (i.e., yard work, small home repairs) as relatively easy and “...it was really not a big deal.”

For all couples, a new equilibrium was sought in an attempt to resolve the impact of the stroke. At the time of each interview, couples were attempting to formulate a new

balance in their relationship by facing practical and emotional issues involved in caregiving. Most marriages experienced major changes in role functions after a stroke.

Sense of Coherence

Current research literature suggests an increasing interest and relevance of individual differences when faced with a stressful life event (Dohrenwend & Dohrenwend, 1974; Goldberger & Berznitz, 1982; Holroyd & Lazarus, 1982). Emotional and physical reactions to a stressful event such as disability, varies significantly among individuals. Personal disposition and environmental factors may account for the some individuals to cope effectively and adjust after experiencing and a stress live event.

According to Antonovsky (1987), one explanation for these differences in the Sense of Coherence (SOC). (SOC) is psychological and social factors that account for individual coping and adjusting differences following a stressful life event (Antonovsky, 1987; Dohrewend, 1981; Garrity & Marx, 1985; Kelly & Lambert, 1992). Examining the connection between the stroke survivor's and his or her spouse personality resources and adjustment to post-stroke disability is best understood when examined in the context of the marital relationship.

A person with a high SOC is one who believes his/her world is understandable and manageable and wants to cope with it. This refers to the personal dispositions that may account for differences in the capability of the individual to cope effectively with a stressful experience of disability. It is an internal coping resource formed by cultural and structurally shapes patterns of life experience, and as such is a mediating factor explaining successful person coping (Antonovsky, 1987; Kulick & Mahler, 1993; Rintala, Young, Hart, Clearman, & Fuhrer, 1992). Accordingly, when individual's are

faced a sudden medical crisis, researchers purport that emotional and physical reactions are understood when examined within the social context in which it occurs (Folman, Lazarus, Gruen, & DeLongis, 1986; McDaniel, Hepworth, & Doherty, 1992, Rolland, 1994). The emotional, social, and physical consequences following a stroke prevail long after the initial stroke occurs and is a source of prolonged stress for both the survivor and his or her spouse, forcing change in the entire family system (Crew & Krause, 1988, 1990; Lewis, 1986; McCubbin, et al., 1982). Post-stroke adaptation process is a shared and multifaceted process experienced by the survivor and his or her spouse and achieved through and within personal and social relationships.

People with high SOC are more likely to believe that their ability to overcome a serious illness is determined by themselves and their behaviors. Something they do or do not do determines their health status

Code: Psychological/Emotional Influence

Theme: Ability to Overcome Depression Related to Post-Stroke Disability

Due to residual physical, social, and behavioral impairments, depression is common after stroke, yet it has proved difficult to measure because language and cognitive skills used to evaluate depressions are often affected post-stroke. Varying levels of depression was reported among all participants. Since depression can slow the stroke survivors' recovery, it is important to accurately measure its prevalence. Stroke survivors mentioned feeling sensitive, helpless, frustrated and worried about getting better. "We are helpless," said a survivor referring to his/her spouse as well. One stroke survivor who had suffered a major stroke regretted that he/she did not feel that he/she was getting any better and thought that his/her life was over. Until the stroke, another stroke survivor

considered himself/herself “indestructible,” and now he/she admitted, “I just feel worthless sometimes.” Many of the participants simply stated, “I was so depressed” or “It was so depressing, I just didn’t feel like life had much to offer anymore.”

Perceived caregiver stress was a common theme among stroke survivors and a source of depression. Many survivors reported increased feelings of guilt regarding the fact that they perceived themselves as burdens to their spouses. One survivor specifically stated, “I felt so depressed because I kept thinking a lot about what a huge burden I was putting on him/her.” Another stated, “I had always been more of a caretaker, I guess because I’m female, and suddenly he is the caretaker. It felt all-wrong to me, like this must be the biggest burden to him. It just made me depressed the more I thought about it.” Another said, “I didn’t want him/her to be responsible for me, like having a baby or kid who never grows up. That’s not the way it is supposed to be. You are supposed to enjoy your retirement years. I just felt depressed thinking about the fact that neither one of us would have the life I imagined...I’m a cripple, he/she never gets a break from it.”

Along with the actual survivors expressing their depression and feelings of guilt related to burdening their spouses, the spouses recognized these feelings in their partners as well. One woman said, “I think that he felt bad, even really depressed at times. He tried to help or do normal things that he would usually do, but he couldn’t.” Another spouse said, “He/she would constantly talk about being such a burden, even when I would reassure him/her that this is just a part of life, it didn’t seem to help. There was a lot of crying, and it just turned into depression.” Another spouse said, “I felt like I watched his/her depression get worse and worse. I told one of the doctor’s and he/she

said it was clinical depression and it was normal after something like a serious illness.”

Another spousal caregiver said:

“He/she was pretty negative at first. Well, he/she was just so used to being so strong and now he/she isn’t as strong. You know, he/she wanted to be the man/woman and take care of me and had to accept help from me for a while and that was hard for him/her. It was real hard for him/her because he/she wanted to be the strong one.”

Despite the high prevalence of depression among the survivors, they all demonstrated a high capacity towards making personal choices to overcome their depressive feelings. Many of the participants stated that once they actually recognized that they were in fact “depressed,” they became active in trying to mitigate the symptoms through a shift in their attitudes. One participant, said, “You know, how long can you just keep feeling like crap and expect it to change by itself, you have to do something about it, so I just started thinking differently about the whole thing.” Another said, “At some point I got sick of ‘wallowing.’” One survivor stated, “I started thinking about this motivational speaker I had seen years ago, it was for some work thing. At the time I don’t remember being really motivated by it or anything, but I remembered this term that he used, ‘stinky thinking’ and I thought that’s exactly what I am doing. I need to stop.” Yet another survivor said, “In some ways it was one of the things I could control. I was having a lot of trouble controlling what had happened to me physically, but I could control my attitude if I wanted...so I changed it, and along with that, other things started going better too.” Finally, one survivor said, “I had felt sorry for myself for a long time, but you go on. I mean what can you do? You have to go on. I was in a wheelchair and

my wife/husband would say “Stay here” and his/her two brothers came over and they closed the pool. I was wheeled out and was sitting in the sun room and I watched them and joked with them and then I really looked forward to the fact that someday I will get out of this chair and then I am not going to be a burden on you and someday I’m going to do this and drive a car and then I’m not going to be a burden on anybody. Just thinking that, and doing the things I could helped me a lot.”

There were come survivors that continued to struggle with depressive feelings despite attempts to change their outlook who utilized counselors/therapists for help. One caretaker said, “He/she would say “I don’t want to feel like this, I’m really trying, but it doesn’t help. I suggested that he/she talk to a counselor and eventually the counseling was what helped.” That particular survivor acknowledged, “I was never really into the counseling thing, but I didn’t want to think that I didn’t try anything in my power to get well. If I chose to sit there my whole life feeling sorry for myself, I would have nobody to blame but myself.” Two other survivors utilized counseling as well. One stated, “It helped to have someone who understands the mind, keep you on track mentally.” The other said, “Counseling was really helpful for me and my wife to deal with our negative feelings.” In addition to counseling, three participants and two caretakers were prescribed anti-depressants to help them overcome their depression. Most all of these individuals made comments similar to one of the participants, “At first, I didn’t think I needed medicine, that I could do it myself, like I didn’t just want to take a pill. But I really think it helped, at least it got me so I wasn’t feeling so bad, and then I took over from there. I think in the end it was learning to have a positive outlook.”

Theme: Tenacity/Perseverance

Along with reported feelings of depression in the survivors, many reported that at some time, “It was just too hard sometimes, I didn’t feel like I could make it.” Similarly, many stated, “It would have been easier to just give up at times.” Much the same as they handled their depressive feelings, they were able to transcend their feelings of hopelessness by the difficulty of the situation with an ability to persevere despite the many obstacles. One survivor remembers, “You know, I would just be at that point where I had had it. Done. I’m not doing anymore....Then there would be something inside me that would say, ‘hey you’ve got to keep working.’” Another said, “It was a game I would play with myself, like just get to this point, and you can call it quits, but once I reached that point, I said I could do more.”

Many of the participants credit their spouses as being “cheerleaders” or even “task masters.” One participant said, “I want to think I have the inner strength to just keep going, but the truth is, I think my husband’s/wife’s constant pushing boosted my own strength. One spouse explained:

“I used to think of myself as sort of a wimp, I was never athletic or anything like that. My husband/wife was, so he was used to pushing himself/herself. He/she did the same to me, and eventually, I realized I’m not a wimp at all, I have a lot in me to keep pushing, even beyond what I thought I could. I’m pretty tough. I didn’t give up.”

The caretakers themselves talked about the fact that they were tenacious in pushing their spouses during the more difficult times. Another spousal caregiver stated:

“When he/she and I went back into the rehabilitation program, and he/she just basically, at that point, he/she just shut down and said that he/she wasn’t going to do this anymore and I was pushing him/her to therapy and h/he was like alright this is therapy but h/she was not putting a lot of effort into it so I said to him/her one time, “you have to fight this if want to go home. I’ll help you all along the way, but you have to do it. And eventually he/she did.”

One spousal care provider described:

“He/she was lying there listening to this guy say, for the third time, that they don’t hold out a whole lot of hope and so he/she just saying it, and it was just like we are trying so hard just to keep him/her alive and he/she was just so upset so that’s when he/she was just got irritated and it spiraled. But then we talked and decided together that we were going to prove them wrong and he had to fight back and prove it.” Another spouse said, “My vision with him/her was that I am his/her caretaker and I am going to kick him/her in the butt and do everything that he/she has to do to get him/her better and on his/her own. It is not my role to make life comfortable for him/her.” His/Her husband/wife agreed, “He/She was pretty tough, but it’s probably why I got tough at some point instead of throwing in the towel.” One spouse believed that his/her husband/wife thought he/she was very “bossy and pushy” as well, “I needed him/her to work and if that meant that he/she was going to be crying and just saying, “I’m just not going to do this anymore,” “well, yes you are.” I felt like I turned into the mean husband/wife, but at some point he/she said ‘thank

you.” Similarly, another spouse stated, “He/she just wanted to give up and I fought him/her the whole way and assumed control and said, ‘I didn’t keep you alive so you that you could give up. You are going to fight this.’ I pushed him/her, I mean, I am such a fish mongers husband/wife, I pushed him/her and pushed him/her so that they would take him/her back to the rehabilitation program. I pushed, but it was him/her that decided to listen to me and keep fighting.”

Code: Philosophical

Theme: Spiritual Beliefs

Many of the participants in this study indicated that their spiritual beliefs heavily informed their philosophy about life in general. In the specific context of the stroke and its impact on their lives, the survivors and their spouses, credit their spiritual/philosophical beliefs as significantly impacting their ability to prosper during the recovery process. Several of the participants described themselves with the adjective “optimistic.” Many related that optimism with a belief in God or a higher power that would help them through. One survivor said, “I have generally been a very optimistic person, I assume, God willing, the best will happen, and this was a test. I could focus on the fact that something bad happened or continue to be optimistic that God would help me through it.” Another couple talked about the idea that God often “tests” people in life and that those difficulties and obstacles provide people with a chance to “grow.” One survivor said, “The Lord never gives you more than you can handle.” His/her husband/wife agreed, but reminded him/her, “this was really a test of our beliefs, but in the end we did handle it.” Another couple talked about the idea that “Everybody has

burdens, some peoples are a lot worse than this, but our faith carried us through.” Finally, one survivor said, “It wasn’t just me alone, I had God there every step of the way, and that gave me strength and made me believe I could get through it.”

Along with a specific belief in God, some of the participants indicated that they viewed their situation as having some predestined quality or having a meaning beyond their immediate understanding. One survivor said, “There was a reason for this, I don’t totally know what it was for, but at some time I thought that and I just had to deal with it.” The spouse of a different survivor similarly observed:

“There is a reason for everything. God knows. We don’t know what it is though, so that can be frustrating when you think, ‘Geez, why would this have to happen?’

But by the same token, knowing that God has a plan, you just have to go along with it sometimes.”

Another survivor simply said, “...I guess this was just one of those things that was meant to happen in my life. Another spouse recalled, “I guess I believe in fate a little bit, it was just our fate.”

Social Constructionism

Social constructionism proposes that each individual stories their life experiences based on perception and construction of reality (Moules, 2000). Insight about one’s process is often strengthened by the ability of the individual to make sense of their experience through personal narratives (White & Epston, 1990). In this study, all of the couples told a story of “successful” adaptation to the circumstances related to one of the members suffering a stroke. While all of the couples perceived that they had adapted successfully to the stroke, each had a very individual perception of the overall experience

on his or her relationship. Common themes were easily identified in terms of the recovery process and the ecosystemic impact on successful adaptation, however with this particular sample, the meaning the participants ascribed to the overall impact of the stroke on their present relationship varied. There was not a common theme that presented itself, therefore the following quotations illustrate the perceptions each couple has attributed to the impact of the stroke on their marital relationship and their constructions regarding it.

Couple 1:

This couples meaning focused primarily on the idea of affirmation of commitment. The survivor stated, “Well, it affirmed for me how much my husband/wife loved me which is something I think you might not realize unless you go through something like this. I think this made me believe that he/she would love me and be there for me no matter what. I probably would have thought she would, but this really proved her loyalty to me...it makes me really secure about her commitment to me.” His/her spouse continued along the theme of commitment by saying, “I could not have imagined not taking care of him/her. Don’t get me wrong...there were days when I was ready to throw in the towel, but I never stayed like that for too long. When you make a commitment to someone, you don’t have a choice, like, oh, I’ll only be committed if things are good. For better or for worse, this is just the ‘worse.’ But I also know he/she appreciated every thing I did and when I look back, it was all worth it. If our places were switched, I know he/she would do the same for me”.

Couple 2:

This couple focused on trust and loyalty. The stroke survivor believed, “Through all of the time I spent in the hospital and rehabilitation I felt that I was just getting lip service from the doctors and nurses. But the one person I could always trust was my husband/wife. I knew he/she would always give me the direct and true answers to my questions no matter how hard it was. Even after all of the years that have past since I had the stroke, he/she is who I trust more than anyone on the world”. The spouse said, “Over the course of our marriage, I always felt we could trust one another, it was sort of an unspoken agreement. We didn’t need to question the trust issue before. I think when you think of trust in a marriage people usually focus on things like whether you would cheat on each other or something like that. This I think was new definition of trust for us...My husband/wife has told me so many times how this was a true test of our marriage and that he/she trusts me so much. You know that I would be there through it all.”

Couple 3:

This couple surprisingly felt the stroke had very little effect on their present relationship. The spouse stated, “It’s just a bump in the road. You have good and bad in life. We had been through different things all through our marriage, this was hard at times, but I really can’t think of how our relationship itself has changed now. There are always adjustments.” The survivor, said, “It mostly changed how we did some things, especially in the beginning there was kind of a dip, but I didn’t want it to change our relationship too much, I liked how it was, so we tried to keep it the same.

Couple 4:

This couple talked about the fact that the emotional stress had originally been so challenging, that it created more strain on their relationship, but that their ability to withstand it over time probably contributed to strengthening their relationship. The survivor said, "There was a long while there that I really didn't want to live, I just wanted for it all to be over, and to tell you the truth, I really wasn't even thinking about our relationship, just me and not having to go through it. And maybe sometimes, there was some guilt about not wanting people to have to take care of me. But I think he/she was the stronger one and kept pushing me even when I would be a real, you know, I guess, SOB. So I think it made me think of her/him as a lot tougher. I still respect her/him being able to go through all that." The spouse admitted, "You know this is a hard thing to say (got tearful), but there were actually times where I wished he/she would just die. It's what he/she wanted, and honestly I didn't see how our quality of life could ever be that good.... I know it was him that did the real work...to get better, but I kind of agree, that I was a lot stronger than I thought I could be, and now I think we have a more equal relationship."

Couple 5:

This couple focused on their relationship getting stronger as it related to a joint commitment to their religion/faith. "I think together, we have gotten more involved in church, and that is a way we spend more time together. I mean we always went to church, but our faith as a couple was renewed." The spouse agreed, "I think I did a lot of bargaining with God, during the stroke, but I think a lot of people, once they get what

they want, forget about it. But I think we really have seen how much your faith is important to you during those hard times and we have together embraced it more fully.”

Couple 6:

This couple had a somewhat similar experience as one of the other couples, in that they believed that enduring this experience affirmed their marital commitment. The survivor simply stated, “It affected our relationship now, but just showing us that this is what commitment is all about. You just have to do it whether you want to or not...because you made a vow. And then you know, ‘Hey I kept my commitment.’” The spouse agreed that this is the part that was most important to her/him, “This was my “husband/wife, what else are you going to do? I guess, you could just walk away. Maybe that would be the easy thing to do for some people, but I couldn’t have lived with myself if I had. I couldn’t have broken our marriage vow. I think we both know that our commitment is forever.”

Couple 7:

The individuals in this couple did not use a lot of words to describe how they felt about the impact of the stroke. “It’s just about love. If you love someone or they love you, nothing is impossible. There’s a lot of love.” The other member of the couple agreed, “We love each other as much as ever, or even more.”

Couple 8:

This couple focused on a similar concept that some of the other couples had mentioned in terms of adversity leading to strength. The survivor said, “It really strengthened our relationship. I don’t think you could go through something really difficult like what we did, and not come out stronger.” The survivor responded “Well,

not everybody would come out stronger, but we did. I think this is the type of thing that could destroy a lot of relationships. You hear it all the time; people just bail out of it. But I agree that it made us stronger...like the quote says, what doesn't kill you, makes you stronger."

Chapter Five discusses emergent findings from the data and implications for clinicians, healthcare providers, and marriage and family therapists. Limitations and future recommendations are also addressed in Chapter Five.

Chapter 5

SUMMARY AND IMPLICATIONS

This qualitative study was one of the few research efforts to explore the influence a various ecosystemic factors, SOC, and social constructionism on one's ability to successfully cope and adapt following a stroke. Selecting, organizing, and reporting data in a coherent and relevant manner is a fundamental challenge in qualitative research (Gilgun, 1992). Qualitative research is conducted through prolonged interaction with the researcher, a purposively selected criterion based sample, and data generated during the course of interaction (Sword, 1999). Prolonged interaction with research participants affords researchers an opportunity to gain a profound understanding of a specific phenomena or life event (Wolcott, 1990). The primary research objective was to provide middle-aged long-term married couples the opportunity to story their post-stroke perceptions and experiences while examining ecosystemic and personal influences on successful post-stroke adaptation.

Utilizing a grounded theory approach did not require a specific detailed summary of each individual's experiences; rather it promoted a progressive and comprehensive consideration of the data as a whole. Participants described their personal post-stroke experiences in a manner that was both poignant and forthright. During the interview process, it was difficult for the researcher to refrain from allowing participants to tell their stories without requiring adherence to the specific research questions.

Determining what information to include while preserving the power and value of each story was at times a struggle, however, re-examining the conceptual and theoretical maps proved to be a valuable guide in data analysis and organization. Overall, the results

fit well with the initial conceptual and theoretical framework theorized allowing the researcher to recognize the value and process of theoretical development throughout the research study.

Initially, the researcher theorized that certain ecosystemic factors, social constructionism, and sense of coherence contributed to one's ability to successfully adapt following and influenced the meaning each member attributed to the stroke impact. Data collected from research participants was analyzed and organized into emergent categories and further developed into data classes, codes, and themes. The subjective exploration of successful post-stroke adaptation will likely contribute to the development of a strengths model relevant to post-stroke couples. Understanding individual post-stroke experiences and its influence on reality construction will also provide insight for clinicians relevant to clinical assessment and subsequent treatment.

A stroke is a devastating medical crisis affecting an increasing number of people each year. The threat of stroke continues to increase at an alarming rate with profound and devastating consequences. This study explored the phenomenon of successful post-stroke adaptation in middle-age long term married couples. Each participant provided valuable information regarding ecosystemic and personal influences relevant to their individual adaptation. This chapter will highlight several key findings within the data. In addition, theoretical, research, and clinical implications will be addressed.

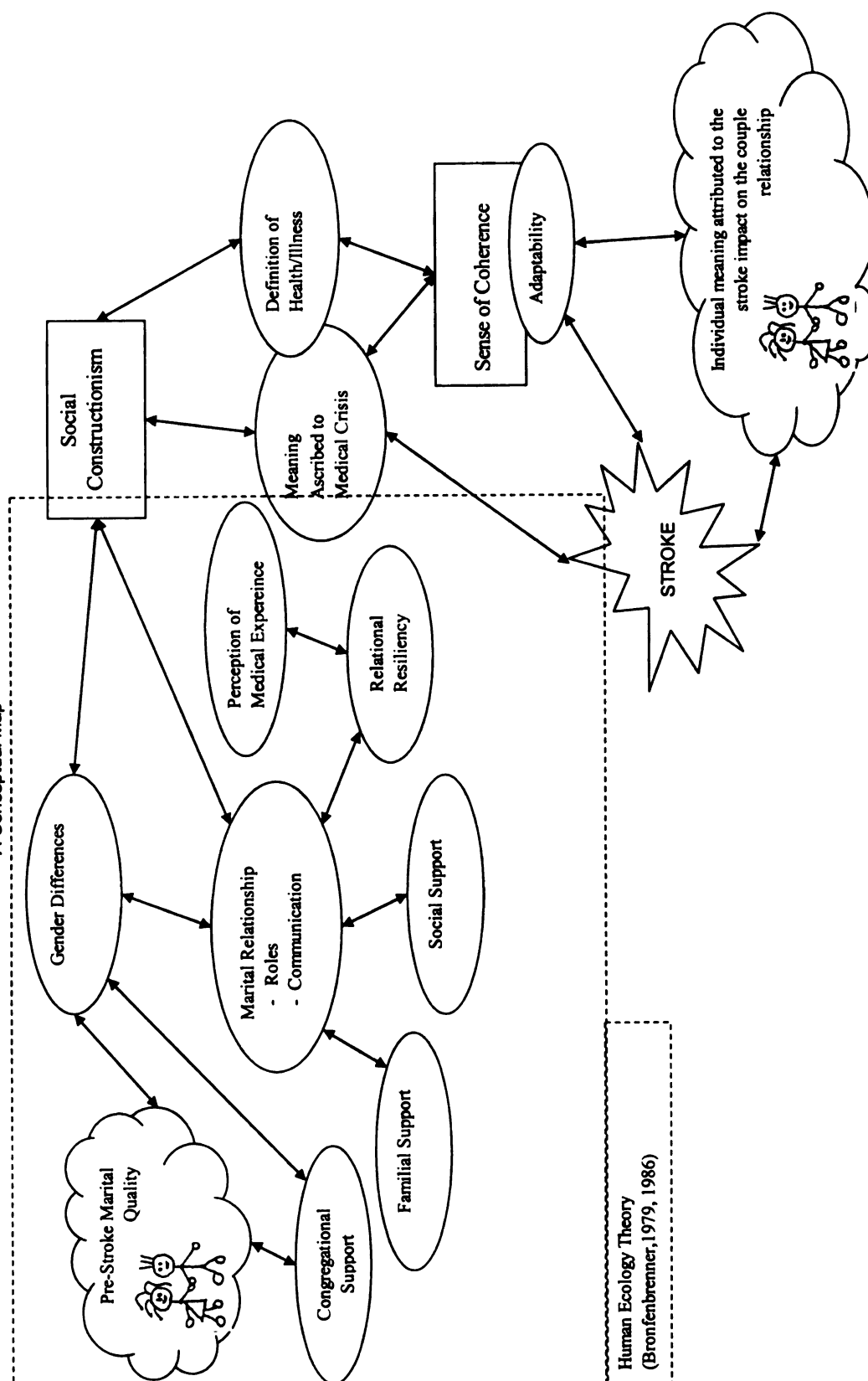
Conceptual Framework

After the data coding and analysis was complete, the conceptual maps presented in Chapter 1 were revisited; one concept found in the literature review and initially hypothesized by the researcher to be an influential post-stroke ecosystemic factor was not

evident in either the participant or ecomaps. The researcher expected gender to influence the level and type of spousal care that was provided. However, in contrast to several studies suggesting gender differences in the nature and extent of spousal caregiving (Brok, 1992; Gwyther, 1990; Vinokur, 1990), there was no evidence in the current research study to substantiate that gender contributed to the adaptation process. Conversely, concepts that were not found in the review of literature but present in the participants' post-stroke stories were marital commitment and relational resiliency. Each concept will be explained in further detail within the Emergent Finding section.

A revised conceptual map (See Figure 5.1) illustrates the influence of ecosystemic concepts relevant to this research study.

Figure 5.1
Ecosystemic Influences on Successful Individual Post Stroke Adaptation
A Conceptual Map



Theoretical Foundations and Implications

Traditional medical outcome studies have primarily focused on biological parameters of disease. As such, research and strength based data relevant to post-stroke adaptation in middle-aged long-term married couples is limited. Qualitative research allowed the researcher to study the essence of individual participant's post-stroke experiences and perceptions (Berg, 1989). Exploring the meaning ascribed to the stroke impact on middle-aged long term marriage partners post-stroke was well-suited for qualitative methodology as it allowed preconceived ideas, beliefs, and construction of one's life to connected with ecosystemic influences.

Impartiality and fairness, both primary tenets of human ecology, provided a non-judgmental forum for participants to story their experiences and perceptions (Bubolz & Sontag, 1993). Based upon in-depth interviews, the researcher collected each participant's "lived experience" and meanings attributed to their post-stroke processes. Processing and analyzing this data allowed the researcher to explore personal characteristics of each post-stroke partner, their dyadic system, and influential ecosystemic factors. Within the guidelines of grounded theory, theoretical concepts are developed through interconnecting observations of phenomena and concepts with existing theory and research (Glaser & Strauss, 1967).

Key Findings

Ecosystemic Influences Related to Post-Stroke Adaptation

Specific components of Bronfenbrenner's (1979, 1992) Ecology of Human Development and Person-Context Process Model were particularly relevant in this study. The influence of ecosystemic factors on the post-stroke adaptation process was reflected

within each participant's story. Analyzing data from this perspective underscores the significant reciprocal influence of individuals and their environment.

The participant's primary microsystem system, the marital relationship, was the most significant environment for post-stroke adaptation to occur. As such, it is not surprising that participants discussed at length their post-stroke perspectives and experiences within this relationship. This microsystem was the setting for both negative and positive experiences following the stroke event and the system where both emotional loss and support occurred. Other important microsystems for participants included nuclear and extended family and various social support systems.

The macrosystemic connections were both the medical and rehabilitation environments which were very influential contributors to the successful adaptation process. Participants described helpful and unhelpful aspects of these environments relative to their overall adaptation process integrating their personal identities and characteristics as stroke patients and spousal caregivers.

Influential personal and environmental factors that contributed to successful post-stroke adaptation were also clearly evident. Participants reported influential ecosystemic factors that facilitated or impeded individual post-stroke adaptation across their systemic environments. According to White and Epston (1990), the ability to explore and make sense through personal narratives, increases insight into one's own process. Participants provided valuable information regarding ecosystemic and personal factors relevant to their success. Bronfenbrenners' Person Context Process (1992) theory provided an opportunity for the researcher to examine reciprocal environmental influences and to explore the adaptation process over time.

Consistent with other empirical studies regarding SOC and health related outcomes; personality constructs have been linked with acceptance and adaptation to disability, marital satisfaction, health, and the ability to seek social support. It was initially hypothesized that a connection existed between the personality resources of stroke survivors and spousal care providers and successful post-stroke adaptation. Resiliency was a personality characteristic detected in participating post-stroke couples. The ability to employ effective coping techniques, optimism, motivation, and comprehension Individual personality constructs were also evident

Relational Resiliency

It appeared that successful post-stroke adaptation was associated with the extent to which individuals found meaning and purpose in their respective circumstances and caregiving duties, and recognized and used micro-, meso-, exo-, and macro-systemic resources. The latter includes supportive personality and effective coping behaviors, relationship factors, including the survivor, his/her spouse, family members, or other communal social support.

It is not surprising that stories of self-reported successful adaptation revealed these traits. In keeping with Antonovsky's theory of sense of coherence, these adaptive traits have been found to be a primary factor in individuals and relationships considered "resilient." These individuals are not only able to withstand stress, but even grow and thrive as a result of those experiences. Consequently, an effective strengths model of post-stroke adaptation would need to include those traits. Resilient individuals are those who are able to elicit nurture and other forms of support from others, have a supportive belief system (including optimism and a desire for appropriate autonomy), and possess

good problem-solving skills (Cicchetti & Garmezy, 1993). Relationships that do not disengage when faced with major external stress and which enhance the coping capacities of one another possess a sense of “togetherness,” a sense of agency, good communication skills around problem-solving, and the capacity to find and use external resources such as support groups (Walsh, 1996). Additionally, they include individuals socialized to provide care to other family members (Walker & Lee, 1998).

Stroke is a circumstance to which not only the survivor must adapt, but also the family system and others that have and will be interdependent with the survivor. Seemingly, the greater the perceived post-stroke physical, cognitive, and social consequences by the survivor, family system, and social system, the greater the challenge to successfully cope and adapt appears. Participating middle-age long-term married couples have indicated that the extent to which they consider themselves bound together in love and positive reciprocal obligation, and the extent to which they can make use of external resources, the more likely they are to progress.

During the acute stage, immediately following the stroke, all participants described feeling sadness, frustration, and fear. Additionally, several spouses experienced anger, emotional detachment, and guilt. According to Fitting, Rabins, Lucas, & Eastham, (1986), spousal care-providers that experience care-giving as an obligatory burden are less likely to express their negative feelings about the caregiving requirements. This may account for the survivor’s description of care provided by his or her spouse in definitive terms including always; “Always felt love,” “Always felt safe,” and never, “I never felt like he/she would abandon me. He/she never complained.” And although several spousal care-providers expressed feelings of apprehension and resentment during the acute post-

stroke stage, they also agreed that as time elapsed, they experienced their care-giving role as “significant” and “necessary.” Several couples, assigned blame outside the family system. Blame was generally directed at the initial medical care received, specifically in cases where the survivor was initially misdiagnosed or did not receive tPA.

TPA has been strongly supported by the American Heart Association, National Stroke Association and American Academy of Neurology however, only a small percentage of stroke patients in fact receive this treatment (Fayad, 2000). Receiving tPA is often considered a medical risk vs. benefit calculation. Stroke patients must immediately undergo an extensive diagnostic evaluation and specific medical criteria met before a patient is considered a viable candidate for tPA. If tPA is administered within three hours following the onset of stroke symptoms, the chances for recovery increase.

Seeking immediate medical attention following the onset of stroke symptoms is critical to identify the specific type of stroke (AHA, 2005). As indicated in Chapter 4, only those patients that have experienced an ischemic stroke are considered as potential candidates and likely to benefit from tPA. An exacerbation of post-stroke symptoms or death can occur if bleeding occurs in the brain subsequent to the administration of tPA. Unfortunately, as was the case for several participating stroke- survivors, medical personnel were unable to accurately diagnose patients within the allotted time frame or other physiological criteria was not met.

As a whole, spousal caretakers reported positive care providing experiences. The majority of male care providers reported higher levels of marital satisfaction after assuming the care-giving role. Similarly, a majority of female care providers reported an increase in marital closeness post-stroke and reportably experienced higher levels of

marital satisfaction. This suggests that couples who reported higher levels of marital quality in long-term marital relationships benefit from assuming a care provider role regardless of the care requirements (Montenko, 1989). In addition, the positive care-giving experience in the context of a long-term marriage in addition to the length of time that had elapsed following the stroke ($M = 4.6$ years) may have also been a factor.

Marital Commitment

Another commonality amongst participants was the strong commitment to their marital relationship. This commitment may have contributed to the couple's ability to effectively provide and receive post-stroke spousal care-taking. Additionally, spousal care-providers were immersed in the medical and rehabilitation experience, beginning their stroke education during the initial hospitalization period. All participants agreed that they received emotional support from medical personnel, especially the rehabilitation staff. Similarly, the rehabilitation program provided both stroke survivors and spouses a valuable opportunity to observe others couples in similar care taking and receiving situations. By utilizing other available resources, such as a stroke support group, most participating couples were able to transcend their negative experience and perceptions. These factors likely contributed to the positive care- providing and receiving experience and may account for the participating couple's successful post-stroke adaptation process.

Contribution to Existing Literature

Ambiguous Loss

As the concept of individual and family resiliency provides insight into the positive wellbeing stroke survivors and family systems, an additional concept, ambiguous loss (Boss, 1999), may explain why others in similar situations do not experience the same outcome. In order to successfully adapt following a stroke, the ability to accept loss may be necessary to complete the grieving process. However, due to the ambiguous post-stroke prognosis stroke survivors and family members are often unable to predict the degree of permanency of the biopsychosocial losses, and therefore may be uncertain as to the nature and extent of the survivor's role in the family.

The concept of ambiguous loss (Boss, 1999) has been useful in providing insight into the complicated perceptions, emotions, and behaviors associated with diverse loss. Consequently, it has also been extended to families experiencing chronic physical illness, specifically, dementia (Adams & Sanders, 2004; Boss & Kaplan, 2004; Brouwer-DudokdeWit, Savenije, Zoetewij, Maat-Kievit, & Tibben, 2002; Perry, 2004; Sandes & Sharp, 2004) and organic brain syndromes (Butera-Prinzi & Perlesz, 2004) as well as non central nervous system diseases (e.g., Boss & Couden, 2002 Mosack, Abbott, & Singer, 2005).

According to the concept of ambiguous loss, family members may be confused regarding their feelings, thoughts, and actions as the patient (their family member) may be physically present but, in other ways, psychologically absent. This ambiguity, regarding the extent to which the patient family member will or will not be involved, within the family's pre-established traditional role structures, may interfere with the

family members' grief resolution, adaptation to the demands of daily living, and progress toward rehabilitation goals. Boss (1999, 2004) and her associates have suggested that there are 10 identifying symptoms:

- "Frozen" (unresolved) grief, including outrage and inability to "move on"
- Confusion and distress; Ambivalence
- Uncertainly, leading to immobilization
- Blocked coping processes
- Experience of helplessness and, consequently, depression, anxiety, and relationship conflicts
- Response with absolutes, (i.e., denial of change or declaration of the loss); Denial of facts
- Refusal to renegotiate or redefine previously established family roles (believing that the patient/family member will return to his/her former family position); indignation at the exclusion of the patient
- Confusion in boundaries and roles
- Guilt, if hope has been given up or if there is the desire to "move on"
- Refusal to talk about the patient/family member and the situation

As stories were collected from each couple, both individually and conjointly, regarding how each experienced and made sense of their lives following a major stroke event, the researcher discover the influence of ambiguous loss in some cases and not in others. For example, in several cases, spousal care providers claimed to not have experienced any major ambiguity or confusion regarding post-stroke role renegotiation, "I just took over what he/she did. We helped each other," another stated, "We always

helped each other out before. We tried to have him/her do as much as the things they did before the stroke rather than me taking over, which would have been easier at times.”

Other spousal care providers indicated, “I was so depressed but I wouldn’t let myself think about it. I tried so hard to keep things normal at home, I ran 100 mph. trying to do and be everything. I was afraid if I really assessed our situation, I would be so depressed I would never get out of bed, and/or be so mad at him/her that I would burst.”

Hopefulness about the survivor’s ultimate recovery may have been helpful in some ways and unhelpful in others. Fostering a sense of subjective optimism, regardless of the objective evidence, may contribute to individual and relational resiliency. However, to the extent that hope makes loss ambiguous, it may make adjustment more difficult.

Clinical Implications

There are several techniques clinicians can employ when working with couples following a stroke event. Encouraging a stroke survivor’s spouse or family members to become and remain intimately involved in the discussions of mutual goals and future expectations allows both partners to feel involved in the adaptation process and reduces anxiety and fear. Stroke survivors, spousal caregivers, and other family members should be fully informed and active participants in the post-stroke rehabilitation process to insure adequate post-stroke preparation for spousal caregivers during each stage of the recovery process. Additionally, encouraging post-stroke couples to re-engage in previously enjoyable activities and people can increase a sense of belonging for both the survivor and his or her spouse. Sufficient opportunities must be available for both the survivor and spousal caregiver to ask questions and address concerns.

It is important that clinicians are informed and able appreciate the relevance of the stroke impact. Utilizing an educational counseling approach has lead to successful transitions for both stroke survivors and spousal caregivers (Teasell et al., 2003). By providing opportunities for families to realize the significance of their involvement and influence in determining and shaping the post-stroke outcome, clinicians and medical personnel can increase levels of meaning, control, and comprehension (Forsberg-Wrleby, Mller, & Blomstrand, 2002). Researchers suggest that combining both education and counseling can reduce conflict within the family system while increasing post-stroke knowledge (Evans, Matlock, Bishop, Stranahan, & Pederson, 1988). Decreasing family dysfunction can provide an excellent opportunity to focus on other issues including the survivor's behavioral and psychosocial needs.

Collaboration between healthcare providers, clinicians, families, patients, and communities can significantly increase the effectiveness and value of the entire post-stroke medical process. Acknowledging that clinical events usually transpire at different levels, could promote uniform collaboration in which all participants are equal contributors. Early intervention has been shown to prevent depression and later biopsychosocial disorders in spousal care providers. Moreover, early intervention can enhance a stroke survivor's quality of life and reduce the likelihood of long-term care institutionalization (Han & Hanley, 1999). Marriage and family therapists can address stressors and unmet needs of both the survivor and spousal caregivers during the acute post-stroke stage.

A stroke is a devastating medical crisis afflicting 750,000 of Americans each year. The threat of stroke continues to increase, remaining the third leading cause of death in

the United States and second leading cause of death in the world. To structure effective clinical interventions, practitioners must be aware of the devastating affect that a stroke has on not only the survivor but the entire family system. Recognizing the physical as well as the profound psychological toll can help those working with stroke survivors, families, and couples, while stressing the importance of addressing personal feelings and conflict from a variety of viewpoints.

It is important for clinicians working with post-stroke couples, to recognize the individual process of each partner and the changes required following a stroke. Recognizing the toll on the couple system due in part to necessary changes in life-long roles and individual identities, can help normalize the significant impact or difficulty the couple may experience. Clinicians should avoid diagnosing or pathologizing what may be normal transitional reactions to a stroke event. The knowledge gained by clinicians will enable them to understand how spousal caregivers and other family members adjust when a spouse or partner has suffered a stroke. It will also provide a framework with which clinicians can understand their reactions and assist in the overall rehabilitation of clients.

Research Implications

This study included data from middle-aged long-term married couples that successfully adapted following a major stroke event. This research shed light on further studies to include couples that were unable to successfully adapt following a stroke. Comparisons could be made of the personal characteristics and ecosystemic factors for couples who were able to effectively cope and adapt. These comparative results would provide clinicians with further insight in regard to individual and systemic resilience

while promoting the development of clinical models and effective therapeutic techniques for couples facing crisis.

Larger, more diverse samples should be utilized and comparison groups of stroke survivors of varying levels of function. Also, there is a need to incorporate specific measures of marital quality and to examine responses of spousal caregivers and stroke survivors within the first few months following the stroke and again at varying increments. Future research examining post-stroke adaptation in younger or elderly married couples could provide insight into the influence of marital longevity and pre-stroke relationship quality.

In the view of ecosystemic influences, individual characteristics, and meaning ascribed to a stroke event, it is essential to assess not only the impact of stroke on the marital relationship but also to assess a couple's ability to cope and respond effectively. Such research can provide clinicians and health care personnel with valuable information in which to predict which couples may experience the greatest difficulty in adjusting to a stroke. In order to attain balance and for the needs of both the stroke survivor and spousal care provider, clinicians should attend to the "make-up" of the pre-stroke and post-stroke marital relationship. Additionally, an ecosystemic focus may advance the growing interest in ecosystemic and personal factors that may contribute to one's ability to effectively cope or adapt when faced with a stressful life event.

Limitations

This study also has some limitations. First, the sample was criterion based and selected from a homogeneous source, which may be biased from the true population of stroke survivors. Successful post-stroke adaptation was "self-rated" by participants and

study did not include an ethnically diverse group of stroke survivors or spousal caregiver and or severe strokes survivors including those that are incommunicative and/or comatose.

Conclusions

This study offers insight into the strengths and environmental influences on the ability of middle-age long-term married couples to successfully adapt following a stroke. Strong support and persuasive evidence exists for the assertion that social connections and social support are significant resources within a couple's relationship. Stroke survivors and spousal caregivers in middle-age long-term married couples also indicate that ecosystemic and personality factors in addition to the shared definition of ascribed to illness, are contributing components to successful and healthy post-stroke adaptation individually and as a marital dyad.

Despite the obstacles and challenges of adaptation following an unexpected medical crisis, these couples overcame their individual circumstances and moved forward with their lives. The couples in this present study offered rich and candid information regarding their struggles and successes in the face of a significant adversity. This can inspire all of us as we inevitably move into our older years to recognize the potential in all human beings to persevere regardless of life's demands.

Appendix: A Sample Letter to Participants

Date:

Dear (Name of Potential Research Participant):

Please allow me to introduce myself. I am currently a doctoral candidate in the department of Family and Child Ecology at Michigan State University. I am in the process of working on my doctoral dissertation which will explore the effect of a post-stroke adaptation on middle-aged couples in long-term marriages. I am seeking stroke survivors and his or her spouse who also meet the following inclusion criteria.

- Participants are 50 and older (middle-age)
- Participants have been married for no less than 10 years.
- Participants have no children living at home
- The stroke survivor is married to the same spouse at the time the stroke occurred and at the time this study is conducted.
- Survivor suffered a stroke within the past five years
- The survivor experienced only one stroke
- Couples must conjointly consider themselves to have successfully adapted following the stroke event.

While there is considerable research on spousal care-giver stress associated with chronic illnesses and disability, the effect on middle-aged couples in long-term marriages has not received comparable attention. Involvement in this study would require you to participate in an interview with the researcher asking open-ended questions regarding your individual post-stroke process and the impact you feel the stroke had on your couple relationship. You will be asked to tell your story, in your own words, including the environments in which you interacted following the stroke and consider what influence you felt these environments had on your ability to successfully adapt. Also, you will be asked to talk about what personal resources you feel helped you to adapt. The meeting and interview is expected to last for 2 hours and can be scheduled at a time and location that is convenient for you.

If you are interested in participating in this study or would like additional information, please contact me by telephone or e-mail. The contact information is provided below. The anticipated number of couples needed for this study is approximately 10. However, it is possible that data saturation may be reached prior to meeting with all interested participants therefore; all interested couples may not be interviewed but will be notified by the researcher should this occur. I would like to thank you in advance for your interest and willingness to participate.

Lori R. Stanley
(616) 942 – 7954 Home - (616) 862 – 7455 Cell
stanleyl@msu.edu

Appendix B: Informed Consent Form

The purpose of this research study is to explore the biopsychosocial impact and post-stroke adjustment in middle-age long term marriage partners. Specifically, this research study will explore the influence and presence of specific ecosystemic factors unique to these couples in an effort to determine if specific factors contribute to adaptive post-stroke coping behavior in both the stroke survivor and his or her spouse.

By listening to stories, we expect to learn how middle-age couples in long term marriages understand and experience the post-stroke consequences from an individual and couple perspective. The common themes and patterns that emerge are expected to contribute to the construction of grounded theory and direct clinicians in the development of effective therapeutic techniques and interventions for middle-age couples attempting to successfully adapt following a stroke.

The participants will share individual and conjoint post-stroke perspectives and experiences during a semi-structured recorded audio interview. The expected duration of each interview is 30 minutes. Stroke survivors and his or her spouse will be interviewed separately for 30 minutes and conjointly for 30 minutes. By hearing the stories of both the stroke survivor and their spouse, we expect to learn how couples perceive and experience a stroke from an individual and couple perspective.

I, _____, have been fully informed regarding the nature, extent, and purpose of participation in this research study conducted by Lori Stanley, a doctoral candidate at Michigan State University. I believe that at this time, I have had the opportunity to make a fully informed decision regarding my participation in this research study. For that reason, I understand the following:

- The purpose of this research study is to explore the biopsychosocial impact and post-stroke adjustment in middle-age long term marriage partners. The expected duration of my participation is approximately 3 hours.
- I will be interviewed in my home unless otherwise specified, individually for 30 minutes and conjointly with my spouse for 30 minutes. Each interview will be recorded with my prior consent and transcribed verbatim by the researcher.
- All information obtained in the interviews will be kept confidential and any written reports relating to these stories will not use names or other identifying data. Your privacy will be protected to the maximum extent of the law.
- My participation is voluntary. I have the right to withdraw or decline to participate at any time during the research study once participation has begun. I am protected from any adverse consequences, penalty, or loss of benefits to which I am entitled related to my withdrawal or refusal to participate.
- Research participants may contact the researcher at anytime during the research process to ask questions, receive answers, and discuss concerns regarding the research project and research participant's rights or in the event of research related injury to a participant. The researcher, Lori Stanley, can be contacted at:

- Home – Grand Rapids, MI (616) 942 – 7954
- Cellular Telephone – (616) 862 – 7954

If you have any questions regarding this study, please contact the Primary Investigator, Marsha Carolan PhD by telephone: (517) 432–3327, fax: (517) 432–3320, email address: email: carolan@msu.edu, or regular mail at: Human Ecology Building 13 D. Michigan State University, East Lansing, MI 48824.

- If you have questions or concerns regarding your personal rights as a study participant, or are dissatisfied at any time with any aspect of this study, please contact – anonymously, if you wish, - Peter Vasilenko, Ph.D., Chair of the University Committee on Research Involving Human Subjects (UCRIHS) by telephone: (517) 355-2180, fax: (517) 432- 4503, email address: ucrihs@msu.edu, or regular mail at: 202 Olds Hall, Michigan State University, East Lansing MI, 48824.

Your signature indicates your voluntary agreement to participate in this research study. If you agree to participate, please sign and date on the line provided:

Signature: _____ Date: _____

Your signature indicates your voluntary agreement to be audio taped. If you agree, please sign and date on the line provided:

Signature: _____ Date: _____

Appendix C: Semi-Structured Interview Guide

Human Ecological Theory

- 1. How do aspects of the ecosystem influence adaptation involving each member in post-stroke couples?**
 - 1a. What is most/least helpful in the medical system in regard to promoting adaptation?**
 - 1b. What types of social support are most/least helpful to post-stroke adaptation?**
 - 1c. How does the marital relationship itself, influence adaptability?**

Adaptive Theory – Sense of Coherence

- 2. How does sense of coherence (SOC) influence individual members of long-term marriages post- stroke adaptation?**

Social Constructionism

- 2. How does each member of the couple make meaning of the impact on their couple relationship?**

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