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*East Tennessee State University*

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Comeback of Appalachian Female Stroke Survivors: The Interrelationships of  
Cognition, Function, Self-Concept, and Interpersonal and Social Relationships

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A dissertation  
presented to  
the faculty of the Department of Nursing  
East Tennessee State University

In partial fulfillment  
of the requirements for the degree  
Doctor in Science of Nursing

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by  
Patricia M. Vanhook  
August 2007

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Keywords: Stroke, Female, Appalachia, Comeback, Chronic Illness Trajectory

## ABSTRACT

Comeback of Appalachian Female Stroke Survivors: The Interrelationships of  
Cognition, Function, Self-Concept, Interpersonal, and Social Relationships

by

Patricia M. Vanhook

The purpose of this descriptive correlational study was to examine the comeback phase of the Trajectory of Chronic Illness Management for Appalachian women stroke survivors. This study predicted comeback as a relationship between physical healing, biographical reengagement, and psychological coming to terms that was mediated by rehabilitation.

The concepts were evaluated through investigation of function and cognitive abilities, self-assessment of recovery, health rating, ability to control life, relationship changes, physical and mental health, and limitations of activities due to poor physical or mental health. Data were collected using, the Stroke Impact Scale (3.0) (Duncan, Bode, Lia, & Perera, 2003), the Relationship Change Scale (Guerney, 1971), and the Health-Related-Quality-of-Life-4 Scale (Morarity, Zack, & Kobau, 2003). Descriptive statistics summarized patient characteristics.

Continuous variables were analyzed using bivariate relationships expressed as Pearson correlation coefficients. The difference between groups (stroke severity and stroke type) and measurement variables were analyzed using independent *t*-test and ANOVA. Multiple linear regressions were completed to evaluate simultaneous effects of the independent variables.

Forty-six English-speaking, Caucasian women ages 40-78 who had experienced stroke at least 1 year prior to enrollment and were independently living in their home environment participated. The mean age was 57 years with survivorship ranging from 1 to 36 years. Function and cognition scores were similar to the established test range for the SIS V 3.0. Women with moderate ischemic stroke scored statistically higher for recovery score ( $p < .001$ ). A positive association was noted between health rating and recovery score ( $p < .001$ ). Women who had rehabilitation scored lower on recovery ( $p < .05$ ), memory ( $p < .05$ ), communication ( $p < .05$ ), handicap ( $p < .05$ ), and function ( $p < .05$ ). Improved relationships were noted for women with minor ( $p < .05$ ) and moderate ( $p < .001$ ) stroke.

Study findings suggest comeback can be predicted by the theoretical propositions of the Trajectory Theory of Chronic Illness Management: physical healing, biographical reengagement, and psychologically coming to terms (Corbin & Strauss, 1991). A strong relationship exists among the phases representative of comeback, while rehabilitation procedures and interpersonal relationships demonstrated only modest significance.

## DEDICATION

While growing up I understood clearly that my parents could not afford to send me to college. Armed with that knowledge, my journey in nursing education began in 1971. I discussed with my parents, James and Lorraine McKenzie, how I could be a nurse by attending the Wise County Vocational Technical School. I knew this would be the first step in a long and arduous journey from L.P.N. to Associate Degree R.N. to Baccalaureate in Science of Nursing to Master in Science of Nursing and finally, Doctor of Science in Nursing. Through my years of continuing education my mom and dad were supportive and proud to see their daughter achieve each milestone. I continue to feel their presence and support though they are no longer living. My most precious and loving support has come from my husband of 32 years, Phillip. He has weathered the storms with me, consoled me when I was inconsolable, given me strength to continue when I wanted to quit, and hugged me so tight after each graduation. My children sacrificed much through this process. Andy and Alicia find it difficult to remember a time when their mom was not going to college. I am eternally grateful to my family for their years of encouragement and support. Without them this journey would not have been possible.

## ACKNOWLEDGEMENTS

Throughout my doctoral program there have been so many individuals who have helped me to reach this goal. First and foremost I thank my dissertation committee members for their guidance and support throughout the dissertation process. I am forever indebted to Dr. Jo-Ann Marrs, my chair and mentor, who believed in this study from the first year of class work. Dr. Marrs understood that in my passion was something that would ultimately be of great significance to the stroke community. Dr. Juliet Corbin, upon whose theory this work has been derived, has lent invaluable support to further nursing knowledge in this one aspect of the Chronic Illness Trajectory. Dr. Judy McCook has led me through investigating health impact on women's lives by example and sharing the close similarities of this work and her work with Polycystic Ovary Syndrome. Dr. Tammy Pearson has provided insight into women with vascular disease and support for pursuing this important disease process. Lastly, Dr. Flowers has challenged me to take this study to the next level and to continue the work post graduation.

I want to thank Joe Smith ETSU public relations for his support to recruit my participants. Without his knowledge of the power of the press, it is unlikely I would be completing this work in 2007. Debi Pfortmiller has been a tower of support and patience as she helped me to analyze my data

Yet another important person in this endeavor is Dr. Lois Lowry. Dr. Lowry's positive reinforcement of my work and challenged me to look from another perspective. Thank you, Dr. Lowry, for your insight and allowing me to

journey into a world of positivism versus staying in my experience of negativism. In addition to Dr. Lowry, Dr. Jane Dunham-Taylor not only provided me the opportunity to be published but also guided me through a learning experience at the University of Alabama, Birmingham. These valuable lessons were not created in the classroom, but were made through professional collegial collaboration and mentorship.

I would not have been successful in this journey if it had not been for the years of faculty support at East Tennessee State University. Dr. Joellen Edwards as a new faculty member mentored me through the process of AD to BSN years before a formal program existed. Dr. Edwards has given me the strength to abandon my comfortable work life and pursue completion of this work. Without her assurance that I could transition into another professional direction, I would be a frustrated A.B.D. Peggy McConnell, RN, MSN has always been someone who I have looked up to as an example of the kind of teacher I would want to be should I ever have the opportunity to teach. Lastly, Dr. Priscilla Ramsey and Dr. Lee Glenn kept me fascinated and intrigued by neuropathophysiology in my master's program which ultimately led to my passion for stroke.

Throughout this process, I have gained some special friends and colleagues. Dr. Chris Smith, APRN who set her sights and her calendar and finished long ago and Joy Magness, APRN, DSN(C) who has shared my joy and pain when thinking all was lost due to no participants are two of the finest nurses and professional colleagues one can have. They frequently remind me life is short and live it to the fullest.

I wish to thank Kathryn Wilhoit, R.N., MSN, CNAA, FACHE for her support of nurses and their pursuit of further education. Without her support I could not have completed the course work in such a timely manner. Kathryn is a soul mate whose visions are greater than any nurse that I have ever had the opportunity to work with.

The women stroke survivors who have come back to live their life to the fullest are phenomenal. I am forever indebted to them for taking their time to share their life after stroke with me. They did not have to allow anyone to invade this very personal part of their lives, but they welcomed me with open arms and gave me such encouragement to continue this work.

The most important people in my life are my family. Without the support of Phillip, Andy, and Alicia, my dream would be unfulfilled. Phillip you have given patience and understanding. You have allowed me to have my books and papers in disarray with out disruption. You have thought of women who have become a part of this study. Lastly, our love has continued to grow throughout these many years of my educational endeavors. Andy and Alicia I am so proud to be your mom. You have grown to be such wonderful adults in spite of your mother being in school most of your lives. Yet I was able to be a part of your concerts, plays, and ballgames and as latchkey kids you have done well for yourselves. I am ending this journey while all the time remaining a wife, friend, lover, and mother. I thank you all.



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## CHAPTER 1

### INTRODUCTION

#### *Comeback*

Comeback: The process of overcoming disability is one of the nine phases described in the Chronic Illness Trajectory Framework (Corbin & Strauss, 1991). In this grounded theory work Corbin and Strauss describe the process of comeback as “returning to a satisfactory way of life, within the physical/mental limitations imposed by a disabling condition” (p. 137). One of the most prevalent disabling conditions occurring in the United States is stroke. Stroke affects more 465,000 people each year (American Stroke Association [ASA], n.d.). As the population ages, the incidence of stroke and stroke survivorship is expected to increase (American Heart Association [AHA], 2005) projecting an even higher prevalence of disability from stroke.

The increase in stroke survivorship will greatly affect aging women. Data from the American Heart Association indicates nationally each year 40,000 more women than men experience stroke (AHA, 2005). A survey conducted by the National Center for Health Statistics suggests the number is substantially higher (Lethbridge-Çejku & Vickerie, 2005). Lethbridge-Çejku and Vickerie discovered there were 5,070,000 self-reported stroke survivors in their survey conducted in 2003. This number included 3,052,000 survivors over the age of 64 of whom 2,649,000 were female (87%) (Lethbridge-Çejku & Vickerie).

Women who survive stroke are older, less educated, and more likely to be widowed or not married at the time of the stroke (Appalachian Regional

Commission [ARC], 2004; Kelly-Hayse et al., 2003). In addition, morbid disability from stroke is higher for women as they experience greater paralysis (57.4% vs. 40%), cognitive deficits (49.2% vs. 42.2%), and aphasia (23.8% vs. 11.6%) than men (Kelly-Hayse et al.). These deficits lead to increased dependency in performing activities of daily living (ADL) and decreased mobility that can lead to institutionalization (Kelly-Hayse et al.). For all stroke survivors, recovery is a life-long event, and for women, recovery may be more complicated due to the magnitude of the deficits, life circumstances, and geographic location of residence (ARC, 2004; Bauer & College, 2003; Bishop, 2005).

There is little research concerning women stroke survivors especially in central Appalachia. In addition, many epidemiologic studies provide data on stroke risk, incidence, and disparities leaving many questions about underserved populations unanswered (Stansbury, Huanguang, Williams, Vogel, & Duncan, 2005). This setting provides a unique opportunity to study women who have been portrayed in the traditional female role of sexual division of labor yet have been educated beyond their male counterparts (Drake, 2001). Research is needed to identify factors that influence stroke comeback and studying this population may provide insight to a unique population. This descriptive correlational study will explore stroke comeback of the Appalachian female.

### *Background of the Problem*

The Appalachian region comprises the state of West Virginia and counties within 12 additional states (Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, and

Virginia). Appalachia extends more than 1,000 miles from the southern tip of New York and ending in Mississippi (ARC, 2004). This region has historically been noted for poverty and limited access to health care (ARC). In 2004 the ARC reported 108 of the 406 counties comprising the Appalachian region were designated as health professional shortage areas (HPSA). The magnitude of the impact of HPSA is noted by a lack of hospitals in 203 counties. Health care access is mirrored by the economics of the counties within Appalachia. The ARC study identified 308 counties “at-risk” with 121 recognized as distressed due to poverty, unemployment rates, low income, and high mortality rate when compared to the national norm (Bauer & College, 2003).

Within the Appalachian region stroke impact on women is markedly increased above the national average. Limited access to care as noted in the ARC (2004) report may contribute to stroke mortality in Appalachia which exceeds that of the nation. The stroke mortality statistics of the border counties of Southwest Virginia, Northeast Tennessee, Northwest North Carolina, and Southeast Kentucky while varied, demonstrate a large gender and ethnic discrepancy (Centers for Disease Control and Prevention [CDC], 2004). The national stroke mortality for women is 117/100,000 yet the regional statistics indicate the mortality rate for women of the study region is much higher than the national average (CDC, 2004). In fact, 93% of the counties within the region of interest (Figure 1) are above the national average mortality for all women and 100% of the counties are above the mortality average for black women (Table 1).

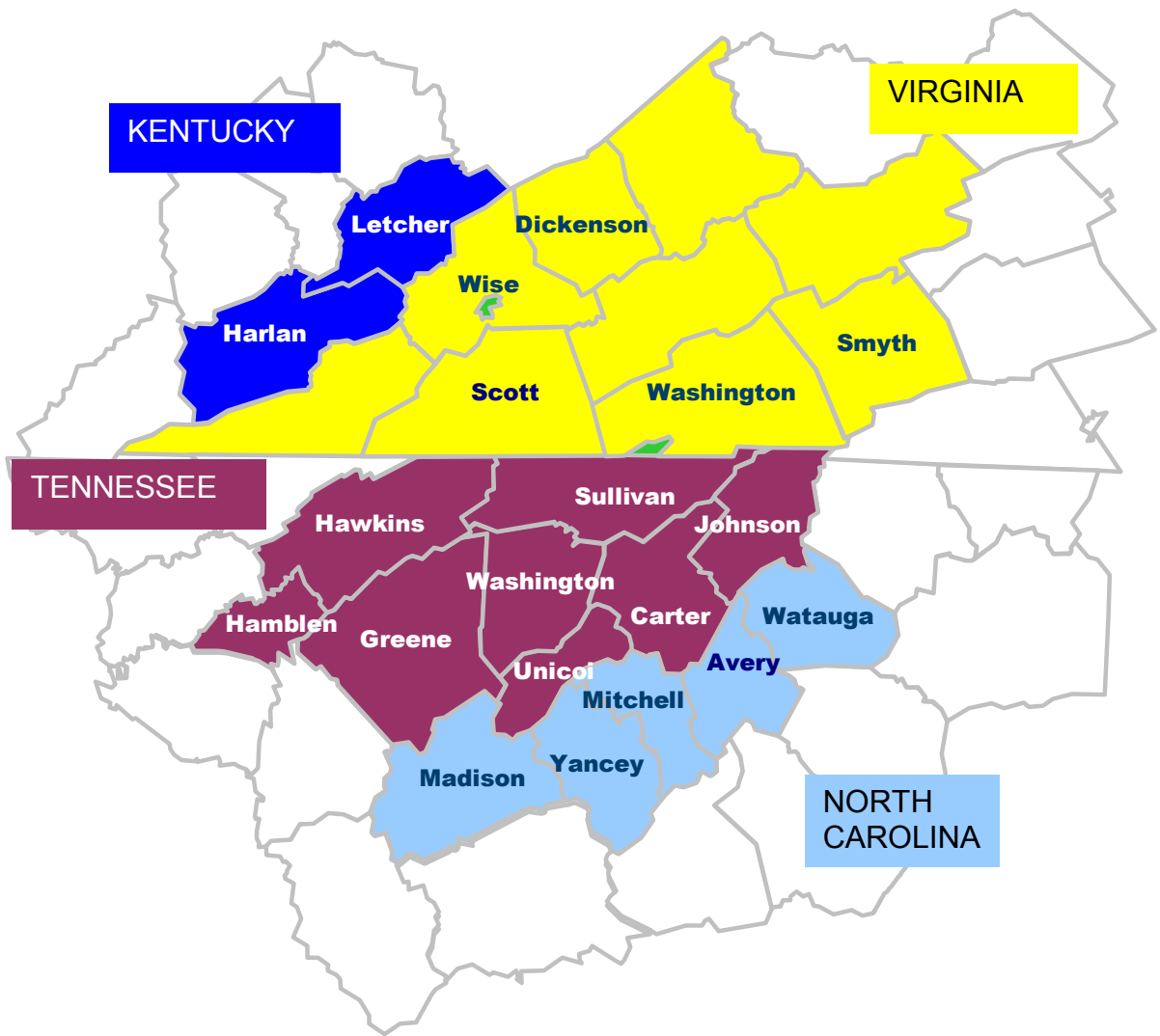


Figure 1. Regional Map.

Table 1

*Stroke Death Rates (per 100,000 age adjusted) 1991-1998 Women Ages 35+ (CDC, 2004)*

\*Insufficient data

| State             | County     | Rate for<br>all Women | Rate for<br>Black Women | Rate for White Women |
|-------------------|------------|-----------------------|-------------------------|----------------------|
| Kentucky          | Bell       | 119                   | 242                     | 116                  |
|                   | Harlan     | 111                   | 170                     | 109                  |
| Virginia          | Lee        | 118                   | 169                     | 117                  |
|                   | Wise       | 118                   | *                       | *                    |
|                   | Scott      | 120                   | 151                     | 119                  |
|                   | Washington | 121                   | 175                     | 120                  |
| Tennessee         | Johnson    | 125                   | 169                     | 124                  |
|                   | Carter     | 131                   | 157                     | 131                  |
|                   | Sullivan   | 130                   | 159                     | 129                  |
|                   | Washington | 136                   | 147                     | 136                  |
|                   | Unicoi     | 141                   | *                       | 141                  |
|                   | Greene     | 162                   | 194                     | 162                  |
| North<br>Carolina | Avery      | 121                   | 173                     | 119                  |
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Women of Appalachia have been identified as “at-risk”. The Greater Cincinnati Community Health Status Survey reported that adults at highest risk for stroke are white, poor, less educated, elderly, and widowed (Institute for Health Policy and Health Services Research at the University of Cincinnati, 1999). Access to health and rehabilitation services are a key issue; but lack of social support may be the reason for this population failing to return home, thus placement in long term care.

Family, independence, and closed community are the hallmarks of the Appalachian culture (Bauer & College, 2003). These characteristics influence the

personal vision of disability in terms of ability to live independently or within their role in the context of family. For many rural counties access to quality rehabilitation may be 200 miles from their home (Bauer & College). Traveling outside of the region for additional care is hindered by economic resources. In addition, venturing into new territory that is geographically different and has unfamiliar health systems is not an accepted cultural practice (Bauer & College).

Geographical barriers, cultural influences, and access to health care and rehabilitative services compound the complexities of stroke recovery for persons residing in rural Appalachia. Therefore, being a resident of Appalachia creates missed opportunities for the services of inpatient rehabilitation.

Many stroke survivors are entered into acute inpatient rehabilitation within days after their stroke. Rehabilitation hospitalization assists the stroke survivor to regain function and mobility with a goal of returning to the community. Yet, stroke survivors return to the community different from their existence prior to stroke. The skills that are gained during and after rehabilitation assist the stroke survivor to adapt to the role of being disabled (Burton, 2000).

The disabilities created by stroke affect the whole being of the stroke survivor. The essence of the disabilities fall into six domains: (1) *cognition* (ability to understand, remember, and be aware of deficits) (Hartman-Maeir, Soroker, Ring & Katz, 2002; Larson et al., 2003; McKinney et al., 2002; Patel, Coshall, Rudd, & Wolfe, 2002), (2) *health perception* (perceived effects of disease on abilities) (Hanger, Fogarty, Wilkinson, & Sainsbury, 2000; Ringler, Studenski, Wallace, Reker, & Duncan, 2002); (3) *role change* (Hopman & Verner, 2002;

MacKenzie & Chang, 2002; Moore, Maiocco, Schmidt, Guo & Estes, 2002; Studenski, Wallace, Duncan, Rymer, & Lai, 2001), (4) *self-concept* (Doswell et al., 2000; Moore et al.; Patel et al., 2006; Ringler et al.), (5) *relationships* (Alexander, Bugge, & Hagen, 2001; Derosier, Rochette, Noreau, Bravo, & Boutin, 2002; Studenski et al., 2001), and (6) *function* (ability to perform basic and independent activities of daily living) (Ahmed et al., 2003; Bagg, Pombo, & Hopman, 2002; Pettersen, Dahl, & Wyller, 2002; Roth & Lovell, 2003; Studenski et al.). Each of these areas has been researched independently or in conjunction with one or two other domains. These studies suggest a lack of stability of rehabilitation efforts over time, which means progress gained through rehabilitation efforts is lost over time and the residual deficits of stroke become the disabling factor(s) (White & Johnstone, 2000). Additional studies support these findings (Hilton, 2002; Patel et al., 2002; Pettersen et al.), thus indicating the need for further research to understand the complexities and interrelationships of stroke recovery domains and geographical and cultural influences.

### *Theoretical Perspective*

#### *Conceptual Framework*

A chronic illness has no known cure and is progressive in nature (Royer, 1998). The 1956 Commission on Chronic illness defined chronic illness as “all impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for



rehabilitation, and may be expected to require a long period of supervision or care” (Mayo, 1956). A stroke survivor meets all the characteristics of the chronic illness definition.

The theoretical base for this study is Corbin and Strauss’ *Trajectory Theory of Chronic Illness Management* (1988). Being a stroke survivor means living with a chronic illness. Living with a chronic illness is multi-faceted and includes more complexity than symptom control. The individual must learn to live with and adjust to physical, social, and psychological changes resulting from the event (Corbin & Strauss, 1992). Following years of research (Fagerhaugh & Strauss, 1977; Strauss et al., 1984; Strauss, Fagerhaugh, Suzeck & Wiener, 1985) Corbin and Strauss (1988) proposed a conceptual model to describe chronic illness. The model, the Chronic Illness Trajectory Framework considers the complexity of chronic illness as a dynamic process that “varies and changes over time” (p. 10). This research will use the tenets of this model as the foundation for the study.

#### *Trajectory Theory of Chronic Illness Management*

Studies of the dying patient by Anselm Strauss, Barney Glaser, and Jeanne Quint Benolell provide the rudimentary foundations of the Chronic Illness Trajectory Framework (Corbin & Strauss, 1992). Their observation of the evolutionary course of management of the dying process by the patient, family, and health professionals was a phenomenon that lacked definition, thus the term trajectory (Corbin & Strauss, 1992). Further development of the framework was a result of master’s and doctoral academic endeavors of nursing and sociology

students' studies of chronic illness, research on pain management, medical technology, and quality of life for the chronically ill. In the work *Chronic Illness and the Quality of Life* (Strauss et al., 1984) the Trajectory Theory of Chronic Illness Management became formalized as a conceptual framework (Corbin & Strauss, 1988). Further qualitative research by Corbin and Strauss (1988) using grounded theory methodology identified specific phases in chronic illness that became the model for chronic illness management.

The Trajectory Theory of Chronic Illness Management is recognized as middle-range explanatory nursing theory (Cooley, 1999). An explanatory theory “specifies relationships between two or more concepts”. An explanatory theory seeks to align with practice and is focused on a central concept (Chinn & Kramer, 1999). Fawcett (2000) contends nursing theory explains a specific phenomenon with a limited number of concrete concepts and propositions that are based on previous research. In addition, the theory has significant social and theoretical underpinnings that provide an opportunity to advance nursing knowledge.

Cooley (1999) completed an analysis and evaluation of the theory using Fawcett and Downs' (1992) formalization technique. Formalization of the theory provides an opportunity to expand and empirically question logic (Fawcett, 2000). Cooley's work identified the theory “has theoretical and social significance but that further clarification is necessary to enhance its use in research and clinical practice” (p. 93).

Nursing theorist, nursing researchers, and nursing academicians have varied world views regarding the evolution and evaluation of nursing theory. The

ultimate goal is to translate theory into practice that supports nursing's social and legal obligation to patients (Silva, 1999).

### *Theoretical Definitions*

*Physical Healing.* A central concept of the Chronic Illness Trajectory Framework is the "failed body" (Corbin & Strauss, 1988, p. 7). The failed body may result from a natural aging process that causes self-imposed decline in activities. When body failure is the result of a chronic illness or the immediate product of stroke, not only is performance decreased but also external and internal appearance may be altered (Corbin & Strauss, 1988). Body failure requires accommodations to be made not only by the individual surviving the stroke but also by family and others with whom there is a relationship.

*Rehabilitation Procedures.* Accommodation by the stroke survivor is accomplished through "work". Work is defined as "a set of tasks performed by an individual, or a couple alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness and the lives of ill people and their partners" (Corbin & Strauss, 1988, p. 9). For the intent and purpose of this research, work denotes rehabilitative efforts of the stroke survivor both formal hospitalization and informal within the home environment and the relationships that contribute to the management of stroke recovery,

*Biographical Reengagement.* Rehabilitative efforts are accomplished through the last major concept of the Chronic Illness Trajectory Framework which is "biography". Biography is defined as "life course stretching over a number of years and life evolving around a continual stream of experiences that result in a

unique –if socially constituted-identity” (Corbin & Strauss, 1988, p. 50). It is life events and relationships that create our self-concept or identity. This research will focus on the stroke survivor’s self-concept and its role in comeback.

*Psychological Coming to Terms.* As a new identity is constructed, the stroke survivor accepts or does not accept the unalterable quality of this chronic illness. Psychological coming to terms “involves a movement toward an understanding and acceptance of the irrevocable quality of chronic illness, of performance limitations accompanying it, death, and of the biographical consequences it brings about such as failed marriages, lost jobs, and dependency” (Corbin & Strauss, 1988, p. 76). As a part of the triad of comeback, interpersonal and social relationships will be measured to determine psychological coming to terms.

### *Summary*

The constitutive definitions physical healing, rehabilitation procedures, biographical engagement, and psychological coming to terms are the basis for comeback. They assist to frame this study of the stroke survivors’ physical issues (failed body), their rehabilitation efforts (work), and their sense of self as it relates to their own self-concept (biography) and that of others (psychological coming to terms).

### *Assumptions of the Study*

“Trajectory” is the foundation for the Trajectory Theory of Chronic Illness Management. The term trajectory is defined by Webster (Agnes & Guralnik, 2000) as a mathematical term: “a curve or surface that fits a particular law such

as passing through a given set of points” (p. 1518). This definition is very fitting as the model presents concepts that show the movement of the chronically ill person through phases that are the culmination of self, family, and health care provider efforts. Corbin and Strauss (1992) define trajectory as “The illness/chronic condition course requires the combined efforts of the affected individual, family, and health care practitioners in order to shape it.” (p.16).

There are nine “trajectory phases” in the model: pre-trajectory, trajectory onset, stable, unstable, acute, crisis, comeback, downward, and dying (Table 2) (Corbin & Cherry, 1997, p. 68-69).

Table 2

*Phases of Chronic Illness Trajectory*

| Phase            | Goal of Definition  | Goal of Management  |
|------------------|---|---|
| Pre-trajectory   | Genetic factors or lifestyle behaviors that place an individual or community at risk for the development of a chronic condition   | Prevent onset of chronic illness  |
| Trajectory onset | Appearance of noticeable symptoms includes period of diagnostic work-up and announcement by biographical limbo as person begins to discover and cope with implications of diagnosis   | Form appropriate trajectory projection and scheme                               |
| Stable           | Illness course and symptoms are under control. Biography and everyday life activities are being managed within limitations of illness. Illness management centers in the home   | Maintain stability of illness, biography, and everyday activities               |
| Unstable         | Period of inability to keep symptoms under control or reactivation of illness. Biographical disruption and difficulty in carrying out everyday life activities. Adjustments being made in regimen centers in the home                                 | Return to stability   |
| Acute            | Severe and unrelieved symptoms of the development of illness complications necessitating hospitalization or bed rest to bring illness course under control. Biography and everyday life activities temporarily placed on hold or drastically cut back | Bring illness under control and resume normal biography and everyday activities |
| Crisis           | Critical or life-threatening situation requiring emergency treatment or care. Biography and everyday life activities suspended until crisis passes  | Remove life threat  |

Table 2 (continued)

| Phase    | Goal of Definition  | Goal of Management  |
|----------|---|---|
| Comeback | A gradual return to an acceptable way of life within limits imposed by disability or illness. Involves physical healing, limitations stretching through rehabilitative procedures, psychosocial coming to terms, and biographical reengagement with adjustment to everyday activities | Set in motion and keep the trajectory projection and scheme |
| Dying    | Final days or weeks before death. Characterized by gradual or rapid shutting down of body processes, biographical disengagement and closure, and relinquishment of everyday life interests and activities   | To bring closure , let go, and die peacefully               |

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*Source:* (This table was originally published in *Advances in Gerontological Nursing: Chronic Illness and the Older Adult*, 1997 (pp. 68-69). Copyright Springer Publishing Company, Inc., New York 10036, Reprinted with permission.

The Trajectory Theory of Chronic Illness Management is multidimensional and includes symptoms, disability, and outcomes that traverse through the nine concepts incorporated within the context of the theory (Cooley, 1999). This constitutes the continuum of care and encompasses the nursing metaparadigm: person, health, environment, and nurse that are the domains of nursing (Fawcett, 2000).

An important aspect of a theory is the semantic clarity that is provided through a clear definition of terms that establish empiric indicators (Chinn & Kramer, 1999). Corbin and Strauss (1992) have presented definitions for each concept. The definitions are clear and concise, and the model has been operationalized in different patient populations including elderly with chronic illness (Robinson et al., 1993), cancer, cardiovascular disease (Hawthorne,

1992), HIV/AIDS (Nokes, 1992), mental illness (Rawnsley, 1992), multiple sclerosis (Smeltzer, 1992), diabetes (Walker, 1992), and a case study in stroke (Burton, 2000).

This study is focused on the comeback phase for the stroke survivor. Comeback is defined as “the process of returning to an acceptable way of life within the physical/mental limits imposed by a disabling condition” (Corbin & Strauss, 1991, p. 139). According to Corbin and Strauss comeback involves physical healing, limitations stretching through rehabilitative procedures, biographical reengagement with adjustment to everyday activities, and psychological coming to terms. The processes of comeback include “(1) mending, the process of physical healing, (2) stretching of physical limitations, pushing the body to the boundaries of its current limitations and thereby increasing the body performance as well as hastening and improving its mending through rehabilitation procedures and (3) reknitting, or putting the biography back together again, around the boundaries of residual body and social performance limitations” (Corbin & Strauss, 1988, p. 175).

*Comeback: The process of overcoming disability* (Corbin & Strauss, 1991) is a thorough description of the journey of recovery and returning to a “meaningful life” (p. 137) after a catastrophic event. The theoretical assumptions pertinent to this study and extracted from this publication are listed below:

- 1) “To comeback means not dwelling on performance impossibilities but on performance abilities” (p. 139)
- 2) “Comeback is not necessarily a physical phenomenon” (p. 139)



- 3) “Biographical work is accomplished through a process of forward and backward reviews. These take place through self-interactions and interaction with others, during which the disabled will grieve, confront the possibility of anymore carrying out certain performances, and also imagine new performances” (pp. 142-143)
- 4) “The aspects of self are lost through illness or injury disability are considered to be biographically significant.” (p. 145)
- 5) “There are appropriate resources-manpower, financial, technological, helpful devices, therapies-that can be drawn upon as needed.” (p.146)
- 6) “Marital partners and others act as “assisting agents”, assisting the disabled to carry out certain performances.” (p. 150)
- 7) “To protect the self, the disabled person may proceed slowly, staying close to the environment and persons know (n) to be supportive.” (p. 152)
- 8) “In time one becomes comfortable with oneself and one’s performance” (p. 154)
- 9) “...others must act as confirming agents by indicating that one’s performance is successful and also that whatever the loss in performance ability is peripheral to the relationships with themselves.” (p. 154)
- 10) “To comeback means to reconnect the body and the person of the past with the body and the person of the present through possible

performances, while accepting that certain performances have changed in nature.” (p.139)

### *Relational Propositions*

The intent of this research is focused on one aspect of the Chronic Illness Trajectory Framework, specifically comeback. Comeback is the process of adapting and rising above the disability. In the comeback phase constitutive definitions and the relational propositions are easily identifiable. According to Fawcett (2000), relational propositions of theories function to link the metaparadigm concepts of person, health, environment, and nursing. As these propositions incorporate global concepts that can serve as a basis for nursing practice in the care of the stroke survivor. The relational propositions for comeback follow (Table 3):

Table 3

*Metaparadigm Concepts*

| <i>Metaparadigm Concepts</i>                    | Relational Propositions  |
|---|--|
| <i>Person and Health</i>                        | "Medical stability and rehabilitation provide the structural conditions that facilitate eventual achievement of desired performances, those that are needed to put life back together again" (Corbin & Strauss, 1991, p. 140).   |
| <i>Person and Environment.</i>                  | "Learning how to work with and overcome limitations through a rehabilitation program provides the structural foundation for comeback" (Corbin & Strauss, 1991, p. 148)   |
| <i>Person and Nursing</i>                       | "There is a comeback initiator-physician, nurse, spouse, others –who gets the process going" (Corbin & Strauss, 1991, p. 145)  |
| <i>Person, Health, Environment, and Nursing</i> | "There is a tailored fit between the comeback plan and the person for whom it is designed medically, rehabilitatively, and biographically. Then, when the initial plan becomes outdated or seems inappropriate, the plan is updated to reflect the present realities" (Corbin & Strauss, 1991, p. 145) |

*Statement of Purpose*

The purpose of this study is to examine the relationships among physical healing, rehabilitation procedures, psychological coming to terms, and biographical reengagement that influence the comeback phenomena of rural Appalachian female stroke survivors. According to Corbin and Strauss (1991), a person encountering an acute illness or exacerbation of a chronic illness must engage in the process of comeback to achieve a new state of being. For the stroke survivor this means recovering some degree of cognition, learning to

accommodate to functional changes, accepting a new self-concept, establishing a new defined role, and maintaining or creating new interpersonal and social relationships. It is through the stages of comeback that transcendence or the overcoming of disability occurs. Successful comeback is crucial for the Appalachian women who survive stroke. Without successful comeback, it is unlikely that women will return to their home because they have more deficits and are more likely than men to enter into long-term care after a stroke (ARC, 2004; Institute for Health Policy and Health Services Research at the University of Cincinnati, 1999).

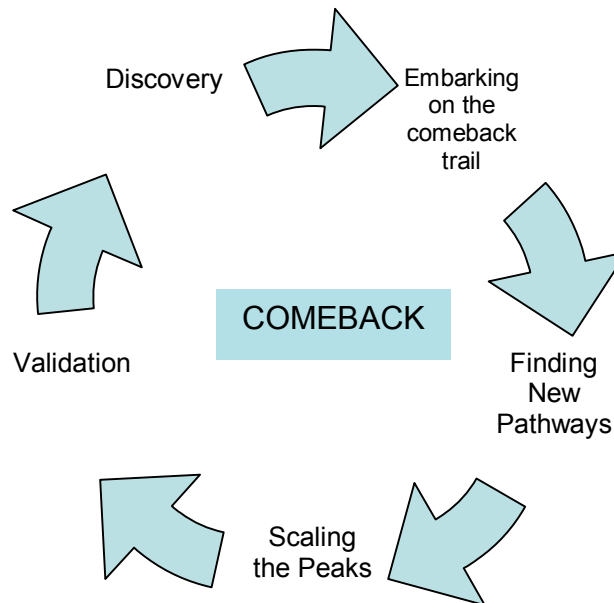
### *Research Question*

Stroke is a chronic illness that often imposes limitations on full return to a previous health state. The recovery process has been described by Corbin and Strauss (1992) in the *Trajectory Theory of Chronic Illness Management* as “comeback”. Comeback is not accomplished by one independent activity but is a process of transitions through stages:

- 1) Discovery
- 2) Embarking on the comeback trail
- 3) Finding new pathways
- 4) Scaling the peaks
- 5) Validation-confirmation of new self-image by sustained supportive relationships

(Corbin & Strauss).

Due to the nature of chronic illness, a person may return again and again to the stages of comeback after an exacerbation (Corbin & Strauss, 1991). The cyclical nature of this process is depicted in Figure 2.



*Figure 2. Cycle of Comeback.*

Beyond validation is transcendence. Transcendence is greater than full acceptance of disability by the stroke survivor. In transcendence, the stroke survivor develops a new self with a different direction and purpose in life (Corbin & Strauss, 1992). The ultimate goal of comeback is the return to an acceptable way of life that is dependent upon physical healing, rehabilitation procedures, biographical reengagement, and psychological coming to terms. A key assumption is that there are attributes that contribute to comeback that allow the stroke survivor to continue to live at home. The question to be determined by this research represents the underlying logic for designing and conducting this study:

Is comeback achieved when the stroke survivor regains cognition and

function (physical healing through rehabilitation procedures), positively envelopes a new self-concept (biographical reengagement), and positively engages in interpersonal and social relationships (psychological coming to terms)?

The independent variables are physical healing (cognition and functional ability), biographical reengagement (self-concept), and psychological coming to terms (interpersonal and social relationships). The dependent variable is transcendence or completion of all stages of comeback. The intervening variable is rehabilitation procedures.

The following diagram (Figure 3) depicts the relationship between the independent variables: 1) cognition, 2) functional ability, 3) self-concept, 4) interpersonal, and 5) social relationships, intervening variable rehabilitation procedures, and the dependent variable comeback.

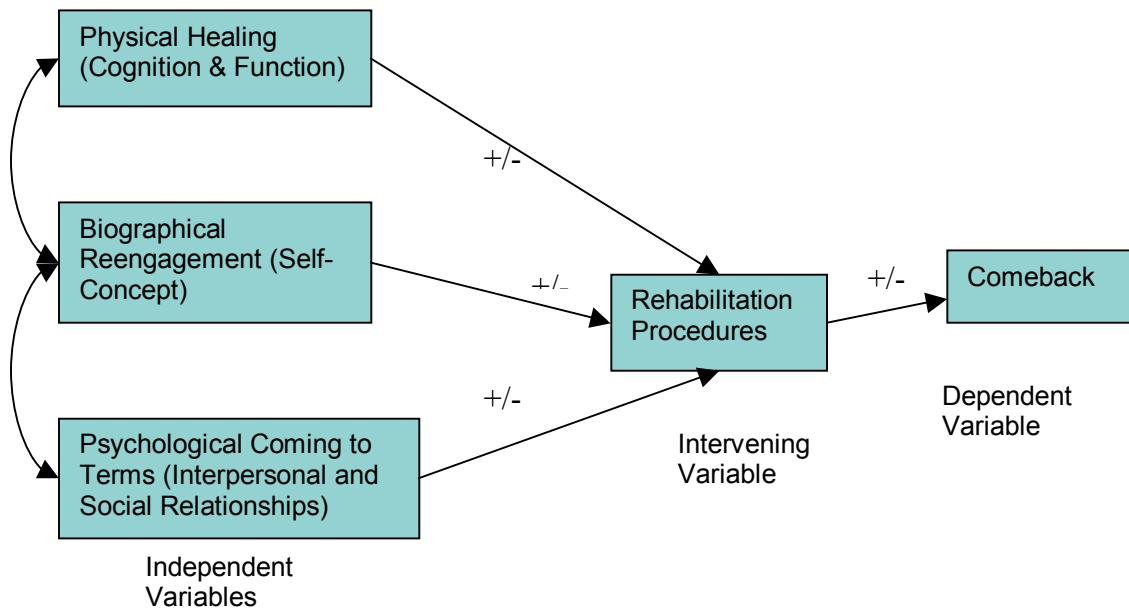


Figure 3. Relationships between Research Variables.

The study is holistic and multidimensional incorporating the known domains of stroke disability recovery including functional ability, self-concept, interpersonal relationships, and social relationships in the setting of rural Appalachia. Through this study the necessary components of comeback for the stroke survivor will be identified thus leading to improved care management beginning at the time of hospitalization.

### *Definitions of the Research Variables*

#### *Physical Healing*

Independence is gained through one's ability to function both physically and cognitively. A stroke is an insult to both mind and body and contributes to body failure. Body failure is defined by Corbin and Strauss (1988) as (1) "the body's inability to perform an activity, (2) the body's appearance, and (3) the

body's physiological functioning at the cellular level" (p. 50). The ability to understand language, to communicate, and to be aware of deficits is critical to stroke recovery (Hartman-Maeir et al., 2002). Those stroke survivors with cognitive impairment at 3 months have a high rate of institutionalization (Pettersen et al., 2002) and a high mortality rate (Patel et al., 2002).

For this study, the first criterion for physical healing is measured by assessing cognitive changes after stroke. The second criterion, functional abilities, which includes ability to perform activities of daily living, strength, hand function, and mobility, assesses the other physiologic parameter of physical healing.

### *Biographical Reengagement*

The term biography denotes "life course" (Corbin & Strauss, 1988, p. 50). There are three aspects of biography: (1) biographical time, (2) conceptions of self, and (3) body. Biographical time consists of past influences that create the present and together the past and present are the foundation for self in a future state (Corbin & Strauss, 1988). Conceptions of self are interwoven with biographical time and change depending on the "situations and social relationships" (1998, p. 53). "Conceptions of self" or self-concept is directly linked to biographical time as individuals adjust their conceptions of self based on the influence of different social and contextual circumstances.

Other authors support Corbin and Strauss' conceptual definition of conception of self. Neill (2005) noted self-concept is multidimensional and complex psychological awareness of the nature of being and one's beliefs of



varying aspects of self. According to Roy and Andrews (1999, p. 101) self-concept is “the composite of beliefs and feelings that is held about oneself at a given time, formed from internal perception and perceptions of others’ reactions.”

Lastly, conceptions of self are created via the body, which is the vehicle for knowledge, understanding, and communication. Self is a symbolic object, is a social being, and is able to function physically and mentally (Corbin & Strauss, 1988). It is the culmination of experiences that occur throughout an individual’s life that creates identity. It is from this identity that the nature of management of a chronic illness occurs. Biography comprehensively defines self-concept and for this study, the constructs of biography, self-concept, conceptions of self, and self-perception are synonymous.

#### *Psychological Coming to Terms*

Other individuals may influence self-perception in a supportive or deterrent role after an individual has a stroke. Interpersonal relationships have a central aim of meeting mutual needs for affection, growth, and the means to develop the relationship (Roy & Andrews, 1999). Being a stroke survivor, the resultant physical changes may limit the interaction in the relationship thus creating tension and emotional strain (Thibaut & Kelley, 1959). The tension and strain is alleviated or ameliorated by the actions and reactions of those closest to the stroke survivor.

Interpersonal relationships of those closest to the stroke survivor function as “assisting agents”, “protective agent”, and “identity agents” (Corbin & Strauss, 1991, p.150). “Assisting agents” serve to assist the stroke survivor in performing

tasks or functions that are limited by the deficits from the stroke. The manner that a stroke survivor proceeds to overcome deficits may be a deterrent to stroke recovery. When this occurs, the interpersonal relationships serve to protect the survivor by facilitating a progression that is conducive to meaningful recovery. While persons are serving to “protect” the stroke survivor, they also contribute to the survivor’s personal identity. The new personal identity is supported by the recognition, acknowledgement of the progress of the stroke survivor, and accepted by those individuals within the survivor’s circle of influence. The interpersonal relationships of the stroke survivor are fundamental to progression through the stages of comeback.

The final stage of comeback encompasses self-perception as validated by others through acceptance of the limitations acquired by the stroke as secondary when compared to interpersonal relationships. Social relationships differ from interpersonal relationships as there is no expectation to meet mutual needs. These relationships are founded within the stroke survivor’s community and could include social activities such as going to church, going grocery shopping, and going to hair salon appointments. The role of social relationships is to provide a source of activities that are meaningful to the stroke survivor’s life (Lai, Perera, Duncan, & Bode, 2003). Social relationships provide the support and acceptance for comeback through validating success in recovery and thereby supporting the stroke survivor’s psychological coming to terms (Corbin & Strauss, 1991).

### *Intervening Variable*

#### *Rehabilitation Procedures*

Rehabilitation procedures are defined as both admission and discharge from a federally designated and licensed rehabilitation hospital or receipt of therapy as an outpatient. The services provided include nursing care, physical therapy, occupational therapy, speech therapy, social services, rehabilitative medicine, and internal medicine.

#### *Delimitations and Limitations*

The group of interest in this study was women stroke survivors living in Northeast Tennessee, Southwest Virginia, Northwestern North Carolina, and Southeastern Kentucky. The selection of the study location was based on the designation of this segment of the United States that is known as the “Stroke Belt”, which has the highest incidence and mortality rate for stroke in the country (Howard, 1999).

Participation in the study was limited to those women that have experienced an ischemic or hemorrhagic stroke. An ischemic stroke is the result of thrombotic or embolic occlusion of a cerebral artery that may result in varied post event deficits depending on location of the occlusion and the area of brain tissue involved. A hemorrhagic stroke is classified as intracerebral (within the brain tissue), subarachnoid (bleeding into the subarachnoid space), intraventricular (bleeding into the ventricles), or subdural. The cause of hemorrhagic stroke may be a result of ischemic stroke or from cerebral aneurysm

or arteriovenous malformation (AV) (Lownie, 1998). Because subdural bleeding is often trauma related, individuals with a history of subdural bleeding were not included in the study. In addition, stroke survivors with a second event stroke were excluded from the study as these survivors add the dimension of multi-infarction that is greater in complexity than the scope of this study.

Participants were excluded from the study if they had severe receptive or expressive aphasia or cannot speak, read, or understand English, or were cognitively impaired. These limitations were established because the stroke survivor with aphasia is limited in the ability to understand the spoken word and those with expressive aphasia are unable to verbally express themselves. The nature of this inquiry required verbal exchange between researcher and participant. Non-English speaking stroke survivors were not included as the researcher is not bilingual and access to diverse non-English speaking stroke survivors was limited by the nature of the geographic area selected for the study.

The limitations to the study included (a) the study used a purposive self-selected sample; (b) the study involved stroke survivors with dissimilar types of cerebral infarctions and who are cognizant and able to communicate; (c) the study results may not be able to be generalized to both sexes, all ages, and stroke types and deficits; (d) the lack of stroke survival data that would provide the foundation for assuring adequate sample size; and (e) stroke survivors who are admitted to long-term care after hospitalization were excluded as the study is focused on the stroke survivor who has returned to the home environment. The

researcher attempted to configure an adequate sample size from local hospital and rehabilitation discharge data.

Internal validity threats were minimized through the use of well validated and reliable tools and the selection of statistical tests that are appropriate for the measurements selected.

The researcher acknowledges the selection bias in this study. Because so little is known about the aftermath of stroke for the Appalachian woman and long-term stroke outcomes, the researcher deemed it essential to limit the study to women of Appalachia who survive a stroke.

### *Significance of the Study*

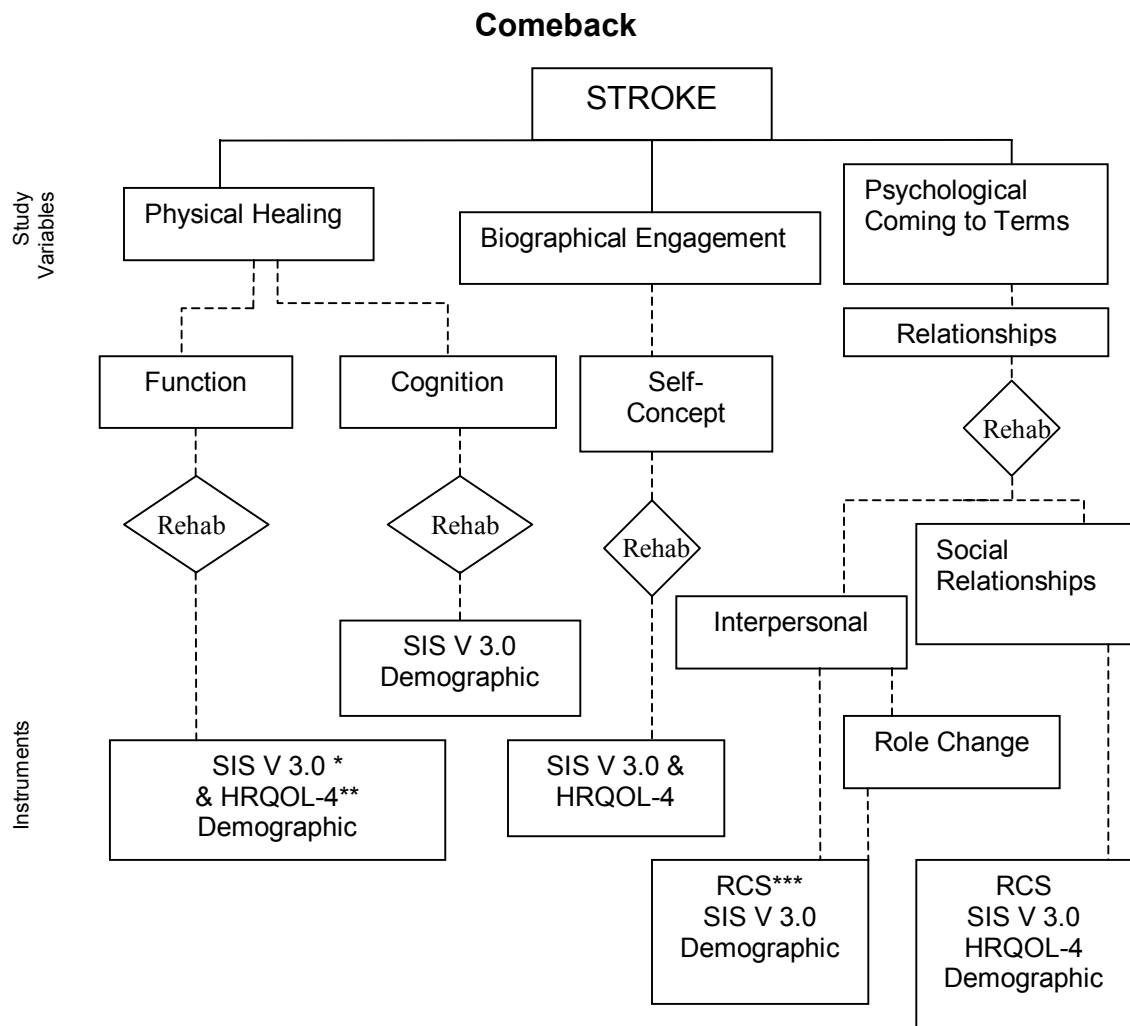
The nature of stroke does not allow the stroke survivor to fully return to life prior to stroke. Nurses lack the armamentarium to fully address not only the actual but also the potential ramifications of stroke. In acute care, the focus for nursing and medicine is management of the body failure crisis. This center of attention often does not encompass the person as a whole individual. The full meaning of stroke to the survivor as a person is lost by goals driven to regain function, cognition, and mobility.

As body failure initial crisis subsides, the focus of rehabilitative work begins to be defined (Corbin & Strauss, 1991). Each specialist becomes intent on recovery in each area of expertise such as speech (Speech/Language Pathologists), function (Occupational Therapy), and mobility (Physical Therapy). The nurse as the coordinator of care has the opportunity to assure the team goals incorporate and support biographical work. Coordination of care through

the theoretical lens of the Trajectory Theory of Chronic Illness Management encompasses a holistic team focused approach to comeback.

The final phase of theory completion is the derivation of testable hypotheses (Fawcett, 2000). One primary objective of this research is to define the attributes that lead to successful comeback after stroke. The characteristics of comeback then should be applicable to both chronic and acute illnesses. The findings may assist nurses to coordinate care that is holistically focused and assists the person to comeback from adversity. The relationship between the study variables and the study instruments is schematically presented below (Figure 4).

## Trajectory of Chronic Illness Management



\*Stroke Impact Scale \*\* Health Related Quality of Life-4 \*\*\*Relationship Change Scale

Figure 4. Links between Comeback, Study Variables, and Instruments.

### *Summary*

In this chapter the multi-faceted problem of stroke recovery was introduced. The sheer numbers presented provide the enormity of stroke as a public health concern. Research indicates as the incidence of stroke increases and individuals survive the stroke event, knowledge of the long-term consequences of stroke is needed to understand and identify interventions to support stroke survivorship as a chronic illness because stroke recovery is a life-long process. To support the stroke survivor in the ongoing process of recovery, it is important to understand the factors that contribute to recovery and independence.



## CHAPTER 2

### LITERATURE REVIEW

#### *Stroke*

##### *Stroke as a Disease Process*

Stroke was first called apoplexy by Hippocrates over 2000 years ago (University of Chicago Hospitals, 2005). While not knowing the pathophysiology of apoplexy, he accurately described the presenting symptoms of stroke as sudden onset of paralysis and change in health. It was not until the 1600s that apoplexy was identified by Jacob Wepher as bleeding in the brain and blockage of cerebral vessels (University of Chicago Hospitals). In 1928 apoplexy became defined as “cerebrovascular accident” or CVA and became officially differentiated as hemorrhagic or ischemic. Over time the term “CVA” has been replaced with stroke as the disruption of blood flow to the brain is not by accident, but caused by diseases of the circulatory system (Adams, del Zoppo, & von Kummer, 1998).

A joint venture by the CDC and National Institutes of Health (NIH) resulted in the publication, A Public Health Action Plan to Prevent Heart Disease and Stroke (U.S. Department of Health and Human Services Centers for Disease Control and Prevention, 2003). This publication provides the following formal definition for stroke: “a sudden impairment of brain function, sometimes termed “brain attack” that results from interruption of circulation to one or another part of the brain following either occlusion or hemorrhage of an artery supplying that area” (U.S. Department of Health and Human Services Centers for Disease Control and Prevention, p. 15). The disruption of blood flow to the brain via

either blockage or hemorrhage may cause death or disability for the stroke survivor.

*Prevalence.* Non-institutionalized stroke survivors increased 60% (1.5 million to 2.4 million) between the early 1970s and the early 1990s (AHA, 2005). In 2002 alone, there were 942,000 hospital discharges for stroke of whom 508,000 (61.5%) were female (AHA, 2005). Lastly, it is known that women who survive stroke experience greater deficits, thus leading to higher institutionalization after stroke (Kelly-Hayse et al., 2003).

*Incidence.* Stroke is the third leading cause of death and the leading cause of disability in the United States (AHA, 2005). There are 4.8 million non-institutionalized stroke survivors experiencing functional limitations on a daily basis (ASA, n.d.). “On the average, every 45 seconds someone in the United States has a stroke” (AHA, 2005, p. 16). The incidence of stroke is rising as the population ages (Bagg et al., 2002) and the numbers of stroke survivors are increasing as a result of greater availability of acute stroke interventions. The CDC (2004) estimates stroke incidence to be 700,000 per year with 500,000 being first ever stroke events. The individuals surviving a stroke often join the ranks of the disabled or become institutionalized (AHA, 2005).

The Southeastern United States has the highest incidence of stroke and has been named the “stroke belt” (Howard, 1999). Tennessee is one of the states with the highest incidence of stroke and stroke mortality and is ranked 33<sup>rd</sup> in the nation for stroke mortality (Tennessee QuickFacts, 2004). For Tennessee, the age adjusted stroke deaths is 73.3 per 100,000 compared to the national

average of 57.4 per 100,000 (CDC, 2004). Within the Northeast region of Tennessee, the counties of Hawkins and Greene have more than twice the stroke mortality rate for the state and three times that of the nation (163/100,000 Hawkins; 174/100,000 Greene) (Tennessee QuickFacts, 2004).

*Impact.* The burden of stroke is both financial and personal. The financial burden of having a stroke in 2007 is estimated to be \$62.7 billion (Rosamond et al., 2007), with an additional cost of \$20.6 billion in lost productivity due to morbidity and mortality (AHA, 2004). The financial cost of stroke is minimal when compared to the personal price that occurs. The personal burden of being a stroke survivor includes physical, mental, emotional, and social changes that can be devastating to both the survivor and the family (Doswell et al., 2000).

The long-term survival rate after experiencing stroke is poor. The American Heart Association (2005) reports 22% of men and 25% of women will die within the first year after stroke. According to the Framingham Study only 10% of stroke survivors under the age of 60 years will survive 20 years (Gresham et al., 1998).

Stroke recovery is a life-long process that needs to be understood. As a chronic illness we must identify interventions to support stroke survivorship as a chronic illness. To support the stroke survivor in the ongoing process of recovery; therefore, it is important to understand the factors that contribute to recovery and independence.

## *Deficits and Rehabilitation*

### *Deficits*

The research indicates the greatest impact of stroke deficits fall within six categories mentioned earlier which include cognition, function, health perception, self-concept, relationships, and role change. Within these categories the research suggests progressive decline occurs after rehabilitation (Hilton, 2002; White & Johnstone, 2000), but little research has been done to explain the interrelated factors that continue to contribute to recovery after discharge from rehabilitation.

There are six areas of consistency demonstrated from the evidence. First, only a small percentage (19%) of the research participants improves and maintains functional abilities 3 years after rehabilitation (Pettersen et al., 2002). Next, a lower ability to perform activities of daily living upon discharge from rehabilitation is congruent with both future cognitive and functional decline (Patel, et al., 2002). It has been determined that health perception plays an important role in determining future abilities as a lower perception of wellbeing is congruent with lower functional abilities (Hanger et al., 2000; Paul et al., 2005; Ringler et al., 2002). Also noted, role change is associated with depression (Derosier et al., 2002; Grant, 2004; Li, Wang, & Lin, 2003; Pound, Gompertz, & Ebrahim, 1998) and lowered self-concept (Doswell et al., 2000; Moore et al., 2002). Stress caused by caregiving is an additive factor that contributes to stroke survivor decline (Doswell et al.; Pierce et al., 2004). Several studies have noted that relationships and social support are significant factors in the perpetuation of

decline after rehabilitation (Derosier et al.; Li et al.; MacKenzie & Chang, 2002; Wang, VanBelle, Kukull, & Larson, 2002). Lastly, the goals of healthcare providers are not congruent with the needs and goals of the stroke survivor and care giver (Bendz, 2003; Moore et al.).

The greatest physical impacts of stroke deficits are cognition and function. The physical deficits influence health perception, self-concept, role change, and relationships. The following is a discussion of the categories identified in the literature beginning with an orientation to the history of rehabilitation followed by a discussion of stroke deficits domains of cognition, health perception, role change, relationships, self-concept, and function. The final discussion points are related to gender differences.

### *Rehabilitation*

Formal rehabilitation has its origins in nursing when the Chartered Society of Physiotherapy was formed in 1894 in England (Eugene Physical Therapy, 2005). A greater need for this service was promoted by World War I with the necessity for these services in the acute hospital setting (Eugene Physical Therapy). In 1914 the first program in the United States opened in Port Oregon in conjunction with Reed College and Walter Reed Hospital. The graduates of the program were hospital nurses educated to manage the multiple disabilities from war injuries.

After the war, polio became the primary disease of disability. Elizabeth Kenny a renowned Australian nurse came to the United States and began sharing her methods of physical treatment for polio. Though controversial, her

methods benefited the patients more than conventional treatment as evidenced by a decrease of residual paralysis from 85% to 15% (Pomerantz, 1999). Much of her work is the foundation for physical therapy today; enabling the disabled to enter or return to the workforce.

Historically anyone with a functional or mental condition was not allowed to enter into the workforce. Over the years, five key legislative acts have created opportunities for the disabled to enter the workforce. The first legislative act was the Randolph-Shepherd Act of 1930 (Standifer, 2000). This act allowed the severely visually disabled to operate vending booths on federal property. Next, as World War II began, the need for workers to replace service men and women was supported by the Rehabilitation Act of 1943 which expanded job opportunity eligibility to individuals with mental illness and mental retardation (Standifer). Following service, men and women returning home from war with disabilities much greater than those of the First World War; therefore, the Rehabilitation Act of 1954 was enacted. From this legislation federal funding for vocational rehabilitation and the National Institute for Disability and Rehabilitation Research (NIDRR) under the Department of education was formed (Standifer).

Under President Lyndon Johnson the “war on poverty” and services provided to the disabled became inundated with the “disadvantaged” that included many non-medical conditions such as repeat criminal convictions and individuals on welfare (Standifer, 2000). The Rehabilitation Act of 1973 refocused rehabilitation efforts on those with physical or mental disabilities and is updated every 5 years to refine definitions and assure equal rights for the disabled.

Lastly, the rights for the disabled were formally established by the Americans with Disabilities of 1990 (ADA) that recognizes disability as a naturally occurring event that does not diminish the rights of individuals to live independently in society, have free choice, and to be empowered to maximize self-sufficiency with respect and dignity (The U.S. Equal Employment Opportunity Commission, 1990).

This historical perspective of rehabilitation and legislation that has come to fruition over the last 75 years is pertinent to this research. Stroke survivors often experience stroke in their prime productivity years (ASA, n.d.). This ultimate financial burden of stroke is a total loss of productivity costing \$20.6 billion that includes \$6.4 billion related to morbidity and \$14.2 billion as a result of mortality (AHA, 2006). Any knowledge gained through this study could have a potential to improve stroke recovery comeback. A successful comeback could lead to return of productivity, thus decreasing the financial impact both personally and nationally.

### *Stroke Rehabilitation*

Many stroke survivors enter into rehabilitation within days after experiencing the event in order to regain function and mobility. However, studies have demonstrated the long-term success of rehabilitation for stroke survivors lacks substantial clinical evidence supporting its efficacy over time (Alexander et al., 2001; White & Johnstone, 2000). In the study conducted by Alexander et al. three significant health outcomes from stroke rehabilitation emerged: (1) those who received the greatest amount of rehabilitation services had the poorest

outcomes; (2) the rehabilitation services provided by Occupational Therapy demonstrated a change in function for first event stroke survivors not living in “deprived areas” (p. 213); and (3) nursing care improved mental health and social function. The conflict in their study comes from short-term changes at 3 months compared to 6 months. It was at the 6-month measure that only the recovery gained from rehabilitation care provided by Occupational Therapy and nursing were sustained.

The goal of rehabilitation is to return the stroke survivor to society with the abilities to function in a handicapped world by adapting to stroke deficits which may include deficits in cognition and functional abilities (Bendz, 2003; Burton, 2000; World Health Organization [WHO], 2002). The key concepts of disability classification include disease (stroke) as causation for physical and neurological symptoms that create impairments leading to disability and ending with handicap (Burton). The concept of transitioning disability into functional disability is linear in nature and is the ultimate outcome of rehabilitation (WHO).

### *Stroke Deficits*

#### *Cognition (ability to understand, remember, and be aware of deficits)*

For the stroke survivor to regain maximal functional ability, the survivor must be aware of deficits in order to learn compensation skills (Hartman-Maier et al., 2002). Detailed cognitive assessments on admission to rehabilitation centers provide some insight to cognitive function (McKinney, Blake, Lincoln, Playford, & Gladman, 2002). The long term effect of stroke on cognition may not be readily



noted during the acute and early rehabilitation phases but become obvious three months after the stroke (Patel et al., 2002).

Patel et al. (2002) studied 645 first event stroke survivors in an attempt to identify factors that may influence cognitive changes over time. Each participant's cognition was assessed using the Mini Mental State Exam (MMSE) at 3 months after the event with repeat assessments at 1, 3, and 4 years. Impairment in cognition at 3 months correlated with the long term outcome of ability to function independently at 3 years (OR=2.0, 95% CI= 1.2-3.3) and 3 years (OR = 2.2 95% CI = 1.1-4.5) after stroke (Patel et al., 2002). Other factors were found independently associated with lower cognitive abilities and included age (OR 2.5, 95% CI = 1.5-4.2), ethnic origin (OR 1.9, 95% CI = 1.2-2.3), and socioeconomic class (OR 4.8, CI = 3.1-7.3) (Patel et al., 2002)

With the aging community and limited resources, it has been suggested that age may become a consideration when determining use of rehabilitation services (Bagg et al., 2002). Cognitive changes are noted to occur more often with a stroke survivor over the age of 75 but cannot be predicted by lesion site or affected cerebral hemisphere (Hartman-Maier et al., 2002; Patel et al., 2002). It is postulated that the cognitive changes associated with stroke are difficult to differentiate from the aging process but are frequently associated with previously undiagnosed stroke and brain atrophy noted at the time of the acute stroke presentation (Tatemichi et al., 1990).

There are conflicting studies on the effect of cognition on rehabilitation outcomes. MacNeill and Lichtenberg (1998) studied the relationship between

cognitive ability on admission to rehabilitation and discharge home. They found low cognitive ability upon entry to rehabilitation predicts the unlikelihood for discharge of a stroke survivor back home for independent living (MacNeill & Lichtenberg). A more recent study by Yu and Richmond (2005) suggests cognitive impairment was not associated with rehabilitation outcomes of functional achievement, length of stay in rehabilitation, or discharge location but more of a factor for admission into rehabilitation services. The study revealed age greater than 80 years and admission function were the predictors of functional gain and rehabilitation efficiency (Yu & Richmond, 2005). Their findings of lack of admission to rehabilitation based on cognition are supported by a prior study by Patel, et al. (2002). Their results revealed that cognitive ability during the immediate post stroke phase precludes survivors from entering into rehabilitation and those survivors that decline cognitively over time have a high rate of institutionalization.

Cognition is a domain for stroke research. The literature suggests cognition is not an independent factor for the prediction of rehabilitation outcomes but when coupled with the effects of stroke from other domains of stroke deficits, it is likely to impede recovery and return to independent living (Meijer et al., 2005).

#### *Health Perception (perceived effects of disease on abilities)*

An indicator and predictor of health outcomes for both acute and chronic illness is an individual's perception of health status (Centers for Disease Control and Prevention [CDC], 2000). Measurement of health perception provides a gage

for current and future health care delivery demands because in general individuals use health services when feeling unhealthy (CDC, 2000). There are two aspects to health perception: that of the individual and that of the social consequences from other's perceptions of the individual's condition (Atchley, 1997). Either aspect may create imposed limitations that decrease quality of life and increase morbidity and mortality.

Health perception is a measure used to ascertain Quality of Life (QoL) and is a common outcome measure for studies involving stroke survivors and individuals with chronic illness. QoL is an individual perception and often reflects the person's perception of themselves, specific to this study is stroke survivor's perceived health status after the stroke. QoL outcome measures are often based on health perception from data obtained using tools such as the Behavioral Risk Factor Surveillance System (BRFSS) (CDC, 2000), Medical Outcomes Study 36-Item Short Form (MOS-SF36) (Alexander et al., 2001; Hopman & Verner, 2002; Ringler et al., 2002), Sickness Impact Profile (SIP) (MacKenzie & Chang, 2002), Assessment of Life Habits (Desrosier, Rochette, Noreau, Bravo, & Boutin, 2002), and General Health Questionnaire (McKinney et al., 2002). The questions included in the tools range from a simple question such as "Would you say that in general your health is excellent, very good, good, fair, or poor?" (Behavioral Risk Factor Surveillance System (BRFSS), CDC, 2000, p. 8) to broader based questions and statements that include items in the domains of general health, mental health, role emotional, role physical, social functioning, and vitality from the MOS-SF36.

The researcher's intuitive sense is those with lower function and disabilities have a lower health perception and thus a lower quality of life. There are inconsistent results from studies to indicate this is true. For example, Samsa and Matchar (2004) found only a weak correlation between function of stroke survivors and QoL with the average QoL reported by the survivors to be high. When they compared the results to findings from the same study completed with individuals without stroke but at risk for stroke, the results were similar. Thus, the intuitive sense that lower function correlates with lower health perception and QoL does not hold up.

Psychosocial factors have been identified as a key contributor to a higher health perception and thus QoL. Studies supportive of this finding have been completed on both healthy and ill individuals. Individuals with chronic illness (Han, Lee, & Park, 2003), men with HIV (Jia, Uphold, Wu, Chen & Duncan, 2005), individuals post hip fracture (Cree, 2004), spinal cord injury (Edwards, Krassioukov, & Fehings, 2002), and college students (Hale, Hannum, & Espelage, 2005; Ramey, 2005) had higher health perceptions when social support was present. The significance of this influence has not been studied in the rural Appalachian woman.

Aside from the social aspect, the psychological impact of depression has been linked to a lowered health perception (Frazier & Waid, 1999; Jia et al., 2005; Sullivan, Kempen, Van Soderen, & Ormel, 2000). Depression perpetuates decreased social interaction (Jia et al.) and functional ability (Saarijarvi, Salminen, Toikka, & Raitasalo, 2002) which further increases disability often

leading to institutionalization (Yu & Richmond, 2005). A perpetual downward cycle occurs when negative health perception is embodied by an individual that leads to decreased function and decreased QoL (Ringler et al., 2002). Thus, not only is health perception lower, the risk for long-term care increases which increases family and societal burden (CDC, 2000).

The fear of institutionalization and the perception of limited stroke recovery is a legacy worse than death for both non-stroke elders and stroke survivors (Hanger et al., 2000). Fifty-six elder adults, 28 stroke survivors and 28 elders with no history of stroke, were asked to rank different stroke outcomes including death. Many studies have previously demonstrated elders who have never had a stroke prefer death to being disabled (Gage, Cardinali, & Owens, 1994; Holbrook, 1982), but little has been studied about the stroke survivors' preference of disability or death. The results of the Hanger et al. study indicate both groups preferred a sudden painless death. However, the interesting finding of the study is the difference between the stroke survivors' view and that of the non-stroke participant. A higher percentage of those who had no history of stroke (61%) preferred death to disability while only 39% the stroke survivor group preferred death. This suggests stroke survivors have found some aspect of living with disability preferable over death.

Lastly, another area of health perception that has limited study is the impact of ethnicity. In a study of active rural Alabama women, health perception varied between African American and Caucasian women with white women reporting higher health perception (Sanderson et al., 2003). This raises the

question of ethnic differences between health perceptions of healthy and chronically ill women living in rural and urban settings. One study that represents health perception ethnic differences in the chronically ill is from Brown, McCauley, Levin, Contant, and Boake (2004). The study involved 218 patients with either mild-to-moderate traumatic brain injury (MTBI) or general trauma (GT). Ethnic differences for African Americans with MTBI was noted for general health perception as related to functioning ( $p < .02$ ) while Hispanic participants reported less availability of social support ( $p < .05$ ). The study suggests an interaction exists between the injury and resultant disability and the influence of culture (Brown et al.).

The factors that influence health perception include physical attributes, psychological grounding, social support, and ethnicity. When some or all of these factors are integrated there is a relationship between health perception and mortality rates (Chin, Zhang, & Rathouz, 2003; Kazis, Anderson, & Meenan, 1990; Ringler et al., 2002). Nurses caring for the acute and chronically ill patient have an opportunity to influence health perception. First, recognize the factors that contribute to low health perception. Then take action to educate the patient and family and work collaboratively with the health care team to influence appropriate referrals for management of issues that affect adjustment to the illness or disability (Harvey, 1992).

### *Role Change*

Adjustment to the disability of any chronic illness including stroke often involves role change not only for the person with the illness or disability but also

a change in roles of family and friends. Change in roles for the individual with an insidious onset of a chronic illness may be a gradual change. The suddenness of stroke creates an immediate (temporary or permanent) role change for the stroke survivor, family, and friends. Whichever the change, sudden or over a prolonged period of time, family dynamics are altered (Froch et al., 1997).

Role change theory proposed by Turner (1990) suggests role change occurs from the perspective of social roles. He divides social roles into four categories: 1) basic role that includes age and gender, 2) structural status role that is connected to one's family, occupation, or organized group, 3) functional group role that is one's place and contribution to a cultural group, and 4) value role that supports or negates values or values system. He defines role change as a "change in the shared conception and execution of typical role performance and role boundaries (Turner, p. 88)." This means that for role change to occur, something is lost or gained and from the loss or gain relationships change. According to Turner, successful role change is complementary; otherwise true role change does not occur but adaptation happens.

Individuals are expected to have certain physical attributes, coping behaviors, and demeanors that are socially acceptable and these attributes align the individual with "groups, organizations, and society (Turner, p. 87)." Disabled or malformed individuals do not have normal physical attributes and may find themselves not valued by society. Add older age to the disability, and the person is moved from a role of participant to nonparticipatory status or isolation (Heller, 1993). The isolation may occur from the perspective of the stroke survivor not

feeling valued. This lack of self-worth may create self-imposed distancing of family and friends. In addition family and friends distancing themselves from the stroke survivor thus contributing to decreased social interaction and support. The effect of isolation and low perceived social support is predictive of early death (Heller).

Doswell et al. (2000) define isolation and real or perceived lack of social support “rolelessness.” Rolelessness supports Turner’s (1990) theory that role change did not occur but the stroke survivor adopted passivity. The passivity is not necessarily self imposed but may be the result of the inability to maintain interactive relationships because of neurological changes, distance from family and friends, functional disability, and loss of economic resources. Adaptation versus role change leads to stress in the home environment with struggles to maintain survivor dignity, identity, and self-esteem (Pierce et al., 2004).

Role identity varies among individuals. For women the role identity may be wife, mother, daughter, bread-winner, companion, and friend just to name a few. Identity evolves from the experience of multiple roles that support personal and societal status and a sense of existence (Menaghan, 1989). The value of a particular role to the person differs based on the sense of its importance, affirmation of others, and continuity (Gillies & Johnston, 2004; Stenius, Veysey, Hamilton, & Andersen, 2005).

The value of the role is also embedded in society’s ideals and preconceptions of the attributes and duties fulfilled by the role (Stenius et al., 2005). The stroke survivor may be unconsciously placed into a devalued role by



society. This devalued role of being disabled may limit the opportunities for the stroke survivor to meet maximum recovery potential. When recovery potential is not met, the survivor has greater disability over time and furthering fewer acceptances by society (Stenius et al.).

There is a plethora of stroke survivor role change research published under the guise of caregiver issues (Blake, Lincoln, & Clarke, 2003; DeLaune & Brown, 2001; Moore et al., 2002; Pierce et al., 2004). These studies often focus on the burden and stress of being a caregiver of the stroke survivor. The findings of the studies demonstrate ill preparation for being a caregiver (DeLaune & Brown), lack of social support (Pierce et al.), and fear (Moore et al.).

Role change of the stroke survivor and caregiver frequently are reversed. What was once deemed matriarchal or patriarchal role changes after the stroke (DeLaune & Brown, 2001). Often the stroke survivor and the caregiver are ill prepared for the role change due to lack of knowledge of the disease process and personal attributes needed to become the primary care recipient and caregiver (Moore et al., 2002). Research suggests professional and community support are essential components of post-stroke recovery for both the stroke survivor and caregiver during the first year post-event as role transitions occur (Grant, 2004; Pierce et al., 2004).

The factors that influence successful role change are complex and multifaceted. Nurses have an opportunity to affect successful role transition through supportive family intervention beginning with the admission of the stroke patient to acute care. The nurse is a primary source for referral of the stroke

survivor and family to consultative resources that can provide continued support after discharge from acute care or from rehabilitation.

### *Self-Concept*

One aspect of successful role change for the stroke survivor is living with and accepting the disability associated with stroke through a positive self-concept (Ringler et al., 2002). Self-concept, self-image, self-esteem are terms often used interchangeably in the literature with measurements of self-esteem used to quantify self-concept. Webster's New World Dictionary (Agnes & Guralnik, 2000) defines self-concept as "self-image" (p. 1300) which is defined as "one's conception of oneself and one's own identity, abilities, worth, etc. (p.1301)". Self-esteem is defined as "belief in oneself; self-respect (p. 1301)." Definitions of self-concept from nursing literature include "an image or view of self and includes dimensions of self-knowledge, self-expectations, and self-evaluation" (Lindow, Shelestak, & Lappin, 2005, p. 249). Self-concept is the manifestation of behavior from the totality of interpretation of appearance, origin, capabilities, attitudes, and feelings (Morris, 1985). For this research positive self-concept is defined as the validation of one's abilities that promotes feelings of worth and self-respect (Corbin & Strauss, 1988).

Recent research pertaining to self-concept has been generated from the fields of sociology (Lewis & Neighbors, 2005), psychology (Kahng & Mowbray, 2005a), education (Moller, 2005), and health care (Lindow et al., 2005; Schneider & Forthofer, 2005). The studies have used varied approaches and theoretical bases. Ultimately, the studies have found determinants of self-concept are from

both internal and external influences. Internal influences include such concepts as egocentricity, locus of control, self-presentation, self-efficacy, and goal orientation to name a few. The external influences include such entities as disease processes, social support, and socioeconomic status. The influences on self-concept are not static but dynamic in nature (Ninot, Fortes, & Delignieres, 2005).

Becoming disabled changes not only physical abilities, but also impacts the entire social being and self-concept of the survivor and the caregiver (Hopman & Verner, 2002). The physical, cognitive, emotional, behavior, and social changes that occur because of stroke alter the stroke survivor's self-image (Pound et al., 1998). The stigma of being disabled and negative social reinforcement of self-worth is predictive of withdrawal (Kahng & Mowbray, 2005b). The stroke survivor withdraws from social interaction because of lack of independence which creates feelings of lack of usefulness (Hopman & Verner), and depression (Li et al., 2003). Social isolation occurs for both the stroke survivor and caregiver and is fostered by feelings of shame based on self-image (Doswell et al., 2000), dependency, and mood of the survivor (Hopman & Verner). Additive to social isolation is the lack of caregiver social support and is noted as another contributing aspect of cognitive and functional decline for the stroke survivor (MacKenzie & Chang, 2002; Moore et al., 2002). The lack of maintenance of self-worth leads to discontinuity, misery, and maladjustment (Doswell et al.).

Coping with the disabilities from stroke often challenges the stroke survivor's self-concept and may foster loss of personal identity. Identity loss is noted to be an aspect of a chronic illness (Gillies & Johnston, 2004), aging (Stenius et al., 2005), and injury-related disability (Sachs & Ellenberg, 1994). How an individual manages changes to identity is theorized by Whitbourne (1996) as a process of assimilation, accommodation, and balance. Identity assimilation is based on past experiences, abilities, values, and personality, while identity accommodation is changing identity as a result of new experiences (Sneed & Whitbourne, 2005). For the stroke survivor, identity assimilation would lead to maintain the status quo through rigid structured processes that were previously successful. Using identity accommodation, the stroke survivor's self-concept would change from a capable, self-respecting, and valued individual to needing external validation of self-worth. According to Sneed and Whitbourne (2005), those individuals using identity accommodation often do not have self-confidence, have low self-esteem, and have a high incidence of depression. A healthy balance between identity assimilation and identity accommodation assists the stroke survivor to preserve self-concept within realistic expectations of living with the disabilities from stroke.

"Managing the impressions of others is instrumental in regulating social rewards and consequences, maintaining or enhancing self-esteem, and constructing and maintaining the self-concept" (Lewis & Neighbors, 2005, p. 470). The preservation of self-concept from both internal and external means is critical for successful comeback for the stroke survivor (Corbin & Strauss, 1991).

## *Relationships*

The significance of relationships to healing and longevity is noted throughout the chronic illness and disability literature (Atchley, 1997; Bagg et al., 2002; Bishop, 2005; DeLaune & Brown, 2001; Frazier & Waid, 1999; Hale et al., 2005; Hansdottir, Malacrne, Furst, Weisman, & Clements, 2004; Holbrook, 1982; Kahng & Mowbray, 2005a; Kilian, Matschinger, & Angermeyer, 2001; Murray & Rhodes, 2005; Roth & Lovell, 2003; Tapp, 2001; Whitbourne, 1996; Yu & Richmond, 2005). The physical disability associated with stroke is only one hurdle for the stroke survivor. As the stroke survivor is recovering, maintaining relationships with family and friends is another aspect of focus by the stroke survivor (Lamer, 2005). Maintenance of relationships within the family and those within the community provide a support system for anyone with a chronic illness. When these relationships become estranged there is both physiological and psychological manifestations (Bediako & Friend, 2004; Craft et al., 2005; Kilian et al.).

Understanding the meaning of relationships in illness has been a spectrum of study from the psychological perspective (Bediako & Friend, 2004; Frazier & Waid, 1999; Papadoupoulos, 1995). The physiological effect of stress is well documented in the literature, but studies of the physiological effects of social support are limited. Recently a study has demonstrated the physiological aspects of social interaction in the reduction of brain ischemia caused by stroke. Craft et al. (2005), using mice models, have demonstrated social interaction decreases C-reactive protein that is suspected to be a risk factor for stroke.

While this finding is interesting, their study also demonstrated cerebral ischemia actually decreased after stroke as a result of socialization. The importance of this research is significant not only in post-stroke but also in the realm of primary prevention. Individuals with wide social support systems may reduce their risk for stroke, and if stroke occurs, the social supportive relationships decreases cerebral ischemia, thus improved outcomes.

The relationship change for both the stroke survivor and the family is sudden onset versus gradual change that is seen with insidious onset of chronic illness. The profound change brings realization of permanence of changes in the relationship, role, and responsibilities. The management of transition impacts not only the well being of the stroke survivor, but also that of family and other close relationships (Papadoupoulos, 1995). In a qualitative study by Pound et al. (1998) relationships post stroke varied from support to alienation. The wide variation was not explained as a consequence of the stroke, but the findings indicate the prior state of the relationship influenced the relationships post stroke.

Dramatic relationship changes may not occur until many months after returning home for the stroke survivor (MacKenzie & Chang, 2002). At this time the expectations of both the person with the chronic illness (stroke), the spouse, family members, or significant others may differ. For the person with the chronic illness (stroke), the expectation to cope, perform at a higher level than possible, and continue the same life-style adds additional stress to the relationship (Bediako & Friend, 2004; Papadoupoulos, 1995).

The strength of the interpersonal relationship is a significant contributor to coping with a chronic illness (Bishop, 2005; Kilian et al., 2001; Papadoupoulos, 1995;) and rehabilitation recovery (Hansdottir et al., 2004; MacKenzie & Chang, 2002; Wang, et al., 2002;). For example, MacKenzie and Chang found statistical significance between high social support and functional abilities at the end of 3 months ( $n=160$ ,  $p < .001$ ) with those stroke survivors perceiving less social support experiencing a decline in function ( $p < .001$ ).

Interpersonal relationships are changed by stroke. In the comeback stage, embarking on the comeback trail (Corbin & Strauss, 1991), support is provided by interpersonal relationships with spouse or family members acting as agents for rescue, assistance, protection, and identity. In these roles, the spouse or family provides assistance when needed versus not allowing the person to act independently, assisting recovery through keeping the recovering person on course, and treating the person with respect through acknowledgement of each and every success (Corbin & Strauss, 1991).

The role reversal that occurs because of the disability and the stress of caregiving leads to either fulfillment in the role (Corbin & Strauss, 1991; Pierce et al., 2004) or becomes an obstacle to recovery (Corbin & Strauss, 1991; Wang et al., 2002). The deterioration of social lives, pre-stroke relationships, and the magnitude of deficits contribute to relationship stress and the ability to provide care (Grant, 2004). When caregiving becomes a chore, relationships deteriorate and a high incidence of nursing home placement of the stroke survivor is noted to occur (Han & Haley, 1999).

Early assessment of the stroke survivor's interpersonal and social relationships has the potential to identify mechanisms for intervention to support throughout the acute crisis, rehabilitation phase, and beyond. We are learning the significance of maintaining positive relationships and their supportive interaction for recovery is not only psychologically sound but also is showing promise for physiological improvement that may affect functional outcomes.

*Function (ability to perform basic and independent activities of daily living)*

Functional disabilities are the hallmark of stroke deficits and are the primary focus of rehabilitation. The strongest relationship to disability is impairment in the use of leg and arm (Derosier et al., 2002). The loss of the ability to walk has a higher correlation with the magnitude of disability (Derosier et al.) and is the function that the stroke survivor and the family associate as progress in recovery (Mayo et al., 1999; Pound et al., 1998). Inability to perform this function often causes restrictions to access areas within the home and the community environments that were once frequented by the survivor (Pound et al.). Therefore, impaired functional ability becomes a significant contributor of social isolation.

As a neuroscience nurse practitioner, the most frequently asked question of the researcher by stroke survivors and their families was “when will I (he or she) be able to walk.” Short- and long-term prediction of functional handicap is extensively published (Hartman-Maier et al., 2002; Pettersen et al., 2002; Ringler et al., 2002; Sanchez-Blanco, Ochoa-Sangrador, Lopez-Munain, Izquierdo-Sanchez, & Fermoso-Garcia, 1999). The prediction of function is made based on



scores obtained from standardized tools (Orpington Prognostic Scale, Barthel Index, Rankin, and Frenchay Activity Index) with measurement periods varying from 2 months to 3 years. The study time frames of measurement and type of patients enrolled in these studies vary greatly. The variation does not create any difference in the ultimate outcome of the studies; stroke survivors decline in function over time.

### *Gender*

Gender disparity in health care is an international problem. In the United States the National Institutes of Health Division of the National Institute of Neurological Disorders and Stroke (NINDS) presented testimony to the House Committee on Energy and Commerce Subcommittee on Health indicating stroke as a major health concern for women, yet there is a need to understand differences that are gender specific (Penn, 2002). For example, carotid endarterectomy is the gold standard for treatment of symptomatic carotid disease as a means for stroke prevention (Barnett, Meldrum, & Eliasziw, 1998). This treatment methodology has not been as successful in women as in men. The North American Symptomatic Carotid Endarterectomy Trial (NASCET) and the ASA and Carotid Endarterectomy Trail (ACE) groups have demonstrated surgical treatment for symptomatic carotid artery disease poses a higher risk of perioperative mortality for women (2.3% versus 0.8%  $p=.002$ ) (Alamowitch, Eliasziw, & Barnett, 2005). Gender differences in stroke symptoms are now being recognized. The classic stroke presentation of change in balance and hemiparesis is less likely to occur in women than in men (Labiche, Chan, Saldin,

& Morgenstern, 2002). The women studied by Labiche et al. presented with “unclassified neurologic and nonspecific” (p. 456) symptoms (69.2% versus 30.1%). The results of this study suggest that increases in stroke mortality and higher incidence of greater debilitation may be related to the lack of recognition of stroke symptoms in women which is often different from the classic and typical presentation.

On the international front, gender differences are also noted. Vos, Gareebo, and Roussety, (1998) reported ethnic and gender differences in cardiovascular (CVD) and cerebrovascular (stroke) mortality on the island of Mauritius. For all ethnic groups, mortality from CVD and stroke are higher than the international standard. Using standardized mortality ratios with Hindu ethnicity as the standard population, the mortality rate from stroke for women as a whole increased from 149/100,000 in 1972 to 210/100,000 between the years of 1989 and 1994 with no difference based on ethnic origin.

The literature supports evidence of barriers for access to rehabilitation services. Menz et al. (1989) studied the outcomes of women referred to Vocational Rehabilitation (Voc Rehab) for retraining. The goal of Voc Rehab is to assist the individual to become personally independent and economically self-sufficient (Menz et al., 1989). The multi-state study was conducted over a period of 13 years from 1972 to 1984. On entry into the program the financial income of both sexes was equitable. The study revealed neither men nor women made great financial strides after completion of the program. There was a striking difference after completion of the program in regards to economic independence.

The earnings for men were 67% higher than that of women and 20% of the women required public assistance. Women were also placed in lower paying skill level rehabilitation strategies that in turn added to the occupational segregation of the disabled woman.

While Menz et al.'s (1989) study is dated; it presents a classic example of gender inequity among disabled women that is consistent with access to services today. In a recent study, disparity in rehabilitation referral for subarachnoid hemorrhage (SAH) has been noted by MacLeod and Smith (2005). The only stroke subtype that is higher for women than men (age-adjusted) is SAH (Mosca et al., 1997). Macleod and Smith noted a distinct disparity in referrals and admissions to neurorehabilitation in Edinburg, Germany for women with (SAH) and traumatic brain injury. Comparison of hospital and rehabilitation admission showed more women ( $p < .01$ ) were admitted to the hospital for SAH and more men ( $p < .05$ ) were admitted to rehabilitation. The authors suggest the differences may be related to bias due to occupation and age, and recovery may have been more significant for women requiring less rehabilitation.

A gender difference in acute care management has been highlighted by a Canadian study by Kapral et al. (2005). Presentation, diagnostic studies, and medication management were similar between men and women. The dissimilar findings included women who were less likely to be admitted to a stroke specialty unit (18% versus 21%), to have lipid assessment (59% versus 64%), to experience longer length of stay ( $p=0.0108$ ), and to be discharged to long-term care ( $p<.001$ ). Even though it has been demonstrated in multiple studies stroke

care in a specialty unit improves patient outcomes, the studies indicate disparity in management for women experiencing stroke (Indredavik, Bakke, Slordhal, Rokseth, & Haheim, 1988; Jergensen et al., 2000; Langhorne, 1997; Rudd, Hoffman, Irwin, Lowe, & Pearson, 2005; Sutler, Elting, Langedijk, Maurits, & Keyser, 2003). Needless to say, the 6-month follow-up revealed significant decrease in Stroke Impact Scale-16 (SIS-16) for women even with adjustment for age and stroke type ( $p=.0001$ ) (Kapral et al.).

The above are only a few examples that demonstrate the need for studies devoted to women's stroke pathophysiology, primary and secondary prevention, acute care, and rehabilitative care. The goal of this research is not intended to study women from the feminist perspective of oppression or to ignore the needs of the male stroke survivor (Thorne, McCormick, & Carty, 1997) but to increase understanding of the issues that promote comeback after stroke in the Appalachian female.

### *Summary*

The literature reviewed includes studies from the disciplines of nursing, medicine, public health, and rehabilitation. Phenomenology using grounded theory is the basis for the all of the qualitative studies and from the researcher's perspective a conceptual framework for the quantitative studies is not evident. The theoretical approaches to the studies are predominately focused on the functional rehabilitation of the stroke survivor.

Stroke has been recognized as a public health problem for over 2000 years (University of Chicago Hospitals, 2005). Stroke, being the number one

cause of disability, continues to create heavy financial burdens for the survivor, the survivor's family, and the public health system. The CDC and the NIH have collaborated to educate the public about stroke in order to facilitate early recognition and intervention that may possibly lead to better outcomes.

The mechanisms of stroke rehabilitation are often limited to physical aspects and the accommodation for deficits. There is minimal consideration of the psychological, social, or environmental needs during or after rehabilitation (Burton, 2000). Once returned to home, the environment is foreign for the disabled survivor and the social support may be non-existent or diminished from fatigue or other family obligations.

Post-stroke research is frequently done on patients who have entered into rehabilitation hospitals. Many stroke survivors may now be discharged home or use skilled care versus inpatient rehabilitation. Longitudinal studies to date have not studied these stroke survivors to assess function, cognition, or quality of life post stroke.

Stroke can be a devastating chronic illness. Long-term survival is poor and little is known about the characteristics that promote a successful comeback that enables the stroke survivor to return home. Successful comeback is not confined to the ability to regain function but is a complex process. The process involves the intricate relationship between the stroke survivor and life-long support systems.

Stroke affects the whole being of the survivor. The literature supports there are many aspects of stroke recovery. Stroke comeback is not only

dependent upon the pathophysiological damage, but the process of physical healing, rehabilitation procedures, and biographical engagement that captures the stroke deficit domains identified in the literature: (1) cognition, (2) function, (3) health perception, (4) role change, (5) self-concept, and (6) relationship change.

The literature supports the need to study women who have stroke. Stroke in women has a high mortality rate and the literature supports suboptimal acute care is afforded women with stroke (Kapral et al., 2005). For those women who survive, there are barriers to access to rehabilitation (Menz et al., 1989).

The literature reviewed indicates stroke recovery is multi-faceted and multi-dimensional. The author believes there is not one single aspect of stroke recovery that can be separated from the other and a study involving rural Appalachian women's comeback after stroke will help understand the interactive processes that support comeback.

Corbin and Strauss' (1988) *Trajectory Theory of Chronic Illness Management*, the comeback phase (Corbin & Strauss, 1991), can be visually depicted (*Figure 2*) to demonstrate the relationship between the known domains affected by stroke and the end point of comeback. The domains do not stand alone but are dependent or co-dependent on each other in order for comeback that allows stroke survivors to return to their home environment. It is these relationships that have yet to be studied.

## CHAPTER 3

### RESEARCH DESIGN

To investigate the study variables a cross-sectional, correlation design was completed. The intent of the research was to recruit a purposive sample of women who had experienced an ischemic or hemorrhagic stroke from Northeast Tennessee, Southwest Virginia, Southeast Kentucky, and Northwest North Carolina. However, only women from Northeast Tennessee and Southwest Virginia responded to the recruitment call. Participants were asked to meet with the researcher. At that time, the demographic tool (Appendix A), Stroke Impact Scale (Appendix B), Relationship Change Scale (Appendix C), and Health-Related Quality-of-Life Scale (Appendix D) were completed. These standardized questionnaires were selected to investigate cognition, functional ability, self-concept, and interpersonal and social relationships that were selected measures of the attributes of comeback.

#### *Study Subjects*

Women between the ages of 40 and 78 years who had been diagnosed with stroke, hemorrhagic or ischemic, at least 1 year prior to the interview and were independently living in a home environment were eligible to participate in the study. Participants were required to be able to read and write English or have a proxy who was able to provide written consent for participation. In addition the women had to be able to communicate and understand oral directions. Study exclusions included men stroke survivors, women less than 40 or older than 78 years or age, those with a second event stroke, and those women who were

unable to speak or read English or did not have a proxy to provide written consent for participation.

### *Sample Size Estimation*

To determine the sample size discharge data from four local hospitals (licensed beds totaling 1,072) were queried using ICD 9 codes 430 (subarachnoid hemorrhage), 431 (intracranial hemorrhage), and 434 (ischemic stroke with infarction) for the time period of October 1, 2004, through September 30, 2005. The data showed 61 women between the ages 40 and 78 were discharged alive from the system with a primary diagnosis of stroke. Based on data from the American Heart Association, 25% of female stroke survivors will die within the first year, the sample size for this study was determined to be 46 (AHA, 2006).

### *Study Procedure*

Permission was obtained from the East Tennessee State University/VA Medical Institutional Review Board. Women were recruited for the study through various means including advertising through newspaper and television, and brochures disseminated to senior centers, health fairs, primary care and neurologists' offices, beauty salons, social services departments, local pharmacies, hospital waiting areas, parish nurses, and community clinics.

Participants were screened via telephone to assure appropriate inclusion criteria are met. Once identified as meeting criteria, participants were invited to meet with the researcher at a place of their choosing within their community. All



participants signed an informed consent and a HIPPA waiver for access to medical records information.

Demographic data were collected following informed consent prior to beginning the interview process Appendix A). The interviews using the SIS V 3.0 (Appendix B), the Relationship Change Scale (Appendix C), and HRQOL-4 (Appendix D) was conducted by the researcher and took approximately 1 to 2 hours to complete. After completion of the interview each participant was presented with a \$20 Wal-Mart gift card as a token of appreciation.

Every attempt was made to assure confidentiality by assigning the participant a case number. It was 0716 followed by a random three-digit number (Appendix E & F). This number was listed on all tools used during each interview. In addition, all paper data were kept in a locked file in the researcher's office and the electronic data were password protected and accessible only by the researcher. The researcher maintained a master list of participants' names, consent forms, study ID number, and any additional essential information necessary for access to abstract medical record information. The researcher was the only individual with access to the participant name, ID, and completed surveys. The study files will be maintained for 10 years as directed by the ETSU/VA IRB.

### *Data Collection*

Women who gained knowledge of the study through flyers, brochures, media, or other health professionals made the initial contact with the researcher inquiring about the study. After learning the specific requirements for

participation, an appointment was made to meet the women at a location of their choosing that was convenient for the participants. Each participant was asked to read and sign the informed consent document and the HIPPA waiver prior to the interview. Upon obtaining consent the interview began. Following informed consent, the questionnaires were read to the participants by the researcher in a private location.

### *Analysis Methods*

All data were entered then analyzed using SPSS 14.0. An alpha level of .05 was established for all statistical tests as appropriate. Descriptive statistics (means and standard deviations) summarized patient demographic characteristics. Continuous variables were analyzed using bivariate relationships expressed as Pearson correlation coefficients. The difference between groups (stroke severity and stroke type) and the measurement variables were analyzed using independent *t*-test and ANOVA. Lastly, multiple linear regressions were used to evaluate simultaneous effects of the independent variables.

### *Independent Study Variables*

“Coming back is the process of returning to a satisfactory way of life, within the physical/mental limitations imposed by a disabling condition (Corbin & Strauss, 1991, p. 137).” The three independent variables for comeback are physical healing, biographical reengagement, and psychological coming to terms. The variables and the attributes of measurement are summarized in Table 4.

Table 4

*Study Variables*

| Independent Study Variables  | Measurement  |
|--|--|
| I. Physical Healing<br>(Cognition and Functional Ability)                      | <ul style="list-style-type: none"> <li>• Memory (SIS V 3.0 section 2)</li> <li>• Communication (SIS V 3.0 section 4)</li> <li>• Physical comprises ADL/IADL, mobility, hand function (SIS V 3.0 sections 1,5,6, &amp; 7)</li> <li>• Number of days physical health not good (HRQOL-4 question 2)</li> </ul>                                |
| II. Biographical Reengagement<br>(Self-Concept)                                | <ul style="list-style-type: none"> <li>• Recovery score (SIS V 3.0 section 9)</li> <li>• Ability to control life (SIS V 3.0 section 8, question g)</li> <li>• Rating of health (HRQOL-4 question 1)</li> </ul>   |
| III. Psychological Coming to Terms<br>(Interpersonal and Social Relationships) | <ul style="list-style-type: none"> <li>• Handicap (participation) (SIS V 3.0 section 8)</li> <li>• Number of poor mental health days(HRQOL-4 question 3)</li> <li>• Limitations due to number of poor physical and mental health days (HRQOL-4 question 4)</li> <li>• Personal relationship changes (Relationship Change Scale)</li> </ul> |

*Physical Healing*

The initial insult of stroke requires much effort for physical healing with the primary focus of “body mending” as the goal of medicine (Corbin & Strauss, 1991). This study involved women who have survived stroke past 1 year and are living independently at home. The measures for physical healing were functional ability and cognition.

### *Biographical Reengagement*

Once physical healing has begun, each woman surviving stroke, encounters the reality of a new self. The initial phase of discovery of the new self may be met with motivation to overcome insurmountable odds (Corbin & Strauss, 1991). Over time, the awareness that the bodies may not recover to pre-stroke capacity may lead to depression and ultimately lowered quality of life (Haacke et al., 2006). When acceptance of the new body change occurs, the women are comfortable with themselves and their performances, a new self-concept arises. The final test is the validation by others (Corbin & Strauss, 1991). The measures for biographical reengagement included recovery score, rating of health, number of poor mental health days, and ability to control life.

### *Psychological Coming to Terms*

The women who survive stroke to accept themselves and to come to terms psychologically must be validated by those closest to them. According to Corbin and Strauss (1991) "Others must act as confirming agents by indicating that one's performance is successful and also that whatever the loss in performance ability is peripheral to relationships" (p. 154). This phase was measured using the SIS V 3.0 subscale domain for participation, the Relationship Change Scale, and the Health-Related-Quality-of-Life-4 questions 3 and 4.

### *Intervening Study Variable*

#### *Rehabilitation*

Comeback is facilitated through rehabilitation (Corbin & Strauss, 1991). Formal programs of rehabilitation may be provided as inpatient hospitalization, outpatient care or may be delivered in the home by a home health agency. Some stroke survivors do not receive any formal rehabilitation procedures if no focal neurological deficits occurs post stroke. This variable was coded as a yes or no item on the demographic information tool.

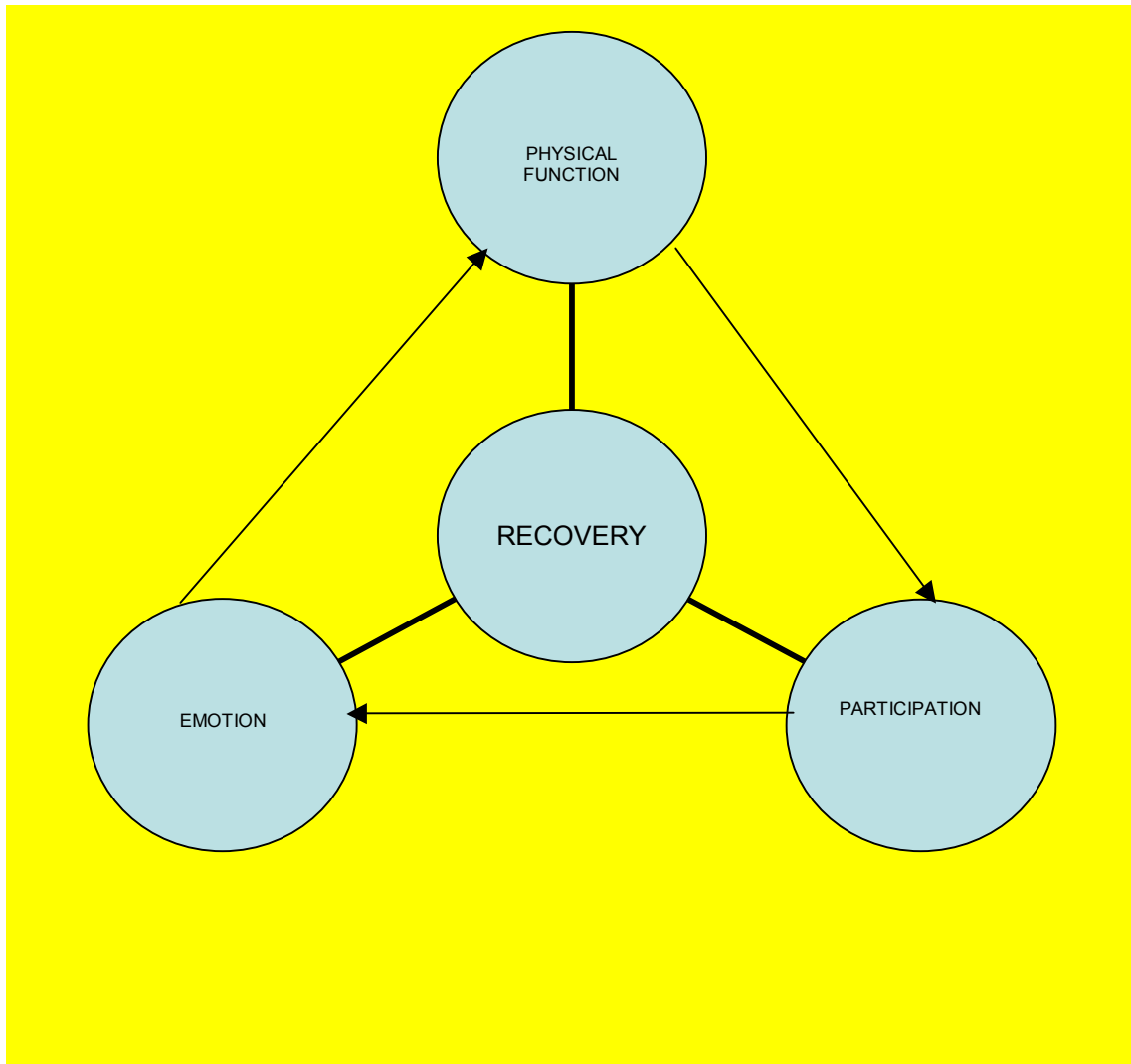
In this study the participants were categorized into stroke type (ischemic or hemorrhagic) and stroke severity (minor, mild, and moderate stroke). Participants without rehabilitation were considered to be minor strokes. Participants receiving outpatient therapy were classified as mild and inpatient therapy as moderate. Separation into these three categories is consistent with rehabilitation literature (Derosier et al., 2002; Duncan et al., 2002; Duncan et al, 2005; Schwamm et al., 2005; Zorowitz, Gross, & Polinski, 2002). Analyses of the data were by stroke type and stroke severity. Stroke severity was indicative of formal rehabilitation as an inpatient in a rehabilitation hospital or as an outpatient in ambulatory rehabilitation therapy.

*Components of Measurement: Stroke Impact Scale, Relationship Change Scale, and Health-Related-Quality-of Life-4*

#### *Stroke Impact Scale*

Multiple tools are used to assess outcomes of stroke survivors with no consensus as to which tool is most definitive or superlative for the practicing

clinician or researcher. The Stroke Impact Scale Version 3.0 (SIS V 3.0) (Appendix B) is a self-reported measure that includes 59 items assessing 8 dimensions. This tool is used to collect data on strength, hand function, activities of daily living (ADL) and independent activities of daily living (IADL), mobility, communication, emotion, memory, thinking, and participation. Each dimension is assessed independently and represents a distinct aspect of stroke recovery (Duncan, Bode, Lai, & Perera, 2003). Global recovery can be predicted by the SIS V 3.0 dimensions physical function, emotion, and participation (Duncan et al., 1999). Figure 5 is a visual depiction of stroke recovery based on the work of Duncan et al. (1999).



*Figure 5. SIS Triad of Recovery.*

The SIS V 3.0 has been validated for use with persons with hemorrhagic and ischemic stroke (Duncan et al., 2003). In addition to its established reliability and validity, the tool was selected because of its comprehensiveness that examines not only functional abilities but also quality of life measures.

The Stroke Impact Scale (SIS V 3.0) has copyright protection but was free to use with a signed agreement for non-profit entities. Permission to use the tool was obtained by the researcher (Appendix G). The original work by Duncan et al.

(1999) reported scale means for minor and moderate stroke at 1, 3, and 6 months. The scores at 6 months were used in this study for comparison.

There are eight dimensions and one domain measured by the SIS V 3.0. The dimensions are strength, memory, emotion, communication, ADL/IADL, mobility, hand function, and participation. The dimensions ADL/IADL, hand function, mobility, and strength create the physical domain. The physical domain then becomes one score for analysis.

*Tool Design.* The SIS V 3.0 is a 59 item Likert scale tool that may be self-administered, administered by proxy, or administered via interview (Duncan et al., 2003; Duncan et al., 2002). Each question is prefaced with “in the past week”. This establishes a frame of reference for short-term comparison. The final question globally assesses the stroke survivors’ perception of stroke recovery (0 to 100%) from the time when the initial event occurred.

Each dimension is measured on a Likert scale from 1 to 5 with 5 indicative of the most improvement except for questions 3f, 3h, and 3i which are reversed. The statements are predicated by time limited descriptors such as “In the past week how difficult was it to...” The time specific period varies from 1 to 4 weeks according to the specific dimension. Depending on the dimension measured, the corresponding Likert scale included defining terms gradation such as “not difficult at all”, “a little difficult”, “somewhat difficult”, “very difficult”, “extremely difficult” (memory, communication, ADL/IADL, mobility, and hand function). For emotion and handicap, the responses were “none of the time”, “a little of the time”, “some of the time”, “most of the time”, and “all of the time”. Last, strength was scored 1



to 5 with these descriptors: “a lot of strength”. “quite a bit of strength”, “some strength”, “a little strength”, and “no strength at all”.

*Components of measurement.* The SIS V 3.0 is a condition-specific health status measure designed for outcome evaluation of stroke survivors. The tool demonstrates sensitivity to ongoing stroke recovery (Duncan et al., 1999; Lai, Studenski, Duncan, & Perera, 2002; Lai et al., 2003). The dimensions of the SIS V 3.0 are: communication, memory and thinking, emotion, handicap (participation role limitations), strength (upper and lower extremity), hand function, ADL/IADL, and mobility.

*Scoring.* The scoring of the tool is based on the same algorithm approach as the SF-36 (Duncan et al., 1999). The items are scored on a five-point Likert scale with 5 being most recovery to 1 being the least. The questions are focused on strength, difficulty, and time. The variation in the questions supports the division of the dimensions along a multifaceted continuum. Scoring of the tool may be by each domain or collapsing the four physical dimensions e.g. hand function, strength, mobility, and activities of daily living/independent activities of daily living into one summed score called physical domain. Communication, emotion, participation, and memory must be scored separately (Duncan et al., 1999). A change in score 10-15 points suggests a meaningful clinical change (Duncan et al., 1999) when used as an interval measurement tool. This study is not intending to measure interval change but instead measures the stroke survivor’s perception within the 8 dimensions after 1 year as a stroke survivor.

The measured dimensions generate normalized scores ranging between 0 and 100. A score of 0 is suggestive of no recovery and 100 reflects full recovery. The following formula was developed to calculate the normalized scores and is the same scoring system used for the SF-36 (Duncan et al., 1999):

$$\text{Transformed Scale} = \frac{[(\text{actual raw score} - \text{lowest possible raw score})]}{\text{Possible raw score range}} \times 100$$

For the three questions with reverse polarity the following equation is used to compute the scores (University of Kansas Medical Center, 2006):

$$6\text{-individual's rating} = \text{item score}.$$

The Landon Center on Aging at the University of Kansas Medical Center (University of Kansas Medical Center, 2007) supplies users of the SIS V 3.0 a downloadable database that calculates the normalized scores for each dimension and the physical domain. This database was downloaded and the participant scores were entered using the study identification numbers assigned to each participant upon enrollment (Appendix F).

*Psychometrics.* The SIS V 3.0 is sensitive to change in both mild (National Institutes of Health Stroke Scale [NIHSS] score <8) and moderate (NIHSS score 8-16) strokes, which is not an attribute of the most commonly used tools due to their floor and ceiling effects (Duncan et al., 1999). The Rasch analysis for the SIS V 3.0 confirmed the reliability of the tool. The separation reliability of all the domains ranged from .93 to 1.00 coinciding with a Cronbach  $\alpha$  .90 (Duncan et al., 2003).

### *Relationship Change Scale*

The SIS V 3.0 assesses participation but is superficial in assessing the role or importance of interpersonal familial relationships. The devastating effects of stroke impact the survivor, partner/spouse, family members, and social relationships. The demand of caring for the stroke survivor affects relationships between the caregiver and the stroke survivor. Only 17% of caregivers report improvement in their relationship with the stroke survivor as a result of the role of caregiving (Draper, Poulous, Cole, Poulos, & Ehrlich, 1992).

The effects of stroke on relationships were measured using the Relationship Change Scale (RCS) (Guerney, 1977) and is reflective of psychologically coming to terms. When the stroke survivor was widowed or single, the questions were read to the participant to reflect relationships with other members of the family who played an important part of each one's life. For example the word "partner" was changed to "daughter", "son", or "children" if the participant was not involved in an intimate relationship with another individual. The maximum score for the RCS is 135. The possible score ranges from 27 (much less) to 135 (much more) with the higher score indicative of a strong relationship. No change in the relationship(s) for all questions was reflected as a score of 81.

*Tool Design and Scoring.* The Relationship Change Scale (Appendix C) developed by (Schlein, 1971) and Guerney (1977) consists of 27 items rated on a five-point scale of “much less”, “less”, “no change”, “more”, and “much more”. The possible score ranges from 27 (much less) to 135 (much more) with the higher score indicative of a strong relationship. For the study purposes, participants were asked to assess the quality of the current relationship with the partner compared to the relationship prior to the stroke. The burden for the participant was an additional 20 minutes of interview time.

*Psychometrics.* Construct validity of the Relationship Change Scale is supported by findings of more positive changes in the quality of the relationship for couples who received relationship improvement training programs than those in the control groups (Rappaport, 1971; Schlein, 1971). Rankin and Campbell (1983) tested the tool with married couples and reported a Cronbach's alpha internal consistency reliability coefficient of .98 and Fawcett (personal communication, April 6, 2004) reported a Cronbach's alpha coefficient of .95 for women at 6 weeks postpartum. The tool is used frequently in couple's therapy but is also found in research studies involving only women (Coleman et al., 2005; Samarel, Fawcett, & Tulman, 1997).

#### *Health-Related-Quality-of-Life-4*

The Health-Related-Quality-of-Life 4 (HRQOL 4, Appendix D), also known as “Healthy Days Measures” is a four-item generic measures questionnaire used by Centers for Disease Control and Prevention (2004) researchers to evaluate health-related quality of life. The questions were taken from the Behavioral Risk

Factor Surveillance System. This is an on-going national random digit dialed telephone survey (Anderson, Catlin, Wyrick, & Jackson-Thomas, 2003). One global assessment question that demonstrates health perception (“Would you say your general health is excellent, very good, good, fair, or poor”) is a powerful representative link to morbidity (Idler & Benyamini, 1997). In addition, the HRQOL-4 has demonstrated utility for identifying unmet health needs and “...characterizing the burden of disabilities and chronic diseases...” (Moriarty, Zack, & Kobau, 2003). The tool has been used in both institutionalized and non-institutionalized adults, including persons with disabilities, adolescents, older adults, and HIV and AIDS survivors (Moriarty et al.).

Other health perception questions ask the participant to indicate the number of physical illness or injury days and poor mental health days (stress, problems with emotion, and depression). The number of physical illness days is reflective of function capacity and self-concept is interpreted by the determination of the level of health (Moriarty et al., 2003). The last question asks the impact of physically and mentally disruptive days has on the ability to continue normal activities of daily living and independent activities of daily living which evaluates social interaction. The HRQOL-4 was used to evaluate functional ability, self-concept, and social interaction.

*Psychometrics.* Construct validity for the HRQOL-4 has been demonstrated in studies in the United States and Canada (Anderson, Fouts, Romeris, & Brownson, 1999; Ounpuu, Chambers, Patterson, Chan, & Yusuf, 2001). These questions have been validated against the Medical Outcomes Short-Form 36 (SF-36), Quality of Well-Being Scale, and Instrumental Activities of Daily Living.

Andersen et al. (2003) report retest reliability of the HRQOL-4 as moderate to excellent. In their study, a random sample of non-institutionalized Missouri adult residents (n=868) were interviewed and re-interviewed using the HRQOL-4. Statistical analysis using intraclass correlation coefficient and two-way random effect model was performed with the establishment of 0.75 as excellent and 0.40 as poor agreement. Table 5 is a summary of the retest reliability and agreement of HRQOL measures for all participants and divided into males, females, and ages 65 and over. Frequent mental distress measurement is noted to be only 0.46 for the older population.

Table 5

*Retest Reliability and Agreement of HRQOL Measures*

| Sample                                  | Self-reported health | Poor physical health days | Poor mental health days | Limited activity days | Healthy days | Frequent mental distress | Frequent physical distress |
|---|----------------------|---------------------------|-------------------------|-----------------------|--------------|--------------------------|----------------------------|
| All<br>(n=868)<br>Reliability<br>95% CI | .75                  | .71                       | .67                     | .57                   | .75          | .58                      | .64                        |
| Men<br>(n=355)<br>95% CI                | .74                  | .76                       | .72                     | .52                   | .76          | .68                      | .70                        |
| Women<br>(n=513)<br>95% CI              | .76                  | .67                       | .64                     | .61                   | .74          | .53                      | .59                        |
| Ages 65+<br>(n=204)<br>95% CI           | .67                  | .66                       | .55                     | .50                   | .72          | .46                      | .63                        |

---

*Note:* Abbreviated from Anderson et al., 2003

**Scoring.** The scoring for the HRQOL-4 is a summary index of unhealthy and healthy days (CDC, n.d.). Scores are calculated based on the number of days the participants reported either their physical or mental health was not good. Responses from questions two and three, representative of physical and mental health, are summed to equal no greater than a maximum of 30 (days per month). The healthy day's component is complimentary to the "unhealthy" days and is calculated by subtracting the sum of questions two and three from 30

days. This methodology is supported through analysis of the actual patterns of responses to questions two and three (CDC, n.d.).

### *Rehabilitation*

In this study rehabilitation was considered the intervening variable. As the intervening variable, it may explain the relationship between independent variables physical healing, psychological coming to terms, and biographical engagement and the dependent variable comeback. Data measuring rehabilitation procedures were collected with the demographic information tool (Appendix A).



## CHAPTER 4 RESULTS

### *Introduction*

Successful comeback is dependent on physical healing, biographical reengagement, and psychologically coming to terms (Corbin & Strauss, 1991). The question to be answered by this study was that if the stroke survivor regains cognition and function (physical healing through rehabilitation procedures), positively envelopes a new self-concept (biographical reengagement), and positively engages in interpersonal and social relationships (psychological coming to terms) would comeback be achieved?

Three standardized psychometric instruments (SIS V 3.0, Relationship Change Scale, and Health-Related Quality of Life-4) were used to determine how scores of women stroke survivors compared to the literature and to published state and national statistics. These tools were applied and their results compared to standard scores and, when applicable state and national norms. The items specifically evaluated included cognition, function, self-concept, and interpersonal and social relationships.

### *Participant Recruitment*

Participants for the study were recruited using a variety of methods. Five thousand brochures and 100 fliers were distributed in physician offices, area senior centers, rehabilitation and physical therapy centers, hospital waiting rooms, and a local health resource center and distributed to interested parties at two health fairs. Brochures were also given to other health professionals upon

their request for distribution in their areas of influence. Another venue for recruitment was through television. The principal investigator was interviewed during the 5:00 p.m. news. Lastly, a news release was sent to area newspapers by the ETSU University Relations Coordinator.

The participants were recruited through the following: newspaper (34.8%, n = 16); referrals from other health professionals (28.3%, n = 13); brochures (15.2%, n = 7); and referrals from friends (13%, n = 6). The referral sources indicated by the participants are summarized in Table 6.

Table 6

*Participant Recruitment Referral Source*

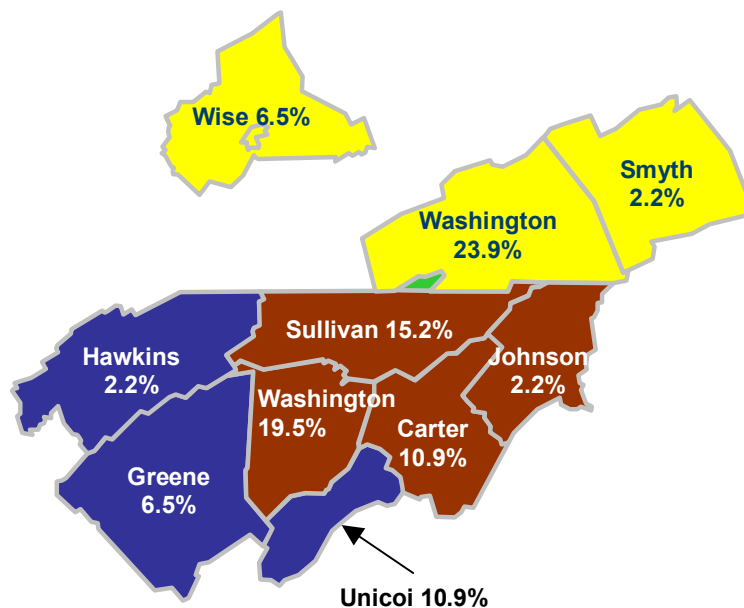
| Referral Source            | n  | %    |
|----------------------------|----|------|
| Newspaper                  | 16 | 34.8 |
| Other Health Professionals | 13 | 28.3 |
| Brochure                   | 7  | 15.2 |
| Friend                     | 6  | 13.1 |
| TV Ad                      | 2  | 4.3  |
| MD                         | 2  | 4.3  |
| TOTAL                      | 46 | 100  |

*Study Exclusion*

Forty-seven women consented and participated in the course of this study. Only one participant was excluded from the study because she did not meet the inclusion criteria of being a minimum of 1 year post stroke.

### *Geographic Representation*

The women who participated in the study were from Southwest Virginia (n = 14, 30.4%) and Northeast Tennessee (n = 32, 69.6%). Washington County, Virginia had the most participants (n = 11, 23.9%) followed by Washington County, Tennessee (n = 9, 19.5%). The number of participants from other counties ranged from one to seven. The counties of the women's residence are noted in Figure 6. Although fliers and brochures were distributed to Southeastern Kentucky and Northwestern North Carolina, there were no participants from those areas.



*Figure 6.* Counties of Participant Residence.

### *Demographic Characteristics*

Although recruitment efforts were designed to reach all women who met the study criteria regardless of race, all of the study participants were Caucasian. All participants were literate, able to communicate in English, and could understand oral directions. All women lived independently in their home environment.

Most of the participants (63%,  $n = 29$ ) worked prior to their stroke full-time. Only 23.9% ( $n = 11$ ) continued to work full- or part-time after stroke. A high percentage of the participants (82.6%,  $n = 38$ ) were married or widowed at the time of the study. The income for the study participants was almost evenly divided when \$20,000 was the dividing point with 52.1% ( $n = 24$ ) having household incomes \$20,000 or less and 47.9% ( $n = 22$ ) with incomes greater than \$20,000. Demographic characteristics are listed in Table 7.

Table 7

*Demographic Characteristics*

| Demographic characteristics        | n  | %    |
|------------------------------------|----|------|
| <u>Race</u>                        |    |      |
| Caucasian                          | 46 | 100  |
| <u>Education</u>                   |    |      |
| College graduate                   | 29 | 63.0 |
| Some college                       | 4  | 8.7  |
| High school graduate               | 12 | 26.1 |
| Did not graduate high school       | 1  | 2.2  |
| <b>TOTAL</b>                       | 46 | 100  |
| <u>Previous Employment History</u> |    |      |
| Full-time                          | 29 | 63.0 |
| Part-time                          | 0  | 0.0  |
| Homemaker                          | 17 | 37.0 |
| <b>TOTAL</b>                       | 46 | 100  |
| <u>Current Employment History</u>  |    |      |
| Unemployed                         | 35 | 76.1 |
| Full-time same job                 | 7  | 15.2 |
| Full-time different job            | 3  | 6.5  |
| Part-time same job                 | 1  | 2.2  |
| Part-time different job            | 0  | 0.0  |
| <b>TOTAL</b>                       | 46 | 100  |

| Demographic characteristics | n  | %    |
|-----------------------------|----|------|
| <u>Marital Status</u>       |    |      |
| Married                     | 23 | 50.0 |
| Widowed                     | 15 | 32.6 |
| Single                      | 8  | 17.4 |
| <b>TOTAL</b>                | 46 | 100  |

Table 7 (continued)

| Demographic characteristics | n  | %    |
|-----------------------------|----|------|
| <u>Annual Income</u>        |    |      |
| <10,000                     | 10 | 21.7 |
| 10,000-15,000               | 4  | 8.7  |
| 15,000-20,000               | 10 | 21.7 |
| 20,001-30,000               | 2  | 4.3  |
| 30,001-45,000               | 12 | 26.1 |
| >45,000                     | 8  | 17.5 |
| <b>TOTAL</b>                | 46 | 100  |

## Age

The age of the women in the study ranged from 46 to 78 years. The mean age of the participants of the study was 63 years ( $M = 62.8$ ,  $SD = 9.91$ ). The age at time of stroke ranged from 22 to 76 years with the mean age at time of stroke 56 years ( $M = 55.74$ ,  $SD = 11.92$ ). The mean age at the time of stroke increases slightly to 57 years when the women who had stroke before the age of 40 ( $n = 3$ ) were removed from the analysis. The age range at time of stroke is represented

by Figure 7. Slightly over half of the women experienced their stroke between the ages of 41 and 60 years ( $n = 26$ , 57%).

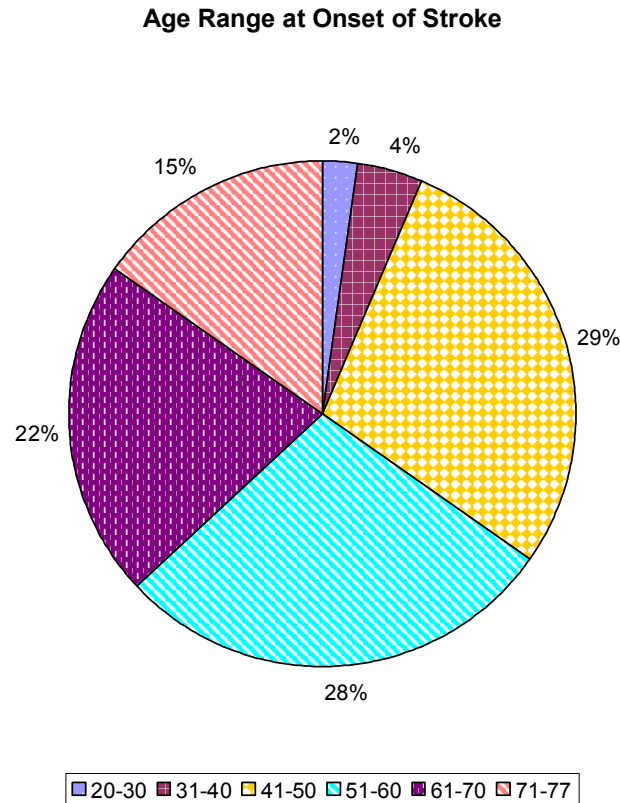


Figure 7. Age Range at Time of Stroke

### *Stroke Risk Factors*

The classic risk factors for stroke include age, family history of stroke, gender, heart disease, smoking, hypertension, atrial fibrillation, diabetes, high cholesterol, and obesity (AHA, 2007a). In this study almost half (41.3%,  $n = 19$ ) of the participants have a family history of stroke. In addition, 59% ( $n = 27$ ) were hypertensive, 34.7% ( $n = 16$ ) had history of cardiovascular disease, 28% ( $n = 13$ ) smoked, and 19.6% ( $n = 9$ ) were diabetic (Table 8). The average BMI for the participants was 26.59 ( $\pm 4.88$ ). The range of BMI was broad (20.3 to 38.2).

Table 8

*Stroke Risk Factors*

| Health Information       | n  | %    |
|--------------------------|----|------|
| Hypertension             | 27 | 58.7 |
| Family history of stroke | 19 | 41.3 |
| Diabetes                 | 9  | 19.6 |
| Heart Attack             | 6  | 13.0 |
| History of blood clots   | 6  | 13.0 |
| Heart murmur             | 6  | 13.0 |
| Congestive heart failure | 4  | 8.7  |
| Smoking history          | 13 | 28.3 |
| Alcohol use              | 13 | 28.3 |
| BMI <24                  | 17 | 37   |
| BMI 24-29                | 20 | 43.5 |
| BMI ≥30                  | 9  | 19.5 |

*Stroke Type*

The most predominant stroke type for the participants in this study was ischemic (82.6%) and the remaining 17.4% experienced hemorrhagic stroke according to self-report. A review of 19 ( $\alpha = .05$ , acceptable absolute error 0.5) medical records confirmed the accuracy of the women's self-reported stroke type.

*Survivorship*

In this study survivorship is defined as the number of years post stroke. All participants were at least 1 year post stroke. The survivorship post stroke of the participants in this study ranged from a mean of 6.54 ( $SD = 7.15$ ) years for



ischemic stroke and 9.96 ( $SD = 9.19$ ) years for hemorrhagic stroke. Women with hemorrhagic stroke were at least 2 years post stroke, while 24% of the women with ischemic stroke were survivors of less than 2 years duration. Table 9 represents the analysis of participants' years of survivorship. Most of the women were survivors less than 5 years. Yet 39.1% were long term survivors ranging from 6 to 36 years.

Table 9

*Years Survivorship Post Stroke*

| <b>Years post stroke</b> | <b>n</b>  | <b>%</b>   | <b>Cumulative %</b> |
|--------------------------|-----------|------------|---------------------|
| 1-5                      | 28        | 60.9       | 60.9                |
| 6-10                     | 10        | 21.7       | 82.6                |
| 11-15                    | 3         | 6.5        | 89.1                |
| 16-20                    | 2         | 4.3        | 93.5                |
| >21                      | 3         | 6.5        | 100                 |
| <b>TOTAL</b>             | <b>46</b> | <b>100</b> |                     |

*Rehabilitation*

Sixty-nine percent of the participants had rehabilitation after discharge from the hospital. Intensive rehabilitation facility (IRF) admission was the most frequent service provided to 58.7% of ischemic stroke and 87.5% of hemorrhagic stroke. After discharge from inpatient rehabilitation, home health services were provided to 23.9% of the women. Eighteen ischemic and 1 hemorrhagic stroke survivor did not enter into inpatient or outpatient therapy after discharge from the hospital. Rehabilitation services are summarized in Table 10.

Table 10

*Rehabilitation Services*

| <b>Post acute care rehabilitation</b>   | <b>n</b> | <b>%</b> |
|---|----------|----------|
| Intensive rehabilitation facility (IRF) | 27       | 58.7     |
| Outpatient therapy                      | 5        | 10.9     |
| Home health after discharge from IRF    | 11       | 23.9     |

*Analysis of Data Collected from Tools**Cognition and Function: Physical Healing*

*Cognition.* The two dimensions that comprise cognition are communication and memory (Duncan et al., 1999). Communication is an essential element of relating information and expressing needs and desires, while memory is critical for the women to maintain their independence. *t*-tests were performed using the test values for mild and moderate stroke abstracted from the original tool validation study by Duncan et. al., (1999). Women with mild ischemic stroke and moderate hemorrhagic stroke scored less than the test value on communication, but this finding was not statistically significant (Table 11).

Table 11

*t-tests Analyses of Communication by Stroke Type and Severity*

| Stroke Type | Severity | n  | Test<br>value | Mean<br>score | Mean<br>difference | SD    | t     | df | p    |
|-------------|----------|----|---------------|---------------|--------------------|-------|-------|----|------|
| Ischemic    | Mild     | 5  | 89.8          | 84.28         | -5.42              | 17.76 | -.682 | 4  | .533 |
| Ischemic    | Moderate | 20 | 83.1          | 85.54         | 17.28              | 17.28 | .633  | 19 | .534 |
| Hemorrhagic | Moderate | 8  | 83.1          | 75            | 26.60              | 26.60 | -.756 | 6  | .478 |

Next, memory was tested for differences between stroke severity and stroke type. As with the communication dimension, all participants scored within range of the test value. All groups of women regardless of stroke type or severity scored slightly lower than the test value (Table 12).

Table 12

*t-tests Analyses of Memory Dimension by Stroke Type and Severity*

| Stroke Type | Severity | n  | Test<br>value | Mean<br>score | Mean<br>difference | SD    | t     | df | p    |
|-------------|----------|----|---------------|---------------|--------------------|-------|-------|----|------|
| Ischemic    | Mild     | 5  | 78.3          | 75            | 23.28              | 23.28 | -.317 | 4  | .767 |
| Ischemic    | Moderate | 20 | 81.7          | 81.25         | -4.50              | 17.46 | -.115 | 19 | .909 |
| Hemorrhagic | Moderate | 8  | 81.7          | 76            | -20.06             | 15.53 | -.971 | 6  | .369 |

*Function.* Functional abilities were measured using the Stroke Impact Scale V 3.0 (SIS V 3.0) physical domain and the HRQOL-4 question 2. The physical domain assesses abilities to perform activities of daily living, independent activities of daily living, general and specific strength (hand), and mobility. The second question in the HRQOL-4 asks “Now thinking about your

physical health which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?”

*Physical Domain.* The SIS V 3.0 dimensions strength, ADL/IADL, hand function, and mobility comprise the physical domain. The physical domain is specific to those activities that require functional capacity to perform an action. The normalized physical domain scores ranged from 26.9 to 100 ( $M = 74.07$ ,  $SD = 20.73$ ).

Statistical analyses using independent t-tests were performed to test differences between stroke type and severity scores on the physical domain. Women with moderate ischemic stroke had statistically significant improvement in these scores ( $p < .001$ ) when compared to the test value. The women with moderate hemorrhagic strokes scored within the test value range yet their mean score is slightly below the test value. Table 13 is the summary of the t-tests analyses.

Table 13

*t-tests Analyses of Physical domain by Stroke Type and Severity.*

| Stroke Type | Severity | n  | Test value | Mean score | Mean difference | SD    | t     | df | p     |
|-------------|----------|----|------------|------------|-----------------|-------|-------|----|-------|
| Ischemic    | Mild     | 5  | 73.2       | 79.42      | 20.97           | 20.93 | .664  | 4  | .543  |
| Ischemic    | Moderate | 20 | 50.2       | 72.43      | 22.23           | 16.71 | 5.948 | 19 | <.001 |
| Hemorrhagic | Moderate | 8  | 50.2       | 49.88      | -3.14           | 18.70 | -.044 | 6  | .966  |

*Physical Health.* Fifty percent of the women stroke survivors experienced physical illness injury within 30 days prior to interview. Eight (17.4%) of the 46 women reported 14 or more poor health days within 30 days prior to their

interview. Data from the CDC (2007) compiled from 2001 to 2005 for women reporting 14 or more poor physical health days were used for comparison at the national and state level. The percentage of women self-reporting more than 14 days in the past 30 days nationally and in the state of Tennessee is 11.9% and 13.2% respectively (CDC, 2007). To determine if the women in this study had fewer or more poor health days, further evaluation was done by comparing the national trend for women of 3.9 days (Table 14) and the state trend of 4.1 days poor health in the past 30 days (Table 15). There were no significant differences for minor, mild, or moderate stroke survivors.

Table 14

*t-tests Analyses Poor Physical Health Days and National Trend*

| Severity | Days | n  | Mean<br>score | Mean<br>difference | SD     | t     | df | p    |
|----------|------|----|---------------|--------------------|--------|-------|----|------|
| Minor    | 3.9  | 14 | 3.5           | -.40               | 6.970  | -.215 | 13 | .833 |
| Mild     | 3.9  | 5  | 14.4          | 10.50              | 11.589 | 2.026 | 4  | .113 |
| Moderate | 3.9  | 27 | 5.74          | 1.84               | 9.280  | 1.031 | 26 | .312 |

Table 15

*t-tests Analyses Poor Physical Health Days and State Trend*

| Severity | Days | n  | Mean<br>score | Mean<br>difference | SD     | t     | df | p    |
|----------|------|----|---------------|--------------------|--------|-------|----|------|
| Minor    | 4.1  | 14 | 3.5           | -.60               | 6.970  | -.322 | 13 | .752 |
| Mild     | 4.1  | 5  | 14.4          | 10.3               | 11.589 | 1.987 | 4  | .118 |
| Moderate | 4.1  | 27 | 5.74          | 1.64               | 9.280  | .919  | 26 | .367 |

Comparison for differences between stroke type and poor physical health also yielded no significance (Tables 16 and 17).

Table 16

*t-tests Analyses Stroke Type and Poor Health Days National Trend*

| Stroke Type | Test | n  | Mean<br>score | Mean<br>difference | SD    | t      | df | p    |
|-------------|------|----|---------------|--------------------|-------|--------|----|------|
| Ischemic    | 3.9  | 38 | 6.89          | 2.995              | 9.866 | 1.871  | 37 | .069 |
| Hemorrhagic | 3.9  | 8  | 1.75          | -2.150             | 3.240 | -1.877 | 7  | .103 |

Table 17

*t-tests Analyses Stroke Type and Poor Health Days State Trend*

| Stroke Type | Days | n  | Mean | Mean<br>difference | SD    | t      | df | p    |
|-------------|------|----|------|--------------------|-------|--------|----|------|
| Ischemic    | 4.1  | 38 | 6.89 | 2.795              | 9.866 | 1.746  | 37 | .089 |
| Hemorrhagic | 4.1  | 8  | 1.75 | -2.350             | 3.240 | -2.051 | 7  | .079 |

*Relationship between Cognition and Function.* Bivariate correlation analyses were used to determine if cognition and function influenced physical health. There was a significant positive correlation between the number of days physical health reported as “fair” or “poor” and the memory component of cognition ( $r = -.229$ ,  $p = .043$ ).

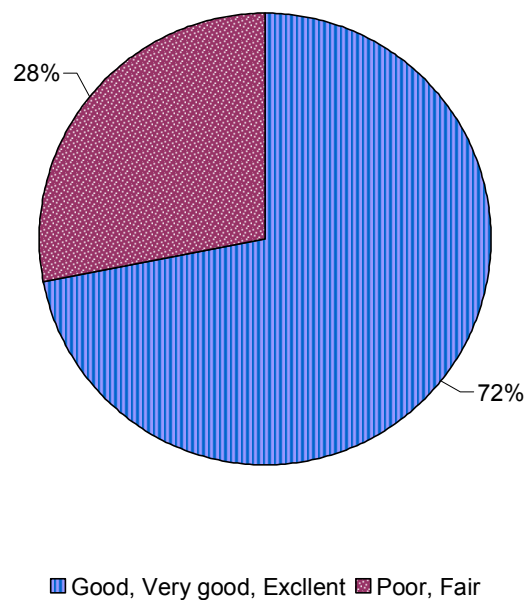
Multiple linear regression analyses were completed for the number of poor physical health days, cognition (memory and communication), and function. Review of the ANOVA table revealed no significance. Thus, neither cognition nor function predicted poor health days.

### *Self-Concept: Biographical Reengagement*

Biographical reengagement was measured by HRQOL-4 rating of health (question 1), SIS V 3.0 recovery score, and ability to control life (SIS V 3.0 section 8 question g).

*Health Rating.* The women's rating of their health was similarly distributed between excellent ( $n = 10$ , 21.7%), very good ( $n = 13$ , 28.3%), and good ( $n=10$ , 21.7%). Thirteen (28.2%) women indicated their health was fair ( $n=10$ , 21.7%) or poor ( $n=3$ , 6.5%). Figure 8 shows health rating scores in percentages of combined data for good, very good, and excellent and poor and fair.

**In general would you say your health is...?**



*Figure 8.* HRQOL-4 Health Rating

Chi-square analyses were computed to test if the percentage of women who rated their health as poor or fair were statistically different from the national

and state data. Thirteen (28.2%) of the women rated their health as poor or fair. The national average for women is 17.1% reporting their health as poor or fair. Based on this average, only 8 women should have rated their health low. There was statistically significant ( $p = .044$ ) difference for this group when compared to the national average and no difference when compared to the state rate of 21.2% ( $p = .241$ ).

**Recovery Score.** The second component of self-concept is the women's self-assessment of recovery (SIS V. 3.0, section 9). Figure 9 shows the recovery scores of the participants. The women were almost evenly split between recovery self-assessment from 50% to 75% (43.48%,  $n = 20$ ) and 80% to 100% (56.52%,  $n = 26$ ). The mean recovery score for women with ischemic stroke was 81.39% ( $SD = 15.39$ ) and hemorrhagic stroke was 76.88% ( $SD = 19.45$ ).

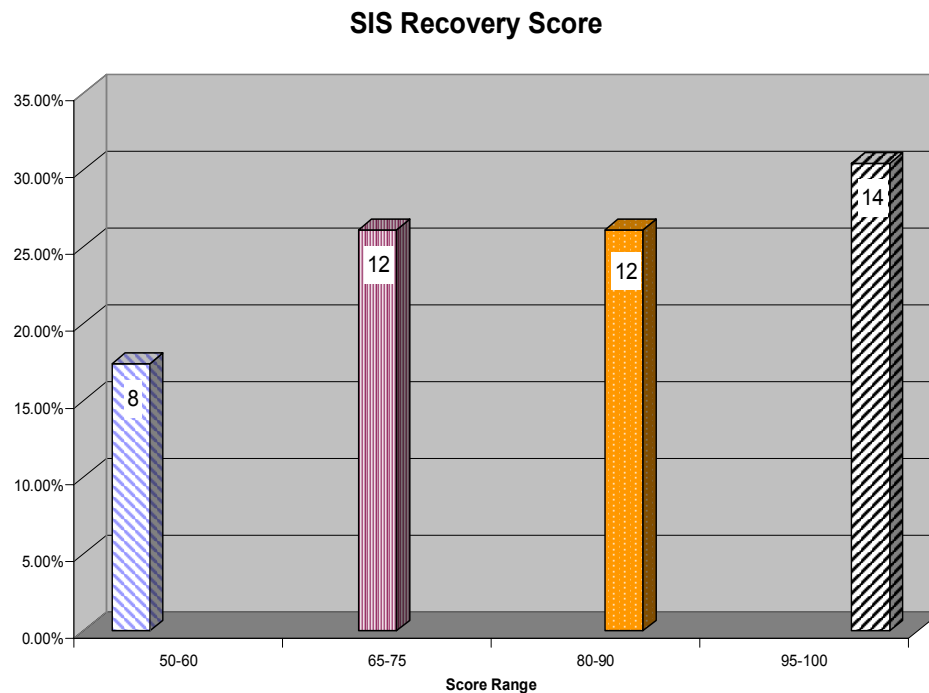


Figure 9. SIS Recovery Dimension



For all women in this study, the mean SIS V 3.0 recovery score was 80.6%. When compared to the SIS V 3.0 scale mean for stroke recovery from the study by Duncan et al. (1999) the women with moderate ischemic stroke scored significantly higher than the test value ( $p < .001$ ) (*Table 18*).

Table 18

*t-tests Analyses Recovery Scores by Stroke Type and Severity*

| Stroke Type | Severity | n  | Test<br>value | Mean  | Mean<br>difference | SD    | t      | df | p     |
|-------------|----------|----|---------------|-------|--------------------|-------|--------|----|-------|
| Ischemic    | Mild     | 5  | 76.2          | 78    | 1.80               | 18.23 | .221   | 4  | .836  |
| Ischemic    | Moderate | 20 | 64.8          | 78.7  | 13.90              | 13.96 | 4.453  | 19 | <.001 |
| Hemorrhagic | Moderate | 8  | 64.8          | 73.57 | 8.77               | 18.42 | 1.2260 | 6  | .254  |

*Control of Life.* The statement "...how much time have you been limited in your ability to control your life as you wish?" is one component of the handicap dimension that was assessed as a separate biographical engagement item. Most of the women felt in control of their life (66%) all or most of the time while 34% indicated they were limited in their ability to control their life as they wished (Figure 10).

### Limited in your ability to control life as you wish

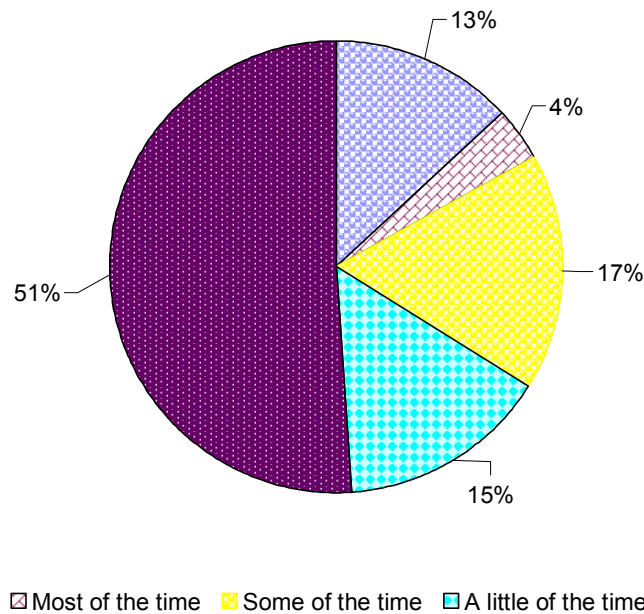


Figure 10. Ability to Control Life

ANOVA was performed to assess for difference of the scores between the levels of stroke severity and the women's rating of their ability to control life. The mean score of moderate stroke survivors was lower than minor and mild stroke survivors. No difference between the groups were found ( $df = 2$ ,  $F = 2.323$ ,  $p = .110$ ).

### *Relationship Between Health Rating, Recovery Score, and Control of Life*

The relationships between health rating, recovery score, and control of life was examined to further define biographical engagement as measured through self-concept.

*Health Rating and Recovery Score.* Testing for congruence between health rating and recovery score was performed using independent *t*-tests. The analysis revealed there was congruence between health rating and the question “How much have you recovered from your stroke?” scores. The health rating recovery scores were converted to a dichotomous variable grouping poor and fair and good, very good, and excellent. Those women who reported their health as good, very good, or excellent rated their recovery significantly higher than the women who rated their health as fair or poor (Table 19).

Table 19

*t-tests Analyses HRQOL-4 Health Rating and Recovery Score*

| Health Rating              | n  | Mean<br>recovery<br>score | Mean<br>difference | SD    | t      | df | p     |
|----------------------------|----|---------------------------|--------------------|-------|--------|----|-------|
| Poor & fair                | 13 | 66.54                     | -19.61             | 14.48 | -4.453 | 44 | <.001 |
| Good, very good, excellent | 33 | 86.15                     |                    | 13.04 |        |    |       |

*Health Rating and Control of Life.* To assess for difference between health rating and the ability to control life an independent *t*-test was performed. There were no significant difference between health rating and life control ( $t = -1.394$ ,  $df = 44$ ,  $p = .170$ ).

*Recovery Score and Control of Life.* The ability to control life was assumed to be related to how the women perceived their recovery. Recovery scores were transformed into ranges 50-70, 75-85, and 90-100. Analysis of variance was performed to assess for congruence or difference between the

groups. No difference was found between the groups ( $df = 2$ ,  $F = 2.711$ ,  $p = .078$ ).

Independent samples  $t$ -tests analyses were computed to test differences between health rating, ability to control life, and recovery score using health rating the grouping variable. The results indicated the self-reported recovery score was statistically significant when compared to health rating. Ability to control life did not impact health rating (Table 20).

Table 20

*t-tests Analyses Health Rating, Recovery Score, and Life Control*

| Test variable  | HRQOL-4 Health Rating      | n  | Mean score | Mean difference | SD     | t     | df | p     |
|----------------|----------------------------|----|------------|-----------------|--------|-------|----|-------|
| Control/life   | Poor & fair                | 13 | 3.38       | -.65            | 1.758  | 1.394 | 44 | .170  |
|                | Good, very good, excellent | 33 | 4.03       |                 | 1.262  |       |    |       |
| Recovery score | Poor & fair                | 13 | 66.54      | -19.61          | 14.489 | 4.453 | 44 | <.001 |
|                | Good, very good, excellent | 33 | 86.15      |                 | 13.039 |       |    |       |

Binary logistic backward step-wise regression analyses were completed in an attempt to identify if recovery score or life control could predict the health rating. Health rating was used as the bivariate dependent variable with recovery score and life control as independent variables. While the recovery score was predictive of health rating ( $OR = 1.10$ ;  $R^2 = 40\%$ ;  $CI 1.04-1.16$ ), the ability to control life as wished did not contribute to the women's overall rating of their health. Table 21 represents the regression model.

Table 21

*Regression Health Rating, Recovery Score, and Life Control (N=46)*

| Model*                  | B     | SE B | $\beta$ | p    |
|-------------------------|-------|------|---------|------|
| Ability to control life | -.040 | .295 | .961    | .163 |
| Recovery score          | .093  | .031 | 1.098   | .003 |

\*Dependent Variable: Would you say that in general you health is...

### *Interpersonal and Social Relationships: Psychologically Coming to Terms*

Interpersonal and social relationships comprise *psychological coming to terms*. The Relationship Change Scale (RCS) was the tool that was used to measure interpersonal relationships. The SIS V 3.0 handicap dimension and the HRQOL-4 questions that measure mental health days and number of days limited due to physical and mental health were used to define social relationships.

*Interpersonal Relationships.* The scores on the RSC ranged from 58 to 132 with a mean score of 97.95. A *t*-test using 81 as the test value (indicating no change in relationship) demonstrated a significant change in the women's relationships occurred for stroke type (Table 22). The mean score was significant for ischemic ( $p < .001$ ) but not for hemorrhagic stroke.

Stroke severity was related to post stroke deficits and graded as minor, mild, or moderate. *t*-tests were once again completed using 81 as the test value for no change. Women with minor and moderate stroke indicative of the least and the greatest impairment also had statistically significant higher scores ( $p = .019$  and  $< .001$  respectively) (Table 23). Women with mild stroke had a mean score of

88.4 which was not significantly different from 81 indicating no change in relationships.

Table 22

*t-tests Analyses Relationship Change Scale by Stroke Type*

| Stroke Type | n  | Test value | Mean score | Mean difference | SD    | t     | df | p     |
|-------------|----|------------|------------|-----------------|-------|-------|----|-------|
| Ischemic    | 38 | 81         | 98.13      | 17.13           | 17.68 | 5.974 | 37 | <.001 |
| Hemorrhagic | 8  | 81         | 97.13      | 16.13           | 21.69 | 2.102 | 7  | .074  |

Table 23

*t-tests Analyses Relationship Change Scale by Stroke Severity*

| Stroke Severity | n  | Test value | Mean score | Mean difference | SD    | t     | df | p     |
|-----------------|----|------------|------------|-----------------|-------|-------|----|-------|
| Minor           | 14 | 81         | 91.86      | 10.85           | 15.25 | 2.665 | 13 | .019  |
| Mild            | 5  | 81         | 88.4       | 7.40            | 10.03 | .738  | 4  | .205  |
| Moderate        | 27 | 81         | 102.89     | 21.89           | 17.75 | 6.407 | 26 | <.001 |

### *Social Relationships*

*Handicap.* The SIS V 3.0 dimension that assesses participation is “handicap”. The statements in this section assess the limitations that may be imposed by stroke deficits including work, social activities, recreation, role as family member or friend, spiritual or religious activities, ability to control life, and helping others. *t*-tests were used to determine whether the mean score for the handicap dimension differed from the validated scores from Duncan et al.’s (1999) original work. Mild and moderate ischemic stroke exceeded the test value

for participation. Interestingly for the moderate ischemic stroke, this was statistically significant ( $p = .001$ ) (Table 24).

Table 24

*t-tests Analyses of Handicap by Stroke Type and Severity*

| Stroke Type | Severity | n  | Test value | Mean score | Mean difference | SD    | t     | df | p    |
|-------------|----------|----|------------|------------|-----------------|-------|-------|----|------|
| Ischemic    | Mild     | 5  | 67.6       | 75         | 7.40            | 30.37 | 1.038 | 4  | .358 |
| Ischemic    | Moderate | 20 | 60.9       | 81.27      | 20.36           | 21.82 | 4.174 | 19 | .001 |
| Hemorrhagic | Moderate | 8  | 60.9       | 63.86      | 2.96            | 19.91 | .393  | 6  | .708 |

*Mental Health.* Thirty percent of the women acknowledged mental distress. Poor mental health days ranged from 1.5 to 8 days ( $M = 6.72$ ). Women with minor stroke had the least poor mental health days (1.5) while women with mild stroke had the highest (8) number of days. The trend for the number of poor mental health days for the nation and the state of Tennessee is 3.9 days (CDC, 2007). *t*-tests were used to determine whether the mean number of poor mental health days were significantly different from the national and state values, no difference was found ( $t = -.398$ ,  $df = 45$ ,  $p = .692$ ).

Ten percent of the women acknowledged more than 14 days per month of mental distress. This was below the national trend of 11.8% and 12.4% for women residing in Tennessee.

*Limitations imposed by Poor Physical or Mental Health.* The last component of psychological coming to terms was assessed by measuring the number of days of poor physical or mental health that kept these women from their usual activities. Activity limitations imposed by poor physical and mental health continued to be the highest for mild stroke ( $M = 6.2$  days) and the lowest for minor stroke ( $M = 0.36$  days). Women with moderate stroke had 50% fewer days ( $M = 3.04$ ) than women with mild stroke.

As a group the number of activity days limited by poor physical or mental health was 2.57 ( $M$ ) days ( $SD = 6.21$ ).  $t$ -tests were used to determine if the women's limitations caused by poor physical or mental health were significantly different from the national trend of 2.3 days (Table 25) and the state trend of 2.5 days (Table 26) (CDC, 2007). Women with minor ischemic stroke scored statistically significantly fewer limited activity days than women with mild or moderate ischemic stroke ( $p < .001$ ).

Table 25

*t-tests Analyses Activity Limitation Due to Poor Physical or Mental Health National Trend*

| Stroke Type | Severity | n  | Days | Mean<br>score | Mean<br>difference | SD    | t      | df | p    |
|-------------|----------|----|------|---------------|--------------------|-------|--------|----|------|
| Ischemic    | Minor    | 13 | 2.3  | .38           | -1.92              | 1.387 | -4.980 | 12 | .000 |
| Ischemic    | Mild     | 5  | 2.3  | 6.2           | 3.90               | 8.556 | 1.019  | 4  | .366 |
| Ischemic    | Moderate | 20 | 2.3  | 3.45          | 1.15               | 7.964 | .646   | 19 | .526 |
| Hemorrhagic | Moderate | 8  | 2.3  | 1.86          | -.44               | 3.185 | -.368  | 6  | .726 |



Table 26

*t-test Analysis Activity Limitations Due to Poor Physical or Mental Health State Trend*

| Stroke Type | Severity | n  | Days | Mean | Mean<br>difference | SD    | t      | df | p    |
|-------------|----------|----|------|------|--------------------|-------|--------|----|------|
| Ischemic    | Minor    | 13 | 2.5  | .38  | -2.12              | 1.387 | -5.500 | 12 | .000 |
| Ischemic    | Mild     | 5  | 2.5  | 6.2  | 3.70               | 8.556 | .967   | 4  | .388 |
| Ischemic    | Moderate | 20 | 2.5  | 3.45 | 0.95               | 7.964 | .533   | 19 | .600 |
| Hemorrhagic | Moderate | 8  | 2.5  | 1.86 | -0.64              | 3.185 | -.534  | 6  | .613 |

*Handicap and Poor Mental Health.* To determine if handicap and poor mental health were related to stroke type and stroke severity, *t*-tests analyses were computed for stroke type and ANOVA for stroke severity. No differences were found according to stroke type (ischemic or hemorrhagic) for handicap ( $t = 1.886$ ,  $df = 44$ ,  $p = .066$ ) or poor mental health days ( $t = -.122$ ,  $df = 44$ ,  $p = .903$ ). When tested by stroke severity (minor, mild, or moderate) using ANOVA no differences were found between the groups for handicap or poor mental health days (Table 27).

Table 27

*ANOVA Handicap and Poor Mental Health*

|                         |                | df | F     | p    |
|-------------------------|----------------|----|-------|------|
| Normalized handicap     | Between groups | 2  | 2.724 | .077 |
| Poor mental health days | Between groups | 2  | 1.267 | .292 |

To determine if there was a relationship between handicap and poor mental health, bivariate correlation was performed. The results demonstrated a significant inverse relationship between the number of poor mental health days and the women who scored themselves as the most handicapped ( $r = -.573$ ,  $p = .000$ ).

*Handicap and Activity Limitations.* A natural assumption is that women with higher handicap would have activity limitations on their usual activities such as caring for themselves and doing their normal routine of daily activities such as work or recreation. Again testing for differences between stroke type and stroke severity,  $t$ -tests analyses were performed. No difference was found according to stroke type for handicap or activity limitations. Significant difference was noted between women with minor stroke and moderate stroke for handicap ( $t = -2.360$ ,  $df = 39$ ,  $p = .023$ ) but not for activity limitations ( $t = 1.408$ ,  $df = 39$ ,  $p = .167$ ).

Bivariate correlation between handicap and activity limitations demonstrated was completed. Women who scored as less handicapped were less limited in their activities of life ( $r = -.494$ ,  $p = .000$ ).

*Activity Limitations and Poor Mental Health.* Following the above assumption, it was postulated that women with activity limitations also suffered more poor mental health days. Bivariate correlations revealed positive correlation between the number of poor mental health days and activity limitations ( $r = .370$ ,  $p = .038$ ).

*Prediction of Activity Limitations and Poor Mental Health.* Multivariate linear regressions were used to determine whether handicap or the number of

poor mental health days predicted activity limitations. In the overall model the  $F$  statistic was significant ( $F = 6.961$ ,  $p = .002$ ). Handicap and the number of mental health days did contribute to the fit of the regression model ( $R^2 = 24.5\%$ , adjusted  $R^2 = 20.9\%$ ).

*Relationship between Interpersonal and Social Relationships.* The change in relationships, handicap, poor mental health days, and activity limitations by poor physical or mental health comprise psychological coming to terms. To compare relationships between these variables, multiple bivariate correlations were performed. Significance was reached among poor mental health, activity limitations, and handicap. The expected finding that that poor mental health contributed to activity limitations was noted ( $r = .307$ ,  $p = .038$ ). Also, the greater the handicap, the more poor mental health days ( $r = -.573$ ,  $p = .000$ ) and activity limitations ( $r = -.494$ ,  $p = .000$ ) were demonstrated.

Multiple linear regressions were computed to determine if poor mental health, days of activities limited, or handicap contributed to relationship changes. None of the factors were associated with relationship changes ( $F = .402$ ,  $p = .752$ ).

### *Comeback*

The relationships between physical healing, biographical engagement, and psychological coming to terms were the last analyses performed using multiple bivariate correlations and multivariate linear regressions. Correlations were used to show relationship between the variables and multiple linear

regressions were used to identify factors that predict physical healing, biographical reengagement, and psychologically coming to terms.

### *Physical Healing*

The physical function domain was positively correlated ( $p < .01$ ) among stroke recovery, ability to control life, cognition (communication and memory), and handicap. There was a positive correlation between physical domain and health rating ( $p < .01$ ). No relationships were identified between physical function domain and relationship change, poor physical or mental health days, and activity limitations.

Multiple linear regressions were completed using physical domain as the dependent variable with the following independent variables:

1. Relationship change score
2. Recovery score
3. Limited in the ability to control life as you wish
4. Communication domain score
5. Memory domain score
6. Health rating
7. Number of poor physical health days
8. Number of poor mental health days
9. Number of days limited by poor physical or mental health

Each of the above factors contributed to physical healing as defined in the model ranging from 22% to 43%. The combination of all factors contributed the most ( $R^2 = 53\%$ , adjusted  $R^2 = 42.5\%$ ,  $F = 5.068$ ,  $p = .000$ ).

### *Biographical Reengagement*

The same factors were used for correlation for biographical reengagement. There was significant correlation between “How much have you recovered from your stroke?” score, physical domain, ability to control life, and communication ( $p < .01$ ). To a lesser extent there was significant correlation between memory and handicap ( $p < .05$ ). Lastly, there was positive correlation with health rating and poor physical health days ( $p < .01$ ).

Multivariate linear regressions using “How much have your recovered from your stroke?” and the above factors resulted in models ranging from  $R^2 = 14.2\%$  (adjusted  $R^2 = 12.2\%$ ) to  $R^2 = 50.4\%$  (adjusted  $R^2 = 37.6\%$ ). Review of the ANOVA table indicated the following factors were most predictive of recovery score ( $F = 5.880$ ,  $p = .000$ ):

1. Ability to control life
2. Communication (cognition and memory)
3. Physical function domain
4. Health rating
5. Number of poor physical health days
6. Number of poor mental health days

### *Psychological Coming to Terms*

Psychological coming to terms was gauged by interpersonal and social relationships. The multiple bivariate correlations yielded surprising results in that there were no correlations between the relationship change scores and any of the other variables. Limitations in activities were positively correlated with health

rating and physical health ( $p < .01$ ) and to a lesser extent number of poor mental health days ( $p < .05$ ). There was positive correlation between limitation of activities, memory, and handicap ( $p < .01$ ).

### *Rehabilitation*

Rehabilitation was assumed to be the intervening variable for comeback. Once again independent *t*-tests analyses were used to test the relationship between rehabilitation services and the variables of physical healing, biographical engagement, and psychologically coming to terms. There were significant differences between those women who had rehabilitation and those who did not for cognition (memory and communication), handicap, and recovery score (Table 28).

Table 28

*t*-tests Analyses Comparing Rehabilitation with Components of Physical Healing, Biographical Reengagement, and Psychological Coming to Terms

| Variable                | Rehabilitation<br>Yes/No | n  | Mean<br>score | SD     | t      | df | p    |
|-------------------------|--------------------------|----|---------------|--------|--------|----|------|
| Ability to control life | No                       | 14 | 4.43          | 1.158  | 1.873  | 44 | .068 |
|                         | Yes                      | 32 | 3.59          | 1.478  | 2.061  |    |      |
| Activity limitations    | No                       | 14 | .36           | 1.336  | -1.624 | 44 | .112 |
|                         | Yes                      | 32 | 3.53          | 7.216  |        |    |      |
| Communication           | No                       | 14 | 96.17         | 5.330  | 2.452  | 44 | .018 |
|                         | Yes                      | 32 | 83.15         | 19.439 |        |    |      |
| Physical                | No                       | 13 | 87.56         | 16.06  | 3.029  | 43 | .004 |
|                         | Yes                      | 32 | 68.59         | 20.07  |        |    |      |
| Handicap                | No                       | 14 | 92.19         | 13.579 | 2.354  | 44 | .023 |
|                         | Yes                      | 32 | 76.48         | 23.208 |        |    |      |
| Health rating           | No                       | 14 | 2.21          | 1.188  | -1.533 | 44 | .132 |
|                         | Yes                      | 32 | 2.81          | 1.230  |        |    |      |
| Memory                  | No                       | 14 | 91.84         | 10.798 | 2.491  | 44 | .017 |
|                         | Yes                      | 32 | 79.13         | 17.646 |        |    |      |
| Poor health days        | No                       | 14 | 3.50          | 6.970  | -1.219 | 44 | .229 |
|                         | Yes                      | 32 | 7.09          | 9.988  |        |    |      |
| Poor mental health days | No                       | 14 | 1.5           | 4.109  | -1.098 | 44 | .278 |
|                         | Yes                      | 32 | 4.28          | 9.035  |        |    |      |
| Recovery score          | No                       | 14 | 87.79         | 15.943 | 2.083  | 44 | .043 |
|                         | Yes                      | 32 | 77.47         | 15.246 |        |    |      |
| Relationship change     | No                       | 14 | 91.857        | 15.245 | -1.528 | 44 | .134 |
|                         | Yes                      | 32 | 100.625       | 18.917 |        |    |      |

### *Summary*

In this analysis physical healing, biographical reengagement, and psychological coming to terms as mediated by rehabilitation were compared to provide a quantitative measurement of the concept comeback.

The components of physical healing, cognition, and function were individually and collectively tested and analyzed. For cognition, communication and memory comprise the dimension. Each component was compared to one another to test their differences among different stroke types and stroke severity. The dimension of function included strength, ADL/IADL, hand function, and mobility was converted to a normalized score called physical domain (Duncan et al., 1999). The second component of measurement for function was the gauging of physical health as self-reported number of poor health days within 30 days of the interview. Each aspect of function was tested against standardized scores and state and national reported data. Then cognition and function were tested and analyzed for corresponding correlations. Lastly, cognition and function were assessed to determine if either predicted poor health days.

The second factor in the triad of comeback was biographical reengagement denoting self-concept. Measurement for this variable included health rating, recovery score, and ability to control life. Each variable was measured against state or national data when applicable or compared to standardized scores. When pertinent, the variables were segregated by stroke type and severity. The variables were then compared to each other for differences, variation, and prediction. Lastly, health rating, recovery score, and



ability to control life were analyzed to determine if the health rating or ability to control life predicted the recovery score.

The last component of psychometric measure was psychologically coming to terms which was derived from interpersonal and social relationships. Change in relationships was the factor used to measure interpersonal relationships while participation as measured by handicap, poor mental health days, and activity limitations caused by poor physical or mental health comprise social relationships.

Change in relationships and participation were tested and analyzed according to stroke type and severity as compared to the score that reflected no change (81). Poor mental health days and activities limited by poor physical or mental health were assessed by stroke type and severity and compared to the national and state norms. Next, each variable was evaluated against each other variable for correlation and prediction of factors that contributed to the concept of psychological coming to terms.

The intervening variable, rehabilitation, was tested for differences between women who had received formal rehabilitation and all the factors composing physical healing, biographical reengagement, and psychologically coming to terms.

The results of this study demonstrate comeback is a concept that lends itself to psychometric testing.

### *Study Limitations*

Study limitations include the use of a non-diverse sample of women. The sample did not include women of color and consisted of 100% Caucasian women living in Appalachia. The homogeneous sample supported the studies internal validity while the lack of diversity limits the intimation of the findings to all women (external validity).

The study sample was not randomized and, thus, the implications for generalization of the study for all women who have survived stroke should proceed with caution. In addition, males were excluded from the study which means comeback as defined by these women cannot be generalized to male stroke survivors.

The sample size for this study was 46 women. Some would argue the sample size is not adequate for interpretation of the study results. Yet some nursing researchers are challenging the status quo of historical sampling procedures (Sapnas & Zeller, 2002) suggesting fewer participants are needed to adequately represent social constructs through psychometric measurement.

The methods used to recruit participants for this study were passive in that information to participate in the study was via letters to primary care providers and neurologists, brochures, fliers, news media release, and television news broadcast. According to Yancey, Ortega, and Kumanyika (2006), active engagement in the population for recruitment is required to assure diversity of sample. Lastly, this study included women who had access to newspaper or telephone or visited facilities where brochures and fliers were available. Women

without access to the above did not have the opportunity to participate in the study.

The study included women who survived hemorrhagic and ischemic stroke. While hemorrhagic strokes have an increased incidence of death in the first month when compared to ischemic strokes (Vermeer, Algra, Franke, Koudstaal, & Rinkel, 2002); hemorrhagic stroke survivors tend to have better functional outcomes (Paolucci et al., 2003). In this study there was a difference in the physical domain measure of the SIS V 3.0 between the hemorrhagic and ischemic stroke survivor ( $t = -2.917$ ,  $df = 43$ ,  $p = .006$ ). The women with hemorrhagic stroke had less recovery than women with ischemic stroke. This finding does not support the literature.

Another limitation of the study is the data findings are subjective based on the participant response versus objective physical measurement. The researcher did not validate all of the women's ability to complete the functional skills ascertained by the SIS V 3.0. The researcher determined the need to validate the participants' functional skills based on the obvious physical deficits which is supported by the SIS V 3.0 tool administration guide.

While not a specific item measured in the study, some women stated fatigue contributes to their inability to function and to think clearly. The women who reported this symptom were interviewed in the late afternoon. Their responses to the questionnaires may have been decidedly different if the tools were administered in the morning hours.

## CHAPTER 5

### DISCUSSION

#### *Comeback*

Comeback does not necessarily mean the individual has recovered 100% and is functioning at the level prior to stroke. Comeback defined by Corbin and Strauss (1997, p. 68) is “a gradual return to an acceptable way of life within limits imposed by disability or illness. Involves physical healing, limitations stretching through rehabilitative procedures, psychosocial coming to terms, and biographical reengagement with adjustment to everyday activities.”

The research question predicted comeback was a relationship between physical healing, biographical reengagement, and psychological coming to terms mediated by rehabilitation. These concepts were evaluated through investigation of functional and cognitive abilities, self-assessment of recovery, health rating, ability to control life, relationship changes, physical and mental health, and limitations of activities due to poor physical or mental health.

#### *Study Participation*

Most of the women in this study learned about the study through their local newspaper or from other health professionals (n = 30). Other methods of recruitment that were less successful included printed material (brochures and fliers), television ads, and requests for referrals from physician practices. The brochure and flier distributions were placed in areas that were thought of having a high potential for notice (Senior Centers, shopping mall, physical therapy outpatient treatment centers, and hospital waiting areas). It was only when the

brochures and study information was provided to nurses, that recruitment increased from this method of recruitment. The lack of responsiveness from the TV news show could be related to the timing of the interview. The interview was conducted on the 5:00 p.m. news. The lack of response from physicians' offices has a potential linkage to the lack of personal knowledge of the researcher (Asch, Conner, Hamilton, & Fox, 2000). The physicians who referred the only two participants from medical practices knew the researcher personally. Lastly, six women were recruited by other women who participated in the study. The women had made connections with other women who were stroke survivors most often through their church activities affiliations.

### *Stroke Survivor Characteristics*

#### *Race*

All women in this study were Caucasian. According to the 2007 census, this region ranges from 93.5% to 98.7% Caucasian (U.S. Census Bureau, 2007).

#### *Age*

The mean age of the women in this study (57 years) was much younger than anticipated because the risk for stroke increases for women as they age (AHA, 2007b). In this study only 28.3% ( $n = 13$ ) of the women experienced stroke after the age of 65 years.

The mean age of the women in this study places them at the age of menopause. While not a specific data collection item, two women stated they were taking hormones at the time of their stroke. Two major studies have supported increase for stroke of post-menopausal women can be related to

hormone therapy (Women's Health Initiative and Women's Estrogen for Stroke Trial [WEST]) (AHA, 2007b).

Lastly, two of the women who had their stroke prior to the age of 40 experienced their stroke either during pregnancy or immediately post-partum. The Baltimore-Washington Cooperative Young Stroke Study (Kittner et al., 1998) found the risk of stroke, ischemic or hemorrhagic to be 2.4 times greater than that for non-pregnant women of similar age.

### *Socioeconomic Status*

Socioeconomic status has been linked to health risk factors and health outcomes (ARC, 2004). The sample of women in this study was not representative of most Appalachian women for education and income. Most of the women in this study had attended or completed college (n=33, 71.7%); while only one woman had not completed high school. The median family income for Appalachian households in 2000 ranged from \$18,034 to \$74,003 (ARC). In this study, the household incomes were almost evenly split between less than \$20,000 (n=24) and greater than \$20,000 (n=22). In addition, those women living in households with higher incomes tended to be married (n=23). Lastly, prior to their stroke, most of the women were employed. After stroke, 22 of the 29 women who were employed full time prior to stroke were no longer able to work full or part-time in their profession.

The inability to return to work following stroke adds to the cost of disability both financially and personally. Work was a part of many of the women's lives in this study. The inability of stroke survivors to return to work impacts their

finances, social interaction, and their personal sense of self and satisfaction with life (Vestling, Tufvesson, & Iwarsson, 2003). Vestling et al.'s study demonstrated when stroke survivors return to work their cognition, physical well-being, self actualization, and socialization greatly improved. The key factors that prevented these women from returning to work included impaired cognition, impaired hand function, and impaired mobility requiring use of assistive devices.

In this study two women were beauticians prior to their stroke. After stroke they were not able to return to work. One of the two women became determined to regain her skills even though she had lost much of the function of her left upper and lower extremity. She told the story of having her father sit on a low stool as she worked to force her left arm to section and lift hair for cutting. When she accomplished this task, she began to volunteer her services in long term care facilities as a beautician. Since her stroke over 17 years ago, she has regained much of the use of her left arm and hand. She has a full salon set-up in her home from which she continues to practice her profession which supports her self-worth, but she has not regained enough abilities for financial compensation. The other woman was not able to return to work not only due to physical limitations but as Vestling et al. (2003) found, cognitive impairment precluded her ability to practice her profession.

### *Survivorship*

Twenty percent of white women who have a stroke between the ages of 50 and 69 years will die within the first year (AHA, 2007b). This number increases to 32% of white women stroke survivors dying within 5 years after first

stroke (AHA, 2007b). The women in this study may be considered long-term stroke survivors as the mean survival rate for the women was 7.12 years.

### *Stroke Type*

Rosamond et al. (2007) reported the national average for ischemic stroke is 87% (male and female combined) with 13% accounting for hemorrhagic stroke. In this study, 17.4% (n=8) of the women participating had survived hemorrhagic stroke. The significance of this may merit further study in the future to assess the prevalence of hemorrhagic stroke in Appalachia.

### *Stroke Risks*

Hypertension is considered a determinant of stroke risk (AHA, 2007a). Greater than 50% of the women in the study were hypertensive. Diabetes is an additive factor to hypertension contributing to ischemic stroke in younger white women before the age of 65 years (Rosamond et al., 2007) and five of the nine women who reported being diabetic were under the age of 65 years. In this study 37.5% of women with history of hemorrhagic stroke were smokers compared to 26.3% of women with ischemic stroke. Lastly, 28% of the women were long-term smokers. For women who smoke a pack a day, the risk of stroke is twice that of women who smoke a half pack per day (Rosamond et al.).

The significance of smoking as a risk factor is noted in Table 29. Less than a third of the participants were smokers at the time of their stroke. Yet, their smoking habits were long term ranging from 15 to 60 years duration.

Interestingly, the 13 smokers continued to smoke after their stroke. This could be



interpreted as fatalistic attitude toward smoking or indicative of the strong addiction properties of cigarettes.

Table 29

*Smoking History*

|            | n                   | %            | M # years<br>smoking | SD    | Range Yr  |
|------------|---------------------|--------------|----------------------|-------|-----------|
| Smoking hx | 13                  | 28.3         | 33.15                | 12.86 | 15-60     |
|            | Minimum<br>pack/day | Max pack/day | M Pack Yr            | SD    | Range     |
| Pack years | .5                  | 2            | 37.92                | 17.73 | 17.5-67.5 |

Data from the Women's Health Study suggests not smoking, moderate alcohol consumption, regular exercise, and a low BMI are associated with a significantly lowered risk for ischemic stroke but not for hemorrhagic stroke (Kurth et al., 2006). Obesity was a predominant characteristic for 72% (n = 33) of the women with their BMI exceeding that expected for height and weight (Department of Health and Human Services National Institute of Health, n.d.). Obesity was slightly higher for ischemic stroke survivors (74%, n = 28) than hemorrhagic stroke survivors (63%, n = 5). While the weight of women at the time of their stroke is unknown, this finding is of concern for the risk of second stroke.

*Physical Healing Summary*

"Physical recovery is limited by the degree of bodily injury" (Corbin & Strauss, 1988, p. 175). The items comprise physical healing include cognition (communication and memory), physical function (physical domain), and poor

health days. These items were measured by the SIS V 3.0 communication and memory dimensions, the SIS V 3.0 physical domain, and the HRQOL-4 measure of poor health days.

Regarding cognition, the communication scores were not statistically different from the test value even though women with mild ischemic and hemorrhagic stroke scored less than the expected score established by Duncan et al. (1999). For the memory aspect of cognition, all groups of women scored slightly lower than the test value. Again, this did not reach statistical significance, thus, congruence with Duncan et al. (1999) findings were noted with this aspect of physical healing.

The normalized scores for the physical domain are reflective of those stroke survivors who did experience specific physical weakness (n=45). The physical domain score incorporates strength, hand function, mobility, ADL, and IADL activities. The mean scores in each of these dimensions that comprise physical domain suggested most of the residual deficits were related to strength and hand function. Women may be able to continue to be mobile and perform ADL/IADL actions, but their strength and full use of the affected hand remained a barrier to full functional recovery. This finding is supported by the study by Kwakkel, Kollen, and Wagenaar (2002) that found residual deficits remain a significant contributor to functional recovery.

Poor health days within 30 days of interview were not statistically different from the national and state average. Yet, the percentage of women having poor health days greater than 14 days exceeded the state average by 4.2% and the

national average by 5.5%. The significance of this finding is yet to be determined. The result could be related to stroke, to comorbid illnesses, or to other factors such as socioeconomic status or cultural environment.

In this study, the factors that comprise physical healing (cognition and function) were used to evaluate their impact on poor physical health days. Neither, in totality, contributed to the number of days women reported as having poor health. Yet, when cognition was separated into memory and communication, memory did correlate with poor health days. The implications of this could include forgetting to follow healthful living strategies, forgetting to take medication, and missed health care provider appointments. All of these factors could have contributed to further health related issues.

Lastly, the memory and communication mean scores are higher than the mean physical domain score. This suggests physical deficits remain long after memory and communication have stabilized.

### *Biographical Reengagement Summary*

Biographical reengagement requires the stroke survivor to have hope and goals (Corbin & Strauss, 1988). Biographical reengagement evolves over time as the stroke survivor envelopes a new identity with the failed body (Corbin & Strauss, 1991). The new self must contend with the physical and mental changes that may occur as a result of stroke. These women must cope with mind, body, and family changes. These changes act to influence their continued participation in their roles of family and community member. Lastly, they must cope with how these changes affect their abilities to control life.

Biographical reengagement was measured by self-assessed health rating, the recovery score, and the specific question “how much have you been limited in our ability to control your life as you wish?”

Most of the women rated their health as good, very good, or excellent (n=33, 72%). When compared to the national (17.1%) and state average (21.2%), the women reporting their health as fair or poor (n=13, 28%) exceeded both levels by 10.9% and 6.8% respectively. Statistical significance was noted at the national level but not at the state level. This brings to question the possibility of health disparity by nature of geographic area or the possibility that this was related to accepted cultural norms.

Women were asked to score their recovery on a scale of 0-100 with 0 being no recovery and 100 being returned to their pre-stroke self. The women scored themselves higher than the expected normalized SIS V 3.0 recovery score but their scores did not reach statistical significance.

Recovery from stroke was less than 75% for nearly one-half of the women. Those women who rated their recovery the highest had the greatest deficits post stroke requiring inpatient rehabilitation (moderate ischemic stroke). These women had obvious physical and cognitive deficits from which to gauge their recovery. In addition, their ability to return to their home and live independently provided them with another level of self assessment of recovery.

While some participants did experience 100% recovery, the mean score across all participants demonstrates as a group that full recovery did not occur. An interesting finding was that women with moderate ischemic stroke scored

statistically higher on recovery than women with mild ischemic or moderate hemorrhagic stroke. All women with moderate ischemic and moderate hemorrhagic stroke experienced inpatient rehabilitation after discharge from the hospital. Conversely, the women with mild ischemic stroke were treated by outpatient therapy. While not a particular measurement item, the women often reflected upon their recovery as being generated by their personal will to comeback and independence.

These findings suggest recovery was relevant to the impact of stroke associated residual deficits. Also, the relationship between health rating and recovery indicated that those who rated their health as fair or poor had lower recovery scores. Lastly, one must question what role the environment had on both health rating and recovery.

As noted by Corbin and Strauss (1991), the environment strongly provides direction for comeback. The environment may allow the stroke survivor to progress or regress. The supportive environment recognizes and supports the efforts of the stroke survivor versus treating the individual as incapable and incompetent. In addition, the stroke survivor may strive to protect self from failure by staying within the confines of home and by staying close to persons who are supportive, even though the support may not allow comeback to the fullest extent.

Most of the women (83%) indicated they were able to maintain control of their lives with minimal interference. Their ability to continue to manage daily life stressors had not changed as a result of their stroke. The women who indicated

loss of control anecdotally reported issues such as inability to drive, having to depend on others for assistance with shopping, doctor's appointments, or dressing, and having to resort to "writing everything down so I don't forget."

The most significant contributions to biographical reengagement were the women's health rating and their recovery score. The data supported the intuitive sense that health rating and recovery are related.

### *Psychological Coming to Terms Summary*

Psychological coming to terms is a component of biographical reengagement (Corbin & Strauss, 1991). The stroke survivor must psychologically accept the changes associated with stroke. The process of accepting a new way of life in a new body is an emotional endeavor as these women seek to reinvent themselves in a new and strange body that has new limitations and possibly dependence (Kvigne & Kirkevold, 2003).

The stroke survivors may be limited in their ability to fulfill their roles as a family member and in the community as a result of residual deficits from stroke. The dimension "handicap" of the SIS V 3.0 measured this important quality of life issue. The questions asked are focused on limitations in eight categories. These include: work, (paid or voluntary), social activities, active and quiet recreation, role as family member and friend, participation in spiritual or religious activities, ability to control life, and ability to help others.

All women continued to be actively engaged in their families and communities as measured by the handicap dimension of the SIS V 3.0. Surprisingly, the women with more deficits from ischemic stroke were highly

engaged ( $p=.001$ ). This finding continues to support the theory of Corbin and Strauss (1991). The women have learned to accept their bodies and live each day accordingly. They have gained confidence in their abilities to manage everyday life experiences and relationships. Lastly, they have developed a renewed sense of self.

The SIS V 3.0 has only two questions that are indicative of the female stroke survivor's personal relationship changes. The two questions are focused on the survivor's role as a family member and friend and ability to help others. For the women surviving stroke, there is much more to interpersonal relationships that needs further exploration (Murray & Harrison, 2004). The Relationship Change Scale probes further into issues such as trust, confidence, recognition of needs and desires, and sexuality.

The effect of stroke on interpersonal relationships was measured by the Relationship Change Scale. Women with minor and moderate strokes had the most significant change in their relationships. This could be interpreted as women with minor stroke were thankful for not having life altering deficits; while women with moderate stroke valued life and their relationships because of their deficits. Women with mild stroke experienced minimal change in their relationships. This could be interpreted as their deficits created some alteration in their lives but not to the point of affecting their relationships with their children or spouses.

The women of this study demonstrated they had reengaged biographically. They also indicate that they have psychologically come to terms

with their life after stroke. Women with mild ischemic and moderate hemorrhagic stroke scored as expected in the recovery domain. Interestingly women with moderate ischemic stroke greatly exceeded the expected normalized score ( $p < .001$ ). This suggested they have not allowed stroke to keep them from engaging in social and interpersonal relationships.

Physical illness or injury and mental distress days did not impact the women's interpersonal relationships when correlated with the Relationship Change Scale even though these days limited their ability to perform their usual activities. This could be reflective of the supportive environment in which the women lived.

The HRQOL-4 physical and mental distress days did not adequately reflect psychological coming to terms. For the long-term stroke survivor many other chronic illnesses and life events were interpreted by the women as factors that contributed to their answers. For example, one participant's husband had Alzheimer's dementia, another woman had one son to die and another son had CABG within 2 months of her interview, and another's husband had died within the year. Yet, the sequence of the comeback model (*Figure 2*, pg. 31) demonstrates these events leads once again to the cycle of comeback that for these women requires readjustment to their lives.

Disability from stroke may last a lifetime. Assessment of the various relationships between multiple domains is essential to provide the most discriminating picture of stroke recovery (Patel et al., 2006). The combination of



the SIS V 3.0, the Relationship Change Scale, and the HRQOL-4 provided much more detailed analysis of psychological coming to terms.

### *Rehabilitation Summary*

The need for rehabilitation services are determined by three evaluation components: 1) probability of recovery, 2) probability of return to the home environment, and 3) clinical assessments (Schwamm et al., 2005). The 18 women who did not require inpatient or outpatient therapy returned home after discharge from the hospital. According to the women, their in-hospital evaluation by therapists determined that the physical, language, and cognitive abilities did not warrant specialized therapy. Their scores on each of the tools provided support that their stroke deficits, or lack thereof, did not impact their physical or cognitive recovery.

In medical terminology, rehabilitation and comeback are synonymous (Corbin & Strauss, 1988). Inpatient rehabilitation has demonstrated improved functional recovery for both moderate and severe strokes (Deutsch et al., 2006; Paolucci et al., 2003). The women in this study who participated in inpatient rehabilitation met or exceeded the mean scores in the SIS V 3.0 that measure function. Yet comeback is the result of many other facets including personal and interpersonal recovery that is difficult to grasp by only measuring function. The women who had rehabilitation scored statistically less in the areas of memory, communication, handicap, and recovery scores probably related to the severity of their stroke. This finding indicated the women continued to have deficits long after their formal rehabilitation.

## Study Conclusions

This study was a journey into the lives of Appalachian women stroke survivors in an attempt to measure their recovery as conceptualized by Corbin and Strauss (1991) and called comeback. The study demonstrated relationships between physical healing, biographical reengagement, and coming to terms that support the theoretical propositions of the Trajectory Theory of Chronic Illness Management (Corbin & Strauss, 1991). Figure 11 was presented in Chapter 1, Figure 3, as the mechanism to demonstrate comeback as the relationships between physical healing, biographical reengagement, and psychologically coming to terms as mediated by rehabilitation.

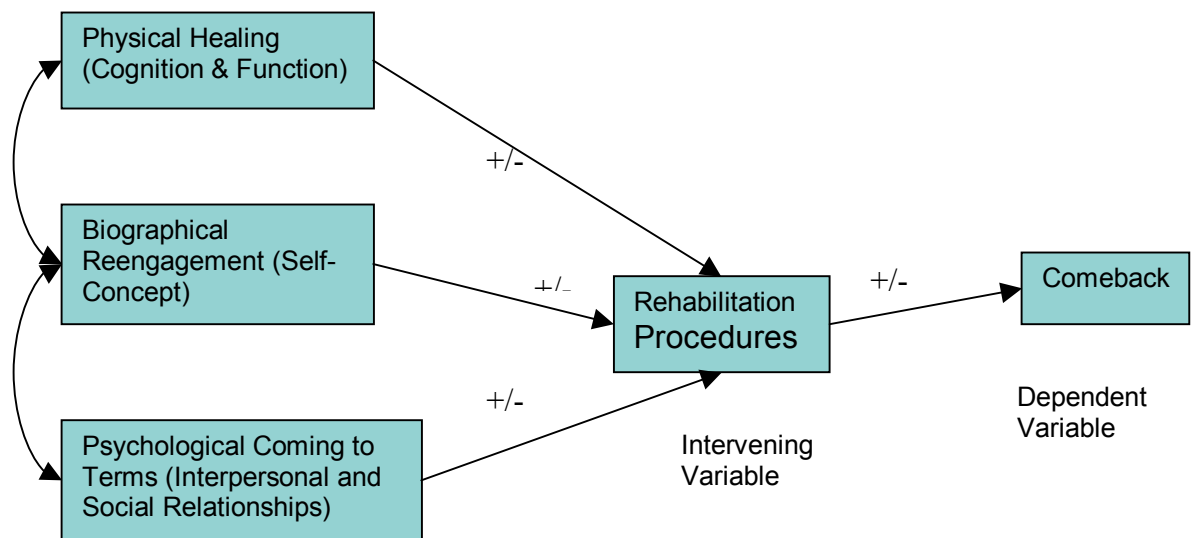


Figure 11. Relationships between Research Variables

Analyses of the data suggested rehabilitation procedures were linked to physical healing but did not have significant impact on the variables biographical reengagement and psychologically coming to terms. Figure 12 is a revision of the schematic to demonstrate the strength of the relationships. While a strong relationship exists among the phases representative of comeback, rehabilitation

procedures and interpersonal relationships demonstrated only a modest impact on the comeback trail. The largest contributors to comeback were the combination of variables used to measure physical healing, biographical reengagement, and psychological coming to terms. The variables that contributed the least to the model included rehabilitation and interpersonal relationships as measured by the Relationship Change Scale.

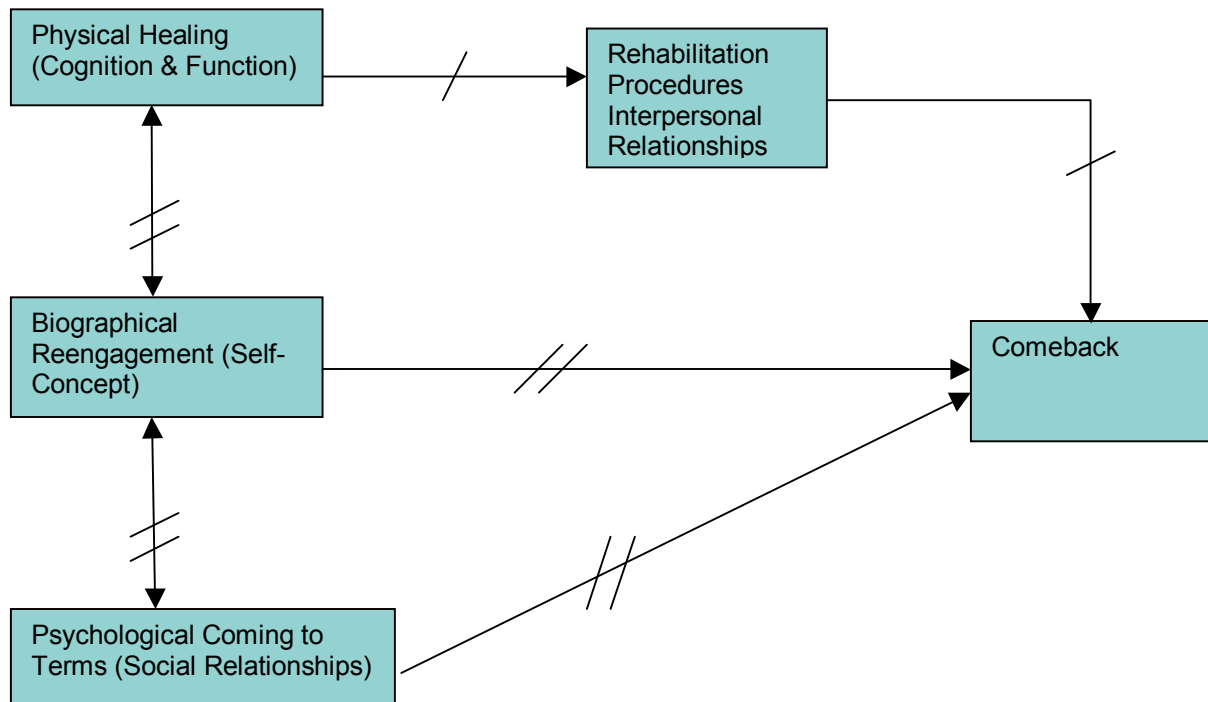


Figure 12. Relationships Predictive of Comeback

NOTE: /=modest relationships  $p < .05$ ; // = significant relationships  $p < .01$

### *Nursing Implications*

The advancement of nursing knowledge and translation of theory into practice is crucial for nurses delivering care and patients receiving care. The fit

between the stroke survivors experience and quantitative tools to measure outcomes match the qualitative data. It also establishes progression or regression of stroke comeback that may be greatly influenced by the actions of the nurse.

Nurses have an important role to facilitate comeback of the stroke survivor. Physical healing, biographical reengagement, and psychological coming to terms are assessable with measurable outcomes that can be incorporated into the plan of care. At the time of the acute event nurses support the stroke survivor toward medical stability as rehabilitation cannot occur without medical stability (Corbin & Strauss, 1991). The initial goal of acute stroke management is to initiate the person's return to health.

Nurses are patient advocates and as such have the opportunity to facilitate care environments for specialty patient populations. Research continues to demonstrate stroke patients cared for by nurses and physicians with specialized training in units dedicated to stroke have improved outcomes (Alberts et al., 2005; Irwin, Hoffman, Lowe, Pearson, & Rudd, 2005).

Formal rehabilitation programs are being scrutinized by insurers and the government. Stroke survivors may be referred to inpatient rehabilitation facilities (IRF), skilled nursing facilities (SNF), home for home health, or home with outpatient therapy depending on the level of the residual physiologic changes from the stroke. The cost of care in an IRF far exceeds that of SNF (Deutsch et al., 2006). Yet for survivors with major motor disabilities, IRF care demonstrates higher functional outcomes compared to SNF (Deutsch et al.). Incorporating the

value of rehabilitation in the home environment, European studies are beginning to demonstrate that home rehabilitation is cost effective with similar outcomes as IRF (Thorsen, Homqvist, & von Koch, 2006). The nurse can play a pivotal political role in demonstrating the value of intensive rehabilitation for the stroke survivor in diverse settings.

According to Corbin and Strauss (1991) “there is a tailored fit between the comeback plan and the persons for whom it is designed medically, rehabilitatively, and biographically. Then when the plan becomes outdated, the plan is updated to reflect the present realities” (p. 145). The holistic care provided by nurses assists patients and their circle of support which influences the move toward comeback.

### *Public Health Implications*

Several areas of Appalachia exceed the nation for stroke mortality (ARC, 2004). For women, the mortality rate often is more than twice that of the national rate (CDC, 2004). With advances in stroke treatment, more people are surviving stroke as noted by a 21% increase in hospital discharges between 1979 and 2004 (AHA, 2007b). In addition, stroke death rates decreased 20.4% between the years 1994 and 2004 which means stroke survivors are living longer (AHA, 2007b). This longer life requires stroke survivors who are capable to adapt to the residual physical and mental challenges of stroke aftermath.

There were two major public health implications from this study. The first was young women in Appalachia experience stroke. While the sample size of this

study was small, only 13 women were over the age of 65 when they had their stroke. This fact alone should raise concern.

The second public health implication was the increased percentage of women in this study who had hemorrhagic stroke compared to the national rate. A limiting factor for implication of the high number of hemorrhagic stroke survivors who participated in the study was the lack of data for the region that provides stroke incidence and prevalence by stroke type. Should the data become available in the future, realistic observational analyses could be completed to identify if the results in this study are representative of the population as a whole.

#### *Continued Study*

There is much work to be done in the study of women stroke survivors. From this study alone other research can be generated. For example, questions such as how can women with stroke regain control of their life, what are the factors impacting both negative and positive relationship changes, and would a larger sample of women with mild stroke provide insight into why they have higher physical illness and mental distress than women with moderate stroke. Exploration of county level data within Appalachia is warranted to evaluate health rating and poor physical and mental health for women stroke survivors. Lastly, longitudinal studies are needed to follow women who experienced stroke in their second and third decade of life.

Looking forward, the baby-boomer generation of women most often has been employed outside of the home. As the generation of working women

experience stroke, the use of technology to facilitate communication and return of function looms on the horizon (Chen, Chen, Lai, Chiang, & Chen, 2005; McClellan et al., 2005; Smith, Herbert, & Reid, 2007). Research is needed to evaluate the use of technology and its significance to physical healing, biographical reengagement, and psychological coming to terms which are the dimensions of comeback.

In conclusion, comeback has been measured quantitatively through the use of validated psychometric instruments. This moves theory from conceptualization to practice application. The women of this study demonstrated consistent congruence with the concepts of the comeback phase in the Trajectory Theory of Chronic Illness. Continued research is warranted to assess this within a larger group of stroke survivors of all ages and both sexes.

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## APPENDICES

### Appendix A

#### Stroke Survivor Study Questionnaire Case #: 0716-

Thank you for your participation in the Stroke Survivor Study. Please complete the following information. All information is confidential and will be coded to eliminate any possibility of self identification.

Zip Code: \_\_\_\_\_ Age: \_\_\_\_\_ Height: \_\_\_\_\_ Weight: \_\_\_\_\_

Month & Year of Stroke: \_\_\_\_\_

Stroke Type: ☐ Ischemic (blood clot) ☐ Hemorrhagic (bleeding)

|  |  |   |  |
|--|--|---|--|
| <b>Referral Source</b>   |  | <b>Race</b>   |  |
| <u>Referral Source</u><br><input type="checkbox"/> MD<br><br><input type="checkbox"/> Newspaper Ad <input type="checkbox"/> TV Ad<br><input type="checkbox"/> Brochure <input type="checkbox"/> Friend <input type="checkbox"/> Other Health Professional  |  | <input type="checkbox"/> African-American <input type="checkbox"/> Hispanic <input type="checkbox"/> Caucasian<br><input type="checkbox"/> Asian <input type="checkbox"/> American Indian <input type="checkbox"/> Other  |  |
| <b>Previous Employment History</b>   |  | <b>Education</b>  |  |
| <input type="checkbox"/> Full-time <input type="checkbox"/> Part-time <input type="checkbox"/> Homemaker   |  | <input type="checkbox"/> HS Grad <input type="checkbox"/> Highest grade completed if not HS grad:<br><input type="checkbox"/> College Grad  |  |
| <b>Current Employment History</b>  |  | <b>Annual Income</b>  |  |
| <input type="checkbox"/> Full-time same job <input type="checkbox"/> Part-time same job<br><input type="checkbox"/> Full-time different job <input type="checkbox"/> Part-time different job<br><input type="checkbox"/> Unemployed  |  | <input type="checkbox"/> < 10,000 <input type="checkbox"/> 10,000-15,000<br><input type="checkbox"/> 15,001-20,000 <input type="checkbox"/> 20,001-30,000<br><input type="checkbox"/> 30,001-45,000 <input type="checkbox"/> >45,000  |  |
| <b>Rehabilitation</b>  |  | <b>Marital Status</b>   |  |
| Inpatient Rehabilitation <input type="checkbox"/> Y <input type="checkbox"/> N<br>If no: Outpatient Therapy <input type="checkbox"/> Y <input type="checkbox"/> N<br>Home Health after Rehabilitation <input type="checkbox"/> Y <input type="checkbox"/> N<br>Home Health with no in-patient rehab <input type="checkbox"/> |  | <input type="checkbox"/> Married <input type="checkbox"/> Single <input type="checkbox"/> Widowed   |  |
| <b>Smoking History</b>   |  | <b>Medical History</b>  |  |
| <input type="checkbox"/> Y <input type="checkbox"/> N<br>If yes: # years:<br># packs/day   |  | <div style="display: flex; justify-content: space-between;"> <div style="width: 48%;"> <input type="checkbox"/> Hypertension<br/> <input type="checkbox"/> Heart Attack<br/> <input type="checkbox"/> Diabetes<br/> <input type="checkbox"/> History of Blood Clots           </div> <div style="width: 48%;"> <input type="checkbox"/> Heart Murmur<br/> <input type="checkbox"/> Congestive Heart Failure<br/> <input type="checkbox"/> Family History of Stroke           </div> </div>                            |  |
| <b>Alcohol Use</b>   |  | <b>Type/Amount</b>  |  |
| <input type="checkbox"/> Y <input type="checkbox"/> Occasional<br><input type="checkbox"/> N <input type="checkbox"/> Daily  |  | <input type="checkbox"/> Beer: <input type="checkbox"/> 1-2 oz<br><input type="checkbox"/> 3-4 oz<br><input type="checkbox"/> 6 oz<br><input type="checkbox"/> > 6 oz<br><input type="checkbox"/> Whisky <input type="checkbox"/> 1-2 oz<br><input type="checkbox"/> 3-4 oz<br><input type="checkbox"/> > 4 oz<br><input type="checkbox"/> Wine <input type="checkbox"/> Red<br><input type="checkbox"/> White<br><input type="checkbox"/> 6 oz<br><input type="checkbox"/> 12 oz<br><input type="checkbox"/> > 12 oz |  |

## Appendix B

### Stroke Impact Scale VERSION 3.0

The purpose of this questionnaire is to evaluate how stroke has impacted your health and life. We want to know from **YOUR POINT OF VIEW** how stroke has affected you. We will ask you questions about impairments and disabilities caused by your stroke, as well as how stroke has affected your quality of life. Finally, we will ask you to rate how much you think you have recovered from your stroke.

# Stroke Impact Scale

These questions are about the physical problems which may have occurred as a result of your stroke.

| 1. In the past week, how would you rate the strength of your....   | A lot of strength | Quite a bit of strength | Some strength | A little strength | No strength at all |
|--|-------------------|-------------------------|---------------|-------------------|--------------------|
| a. Arm that was <u>most affected</u> by your stroke?               | 5                 | 4                       | 3             | 2                 | 1                  |
| b. Grip of your hand that was <u>most affected</u> by your stroke? | 5                 | 4                       | 3             | 2                 | 1                  |
| c. Leg that was <u>most affected</u> by your stroke?               | 5                 | 4                       | 3             | 2                 | 1                  |
| d. Foot/ankle that was <u>most affected</u> by your stroke?        | 5                 | 4                       | 3             | 2                 | 1                  |

These questions are about your memory and thinking.

| 2. In the past week, how difficult was it for you to...                         | Not difficult at all | A little difficult | Somewhat difficult | Very difficult | Extremely difficult |
|---|----------------------|--------------------|--------------------|----------------|---------------------|
| a. Remember things that people just told you?                                   | 5                    | 4                  | 3                  | 2              | 1                   |
| b. Remember things that happened the day before?                                | 5                    | 4                  | 3                  | 2              | 1                   |
| c. Remember to do things (e.g. keep scheduled appointments or take medication)? | 5                    | 4                  | 3                  | 2              | 1                   |
| d. Remember the day of the week?  | 5                    | 4                  | 3                  | 2              | 1                   |
| e. Concentrate?   | 5                    | 4                  | 3                  | 2              | 1                   |
| f. Think quickly?   | 5                    | 4                  | 3                  | 2              | 1                   |
| g. Solve everyday problems?   | 5                    | 4                  | 3                  | 2              | 1                   |

These questions are about how you feel, about changes in your mood and about your ability to control your emotions since your stroke.

| 3. In the past week, how often did you...         | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|---|------------------|----------------------|------------------|------------------|-----------------|
| a. Feel sad?                                      | 5                | 4                    | 3                | 2                | 1               |
| b. Feel that there is nobody you are close to?    | 5                | 4                    | 3                | 2                | 1               |
| c. Feel that you are a burden to others?          | 5                | 4                    | 3                | 2                | 1               |
| d. Feel that you have nothing to look forward to? | 5                | 4                    | 3                | 2                | 1               |
| e. Blame yourself for mistakes that you made?     | 5                | 4                    | 3                | 2                | 1               |
| f. Enjoy things as much as ever?                  | 5                | 4                    | 3                | 2                | 1               |
| g. Feel quite nervous?                            | 5                | 4                    | 3                | 2                | 1               |
| h. Feel that life is worth living?                | 5                | 4                    | 3                | 2                | 1               |
| i. Smile and laugh at least once a day?           | 5                | 4                    | 3                | 2                | 1               |

The following questions are about your ability to communicate with other people, as well as your ability to understand what you read and what you hear in a conversation.

| 4. In the past week, how difficult was it to...  | Not difficult at all | A little difficult | Somewhat difficult | Very difficult | Extremely difficult |
|--|----------------------|--------------------|--------------------|----------------|---------------------|
| a. Say the name of someone who was in front of you?  | 5                    | 4                  | 3                  | 2              | 1                   |
| b. Understand what was being said to you in a conversation?  | 5                    | 4                  | 3                  | 2              | 1                   |
| c. Reply to questions?   | 5                    | 4                  | 3                  | 2              | 1                   |
| d. Correctly name objects?   | 5                    | 4                  | 3                  | 2              | 1                   |
| e. Participate in a conversation with a group of people?   | 5                    | 4                  | 3                  | 2              | 1                   |
| f. Have a conversation on the telephone?   | 5                    | 4                  | 3                  | 2              | 1                   |
| g. Call another person on the telephone, including selecting the correct phone number and dialing? | 5                    | 4                  | 3                  | 2              | 1                   |

The following questions ask about activities you might do during a typical day.

| 5. In the past 2 weeks, how difficult was it to...   | Not difficult at all | A little difficult | Somewhat difficult | Very difficult | Could not do at all |
|--|----------------------|--------------------|--------------------|----------------|---------------------|
| a. Cut your food with a knife and fork?  | 5                    | 4                  | 3                  | 2              | 1                   |
| b. Dress the top part of your body?  | 5                    | 4                  | 3                  | 2              | 1                   |
| c. Bathe yourself?   | 5                    | 4                  | 3                  | 2              | 1                   |
| d. Clip your toenails?   | 5                    | 4                  | 3                  | 2              | 1                   |
| e. Get to the toilet on time?  | 5                    | 4                  | 3                  | 2              | 1                   |
| f. Control your bladder (not have an accident)?  | 5                    | 4                  | 3                  | 2              | 1                   |
| g. Control your bowels (not have an accident)?   | 5                    | 4                  | 3                  | 2              | 1                   |
| h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)? | 5                    | 4                  | 3                  | 2              | 1                   |
| i. Go shopping?  | 5                    | 4                  | 3                  | 2              | 1                   |
| j. Do heavy household chores (e.g. vacuum, laundry or yard work)?                            | 5                    | 4                  | 3                  | 2              | 1                   |

The following questions are about your ability to be mobile, at home and in the community.

| 6. In the past 2 weeks, how difficult was it to... | Not difficult at all | A little difficult | Somewhat difficult | Very difficult | Could not do at all |
|--|----------------------|--------------------|--------------------|----------------|---------------------|
| a. Stay sitting without losing your balance?       | 5                    | 4                  | 3                  | 2              | 1                   |
| b. Stay standing without losing your balance?      | 5                    | 4                  | 3                  | 2              | 1                   |
| c. Walk without losing your balance?               | 5                    | 4                  | 3                  | 2              | 1                   |
| d. Move from a bed to a chair?                     | 5                    | 4                  | 3                  | 2              | 1                   |
| e. Walk one block?                                 | 5                    | 4                  | 3                  | 2              | 1                   |
| f. Walk fast?                                      | 5                    | 4                  | 3                  | 2              | 1                   |
| g. Climb one flight of stairs?                     | 5                    | 4                  | 3                  | 2              | 1                   |
| h. Climb several flights of stairs?                | 5                    | 4                  | 3                  | 2              | 1                   |
| i. Get in and out of a car?                        | 5                    | 4                  | 3                  | 2              | 1                   |

The following questions are about your ability to use your hand that was MOST AFFECTED by your stroke.

| 7. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to... | Not difficult at all | A little difficult | Somewhat difficult | Very difficult | Could not do at all |
|---|----------------------|--------------------|--------------------|----------------|---------------------|
| a. Carry heavy objects (e.g. bag of groceries)?   | 5                    | 4                  | 3                  | 2              | 1                   |
| b. Turn a doorknob?   | 5                    | 4                  | 3                  | 2              | 1                   |
| c. Open a can or jar?   | 5                    | 4                  | 3                  | 2              | 1                   |
| d. Tie a shoe lace?   | 5                    | 4                  | 3                  | 2              | 1                   |
| e. Pick up a dime?  | 5                    | 4                  | 3                  | 2              | 1                   |

The following questions are about how stroke has affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you to find purpose in life.

| 8. During the past 4 weeks, how much of the time have you been limited in... | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|--|------------------|----------------------|------------------|------------------|-----------------|
| a. Your work (paid, voluntary or other)                                      | 5                | 4                    | 3                | 2                | 1               |
| b. Your social activities?   | 5                | 4                    | 3                | 2                | 1               |
| c. Quiet recreation (crafts, reading)?                                       | 5                | 4                    | 3                | 2                | 1               |
| d. Active recreation (sports, outings, travel)?                              | 5                | 4                    | 3                | 2                | 1               |
| e. Your role as a family member and/or friend?                               | 5                | 4                    | 3                | 2                | 1               |
| f. Your participation in spiritual or religious activities?                  | 5                | 4                    | 3                | 2                | 1               |
| g. Your ability to control your life as you wish?                            | 5                | 4                    | 3                | 2                | 1               |
| h. Your ability to help others?  | 5                | 4                    | 3                | 2                | 1               |

9. Stroke Recovery

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered from your stroke?

|       |                   |
|-------|-------------------|
| _____ | 100 Full Recovery |
| _____ |                   |
| _____ | 90                |
| _____ |                   |
| _____ | 80                |
| _____ |                   |
| _____ | 70                |
| _____ |                   |
| _____ | 60                |
| _____ |                   |
| _____ | 50                |
| _____ |                   |
| _____ | 40                |
| _____ |                   |
| _____ | 30                |
| _____ |                   |
| _____ | 20                |
| _____ |                   |
| _____ | 10                |
| _____ |                   |
| _____ | 0 No Recovery     |

## Appendix C

### Relationship Change Scale

This is a questionnaire to determine whether, and in what ways, your relationship with your partner has changed since your stroke. Please complete the statements by making an X in the column that most accurately completes each statement. Please give as accurate and honest an account of your own feelings and beliefs as possible.

SINCE THE STROKE:

|   | Much Less | Less | No Change | More | Much More |
|---|-----------|------|-----------|------|-----------|
| My satisfaction with myself in this relationship is:              |           |      |           |      |           |
| My satisfaction with my partner in this relationship is:          |           |      |           |      |           |
| I think my partner considers me a satisfactory mate:              |           |      |           |      |           |
| I think my partner considers him/herself a satisfactory mate:     |           |      |           |      |           |
| The strength of our relationship with each other is:              |           |      |           |      |           |
| I am aware of my partner's needs and desires in our relationship: |           |      |           |      |           |
| I understand my own feelings about our relationship               |           |      |           |      |           |
| I understand my own needs and desires in our relationship:        |           |      |           |      |           |
| My ability to understand my partner's feelings is:                |           |      |           |      |           |
| Our ability to communicate is:                                    |           |      |           |      |           |
| My sensitivity towards my partner as a person is:                 |           |      |           |      |           |
| My concern and warmth toward my partner is:                       |           |      |           |      |           |
| My self-expression and openness in relation to my partner is:     |           |      |           |      |           |
| My ability to understand my partner's likes and dislikes is:      |           |      |           |      |           |
| My ability to listen well to my partner is:                       |           |      |           |      |           |
| My trust in my partner is:  |           |      |           |      |           |
| My feeling of intimacy with my partner is:                        |           |      |           |      |           |



|   | Much Less | Less | No Change | More | Much More |
|---|-----------|------|-----------|------|-----------|
| My confidence in our relationship is:   |           |      |           |      |           |
| Our ability to handle disagreements constructively is:  |           |      |           |      |           |
| Our satisfaction with our sexual relationship is:   |           |      |           |      |           |
| My ease in talking with my partner is:  |           |      |           |      |           |
| My ability to express positive feelings toward my partner is:                                 |           |      |           |      |           |
| My ability to constructively express negative feelings towards my partner is:                 |           |      |           |      |           |
| My willingness to share my personal concerns with my partner is:                              |           |      |           |      |           |
| My capacity to believe and accept positive feelings my partner expresses toward me is:        |           |      |           |      |           |
| My capacity to deal constructively with negative feelings my partner expresses toward me is:  |           |      |           |      |           |
| My understanding of the kind of relationship I want to have in the future with my partner is: |           |      |           |      |           |

## Appendix D

### Health-Related-Quality-of Life 4 (HRQOL-4)

Health Care and Aging Studies Branch

Division of Community Health

National Center for Chronic Disease Prevention and Health Promotion

Center for Disease Control and Prevention

1. Would you say that in general your health is: excellent, very good, good, fair, or poor?
2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? \_\_\_\_\_ days
3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good? \_\_\_\_\_ days
4. During the past 30 days, for about how many days did physical or mental health keep you from your usual activities, such as self-care, work, or recreation? \_\_\_\_\_ days

## Appendix E

### Log

| Date | Participant Name/DOB | Identifier-0716 + Random Digit |
|------|----------------------|--------------------------------|
|      |                      | 0716-136                       |
|      |                      | 0716-88                        |
|      |                      | 0716-118                       |
|      |                      | 0716-93                        |
|      |                      | 0716-18                        |
|      |                      | 0716-147                       |
|      |                      | 0716-15                        |
|      |                      | 0716-40                        |
|      |                      | 0716-30                        |
|      |                      | 0716-148                       |
|      |                      | 0716-143                       |
|      |                      | 0716-123                       |
|      |                      | 0716-32                        |
|      |                      | 0716-39                        |
|      |                      | 0716-125                       |
|      |                      | 0716-24                        |
|      |                      | 0716-114                       |
|      |                      | 0716-11                        |
|      |                      | 0716-23                        |
|      |                      | 0716-107                       |
|      |                      | 0716-13                        |
|      |                      | 0716-35                        |
|      |                      | 0716-20                        |
|      |                      | 0716-47                        |
|      |                      | 0716-50                        |
|      |                      | 0716-113                       |
|      |                      | 0716-112                       |
|      |                      | 0716-48                        |
|      |                      | 0716-77                        |
|      |                      | 0716-85                        |
|      |                      | 0716-33                        |
|      |                      | 0716-144                       |
|      |                      | 0716-110                       |
|      |                      | 0716-82                        |
|      |                      | 0716-121                       |
|      |                      | 0716-74                        |
|      |                      | 0716-91                        |
|      |                      | 0716-114                       |
|      |                      | 0716-128                       |
|      |                      | 0716-31                        |
|      |                      | 0716-53                        |
|      |                      | 0716-122                       |
|      |                      | 0716-126                       |
|      |                      | 0716-16                        |
|      |                      | 0716-102                       |
|      |                      | 0716-38                        |

## Appendix F

### Random Integers

**How:** Place the number of random numbers required in the first text box, an integer number (0 to 32767) in the second box, the maximum and minimum desired values of the integers in the last 2 boxes. Press Generate random integers button, and the numbers will show.

|   |                                    |                          |       |
|---|------------------------------------|--------------------------|-------|
| 49  | Number of random integers required |                          |       |
| 3   | Random seed (any integer)          |                          |       |
| 10  | Minimum value                      |                          |       |
| 150   | Maximum value                      |                          |       |
| <table><tr><td>Generate random integers</td><td>Reset</td></tr></table> |                                    | Generate random integers | Reset |
| Generate random integers  | Reset                              |                          |       |

### Results

136 88 118 93 18 147 15 40 30 148 136 143 123 32 39 125 24 114 11 23 107 13 35 20 47 50  
113 112 48 77 85 33 144 110 82 121 126 74 91 144 114 128 31 53 122 126 16 102 38

Table obtained from:

[http://department.obg.cuhk.edu.hk/ResearchSupport/Random\\_integer.asp](http://department.obg.cuhk.edu.hk/ResearchSupport/Random_integer.asp)  
4/19/2006

## Appendix G

### SIS V 3.0 Permission

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#### University of Kansas Medical Center

##### AGREEMENT FOR TRANSFER OF RESEARCH MATERIAL (NON-PROFIT REQUEST)

Pursuant to your request that certain copyrighted research material(s) be made available for research and/or testing purposes, the INVENTOR and the University of Kansas Medical Center (KUMC) are pleased to provide this material under the following terms and conditions:

1. The parties to this Agreement are:
  - X The University of Kansas Medical Center, hereinafter KUMC AND
  - X Pamela W. Duncan, Lu M. Lai, PhD, hereinafter PROVIDER
  - X East Tennessee State University, hereinafter ORGANIZATION AND
  - X Patricia M. Vanhook, hereinafter RECIPIENT.
2. The research material covered by this agreement includes the:  
Stroke Impact Scale, or SIS, that was developed by Provider at KUMC, hereinafter Material(s).
3. The Material shall be used in research studies as described by the RECIPIENT in Attachment 1 and will not be redistributed or released by RECIPIENT or ORGANIZATION to any third parties or entities for any purpose; RECIPIENT/ORGANIZATION agree to refer requests for the Material to KUMC.
4. The Material is owned by KUMC and will continue to be owned by KUMC after it is transmitted to RECIPIENT/ORGANIZATION. RECIPIENT/ORGANIZATION may make "Authorized Copies" of the Material in its most recently revised form only for use in a manner as covered by Attachment 1. "Authorized Copies" shall include one or more photocopies of the Material onto 8 1/2" x 11" paper, without reformatting, reduction or enlargement of the Material, except for in the case of reproduction by RECIPIENT/ORGANIZATION of the Material for placement in a written publication, which requires reformatting for the placement in said publication only, subject to the terms of section 8 below. No right is granted to alter the wording of the Material or to translate the Material into any other language or means of communication. No other right or license to the Material is granted by this agreement.
5. Ownership of any invention or marketable commercial product made by RECIPIENT/ORGANIZATION using the Material will be determined in good faith by the parties hereto depending upon (a) their relative contributions to the creation of such inventions of commercial products, and (b) any applicable laws and regulations relating to inventorship.
6. The Material will be used by RECIPIENT/ORGANIZATION only under suitable conditions, in compliance with all laws and governmental/NIH regulations and guidelines applicable to the Material.
7. The Material, and any information relating to it that may be disclosed to RECIPIENT/ORGANIZATION by KUMC (the "Information") are being provided to and accepted by RECIPIENT/ORGANIZATION *without any warranty of merchantability or fitness for any particular purpose or any other warranty, express or implied*. KUMC and its directors, officers, employees, or agents assume no liability and make no representations in connection with the Material or the derivatives of the Information or their use by ORGANIZATION or its research investigators. RECIPIENT/ORGANIZATION hereby agrees to assume responsibility for the negligent acts of its employees or agents in regard to their use and possession of the Material, Derivatives, or Information by RECIPIENT/ORGANIZATION or

anyone to whom RECIPIENT/ ORGANIZATION may make them available pursuant to this Agreement.

8. If publication results from research using the Material, RECIPIENT agrees to acknowledge PROVIDER and KUMC and/or give credit to PROVIDER, as scientifically appropriate. RECIPIENT will provide KUMC and PROVIDER with a reprint of publications that describe work with the Material. PROVIDER agrees that it will reference or acknowledge RECIPIENT's publications, as scientifically appropriate, in its publications that may refer to the data developed by RECIPIENT. RECIPIENT and ORGANIZATION agree to properly evidence the copyright notice on the Material in the following form: ©1998, The University of Kansas Medical Center.
9. KUMC or its designee shall have the right to audit the books of RECIPIENT/ORGANIZATION during regular business hours and following written notice to RECIPIENT.
10. If you agree to accept this material under the above conditions, one copy of this agreement should be signed and dated by the Scientist and an authorized representative of the Organization and returned to the representative of KUMC indicated below. Any inquiries regarding the use, publication, or incorporation of the Material should be directed to:

James G. Baxendale, M.S., M.B.A.  
 Director of Technology Development  
 University of Kansas Medical Center Research Institute  
 5009 Wescoe Pavilion  
 3901 Rainbow Boulevard  
 Kansas City, Kansas 66160-7702  
 phone: 913.588.1495  
 fax: 913.588.5242  
 E-mail: jbxenda@kumc.edu

**AGREED TO AND ACCEPTED:**

RECIPIENT:

ORGANIZATION: East Tennessee State University

Patricia M Vanhook 12/12/05 Jo-Ann Marrs 124-06  
 NAME: Patricia M Vanhook Date: 12/12/05 NAME: Jo-Ann Marrs, RN, EdD Date:  
 TITLE: Student TITLE: Associate Dean & Chair of Dissertation Committee

UNIVERSITY OF KANSAS MEDICAL CENTER (KUMC):

Sue M. Lai 2/4/06 Ted Knous 2-10-06  
 Sue M. Lai, PhD MS MBA Date: Ted Knous, Ph.D. Date:  
 Professor Associate Vice Chancellor for  
 Preventive Medicine & Research Administration  
 Public Health

ATTACHMENT 1

Please provide specific details about the use of the Materials provided herein: (Please print or type)

This tool will be used by graduate student Patricia M Vanhook in conjunction with nursing doctoral research conducted at East Tennessee State University College of Nursing, Johnson City, TN. The research is titled The Chronic Illness Trajectory of the Appalachian Female Stroke Survivor: The Interrelationships of Functional Ability, Self-Concept, Interpersonal, and Social Relationships. The research involves women stroke survivors ages 40 to 78 living in rural Appalachia.

## Appendix H

### IRB Approval



East Tennessee State University  
Office for the Protection of Human Research Subjects • Box 70565 • Johnson City, Tennessee 37614-1707 • (423) 439-6053  
Fax: (423) 439-6060

#### IRB APPROVAL - Initial Review

May 17, 2006

Patricia Vanhook, APRN  
Nursing  
800 Glen Oaks Ct.  
Johnson City, TN 37615

Re: Chronic Illness Trajectory for the Appalachian Female Stroke Survivor: The Interrelationships of Functional Ability, Self-Concept, Interpersonal and Social Relationships

IRB#: 05-206s

The following items received expedited review:

- Form 103 (05/02/2006)
- \* Narrative (02/12/2006)

Questionnaire is included as part of the Narrative

- \* Informed Consent Document (02/12/2006)

Included as part of the narrative

- HIPAA Authorization to Use & Disclose
- HIPAA De-Identification Certification Form
- Advertisement - Included as part of Narrative poster and newspaper ad
- CV
- Conflict of Interest Form

The following documents with the incorporated requested changes have been received by the IRB Office:

revised ICD (version date 5/17/06)  
revised Narrative (version date 4/19/06)

The revised ICD (version date 5/17/06) and Narrative (version date 4/19/06) incorporating the requested changes was reviewed and approved by an expedited process on May 17, 2006 by Kenneth E. Olive, MD, Chair, ETSU/VA Medical IRB.



Accredited Since December 2005

Page 1 of 2



On May 17, 2006, a final approval was granted for a period not to exceed 12 months and will expire on 05/16/2007. Your Continuing Review is scheduled for 04/03/2007. The expedited approval of the study and requested changes [ICD (version date 05/17/2006) and Narrative (version date 04/19/06)], will be reported to the convened board on June 6, 2006.

The following enclosed stamped, approved ICD has been stamped with the approval and expiration date and this document must be copied and provided to each participant prior to participant enrollment:

- Informed Consent Document (version date 05/17/2006)

Federal regulations require that the original copy of the participant's consent be maintained in the principal investigator's files and that a copy is given to the subject at the time of consent.

Unanticipated Problems Involving Risks to Subjects or Others must be reported to the IRB (and VA R&D if applicable) within 10 working days.

Proposed changes in approved research can not be initiated without IRB review and approval. The only exception to this rule is that a change can be made prior to IRB approval when necessary to eliminate apparent immediate hazards to the research subjects [21 CFR 56.108 (a)(4)]. In such a case, the IRB must be promptly informed of the change following its implementation (within 10 working days) on Form 109 ([www.etsu.edu/irb](http://www.etsu.edu/irb)). The IRB will review the change to determine that it is consistent with ensuring the subject's continued welfare.

Sincerely,

  
Kenneth E. Olive, M.D., Chairperson  
ETSU/VA Medical Institutional Review Board

## VITA

PATRICIA M. VANHOOK

- Personal Data: Date of Birth: December 23, 1953  
Place of Birth: East Stone Gap, Virginia  
Marital Status: Married to Guy Phillip Vanhook May 9, 1975
- Education: Public Schools: Big Stone Gap, Virginia  
A.D.N. Mountain Empire Community College, Big Stone Gap, Virginia 1982  
B.S.N. East Tennessee State University, Johnson City, Tennessee 1991  
M.S.N. East Tennessee State University, Johnson City, Tennessee 1994  
D.S.N. East Tennessee State University, Johnson City, Tennessee 2007
- Professional Experience: Registered Nurse. Lonesome Pine Hospital; Big Stone Gap, Virginia 1982-1991  
Director Special Care & ED Lonesome Pine Hospital; Big Stone Gap, VA. 1983-1991  
Critical Care Educator, Indian Path Medical Center; Kingsport, Tennessee 1991-1993  
Projects Administrator, Indian Path Medical Center, Kingsport, Tennessee 1993-1995  
Family Nurse Practitioner, Physician Access 1995-2002  
Stroke Center Coordinator and Director of Critical Care and Progressive Care, Indian Path Medical Center, 1998-2003  
Magnet Coordinator, Mountain States Health Alliance 2003-2006  
Research Associate, Center for Nursing Research, East Tennessee State University, Johnson City, Tennessee 2006-Present
- Publications: Vanhook, P.M. (2005). Comparing reimbursement with costs of care. In Dunham-Taylor & Pinczuk, J.Z. *Health care financial management for nurse managers: merging the heart with the dollar*. (ISBN: 0-7637-3149-8). Boston, MA: Jones & Bartlett Publishers  
Vanhook, P.M., & Jones, M.L. (2007). Reducing patient falls as a quality improvement effort at

Johnson City Medical Center in *Transforming Nursing Data into Quality Care: Profiles of Quality Improvement in U.S. Healthcare Facilities*. Washington, DC: American Nurses Association

Vanhook, P.M. & Richmond, T. (2007) Post acute levels of care: A tool for referral. *Lippincott's Case Management: The Journal for Professional Practice*.

Grants:

\$75,000 Virginia Healthcare Foundation to establish NP managed rural health clinic, Mendota, Virginia

\$500 Stroke Belt Consortium, October 2001.  
Standardization of EMS stroke Assessment using the Cincinnati Stroke Scale

\$1500 Stroke Belt Consortium, Assessment of Northeast Tennessee African American Knowledge of Stroke Risk Factors

Honors and Awards:

1982 Dean's Outstanding Student Award, Mountain Empire Community College

1999 Nursing Excellence, NE Tennessee Nurses Association

2004 Betsy Brogan Award for Outstanding Dedication and Commitment to Nursing, Mountain States Health Alliance

2006 Nursing Excellence in pursuit of Magnet Designation. Mountain States Health Alliance

2007 Rising Star in Nursing Scholarship, Epsilon Sigma, Sigma Theta Tau International

2007 Magnet Appraiser Fellow. American Nurses Credentialing Center.