



## APPROVAL SHEET

Title of Dissertation: Experience of Stroke Recovery for Women 60 or Older

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## ABSTRACT

Title of Document: EXPERIENCE OF STROKE RECOVERY FOR WOMEN 60 OR OLDER

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Stroke is a common health concern in the U.S. with 795,000 new strokes each year. Women dominate these numbers, with 55,000 more strokes per year than men, yet they are disproportionately underrepresented in stroke research. Some research indicates that women have worse physiological and psychosocial outcomes after stroke than men, yet little is known about how they experience recovery. This research fills a gap in focusing on how women experience recovery after stroke. Through use of a qualitative phenomenological approach, this study provides insight regarding their lived experiences. The research asks, “What is the experience of stroke recovery for community dwelling women age 60 or older?” The following aims were developed: 1) To describe women’s experiences of recovery after stroke, 2) To determine how women experience self during the stroke recovery process, and 3) To establish how women define normal life before and after stroke.

The participants were 10 women, ages 60 – 78, with times post-stroke ranging from 4 months to 15 years. They participated in 2 semi-structured interviews, with auto-photography used to enhance their sharing of information. Between the two interviews, they were provided with a digital camera and asked to take pictures that helped to explain their lives before and after stroke. During the 2<sup>nd</sup> interview,

participants shared and described their pictures, and answered additional questions about their recovery. Interviews were transcribed verbatim and the narrative transcripts were the primary data source for analysis. The narratives were coded and analyzed thematically to describe how this sample of individuals experienced stroke recovery.

Four overarching themes emerged from the data: 1) the stroke event, 2) a new chapter, 3) meaning and process of recovery, and 4) self-identity. Various subthemes emerged under each theme and are discussed in detail in the dissertation. In general, narratives revealed that recovery is described as a complex, individualized, and subjective experience that extends beyond overt physical abilities. Participants in this study experienced changes in self-identity and described a “new normal” after stroke. Implications and recommendations for rehabilitation, research, and policy are discussed.

EXPERIENCE OF STROKE RECOVERY FOR WOMEN 60 OR OLDER

By

Iona Johnson

Dissertation submitted to the Faculty of the Graduate School of the  
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## Dedication

In memory of my mother, Iona Ringgold Hutton, who passed away the year before my final defense. Although she stood only about 5 feet tall, she was a giant in my eyes. Her unshakeable faith, quiet strength, enduring patience, sharp wit, perseverance, and love of life and family molded and inspired me to be who I am.



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Working full-time throughout this journey was a challenge at times, and I was blessed with an entire village of people who helped me to keep all the balls in the air, and sometimes held a few for me while I caught my breath. I extend my warmest gratitude to Dr. Sharon Glennen and Dr. Sonia Lawson, my friends and colleagues from Towson University. They both always seemed to be there when I needed an extra boost of encouragement. My deepest gratitude also goes out to my career long mentor, Dr. Paul Rao. He was always there in the background as a role-model and

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## **Chapter 1: introduction**

This dissertation employs a qualitative, phenomenological approach to better understand how mature women conceptualize recovery after a stroke. Stroke is a leading cause of disability in the United States and, because death rates for stroke have decreased over the past few decades and Americans are living longer, the number of stroke survivors will continue to increase (Bushnell, et al., 2014a; Mozaffarian, et al., 2016; Ovbiagele, et al., 2013). This increase in the number of stroke survivors will have individual, as well as larger social and economic implications. The increase in stroke survivors is especially relevant among women, who are disproportionately affected by stroke (Bushnell, et al., 2014a, 014b). Women have a higher lifetime risk of stroke, and nearly 56% of stroke survivors are women (Bushnell, et al., 2014a; Mozaffarian, et al., 2016). Stroke in women is a public health concern that researchers describe as “neglected” (Bousser 1999), largely because they are typically underrepresented in clinical trials and research. In addition, gender-related issues are not widely addressed in stroke research (Davidson, Digiacomio, & McGrath, 2011; Kosiak, Sangl, Correa-de-Araujo, 2004). Women have worse physiological and psychosocial outcomes after a stroke, yet the reasons for this gender disparity are not well understood (Di Carlo, et al., 2003; Fukuda, Kanda, Kamide, Akutsu, & Sakai, 2009; Gargano & Reeves, 2007; Persky, Turtzo & McCullough, 2010). The purpose of this dissertation is to gain better understanding of women’s recovery experiences from their own points of view, to identify related theory as to why women have poorer outcomes and identify implications for improved treatment approaches after stroke.

The qualitative methodology chosen for this dissertation includes integrated use of in-depth, semi-structured interviewing and auto-photography. Auto-photography is a photo elicitation method in which participants take pictures that represent personal meaning relating to the topic of study (Harper, 2002); the procedure is described in greater detail elsewhere in this dissertation. Finally, a phenomenological approach is used to analyze the data and describe the lived experience of the participants, because the focus here is on women's experiences post-stroke, in contrast to a medical model of recovery.

### *1.1. Rationale for Study*

The World Stroke Organization (n.d.) conducted a campaign, for 2014 – 2016, with the theme, “I am Woman.” This campaign was devoted to raising awareness of women's issues, given the disparities in disability and recovery post stroke, and overall poorer outcomes for women (Fukuda, et al., 2009; Paolucci, et al., 2006; Persky, Turtzo, & McCullough, 2010). In fact, gender-related disparities in stroke and its consequences occur worldwide. Accordingly, taking a gender-based perspective is important in understanding the distinct physiological and psychosocial factors underlying differences in health and recovery (Davidson, Digiacomo, & McGrath, 2011).

There are several reasons why a study on perceptions and meanings related to recovery of older female stroke survivors is important. First, women live longer than men. Consequently, female stroke survivors will continue to outnumber male stroke survivors and become an increasingly larger group. In fact, the overall health and economic burden of stroke in the U.S. is projected to rise dramatically by the year



2030 (Ovbiagele, et al., 2013). The American Heart Association (AHA)/ American Stroke Association (ASA) developed a multidisciplinary writing group to study the projected dramatic increase in stroke prevalence and economic burden (Ovbiagele, et al., 2013). This group of experts found that, as compared to 2012, by the year 2030, nearly 4% of the population is projected to have had a stroke (as compared to 3.2% in 2012), and total direct costs are projected to triple from \$71.55 to \$184.13 billion (Ovbiagele, et al., 2013). Further, indirect costs, based on premature mortality and lost productivity from morbidity (includes lost wages for the stroke survivor and members of the household), are projected to increase by 68%, from \$33.65 billion in 2012 to \$56.54 billion in 2030. Risk of stroke increases with age, based on prevalence rates per age group: 2.8% for ages 45 – 64, to 9.04% for ages 65-79, with a dramatic increase in prevalence to 15.41% for persons age 80 and older (Ovbiagele, et al., 2013). Based on data for 2014, and given the current prevalence of stroke for women, there are approximately 200,000 more disabled women than men living as stroke survivors (Bushnell, et al., 2014a). With changing demographics, there will continue to be increasingly large numbers of older women with various degrees of disability and potential for lower quality of life after stroke (Bushnell, et al., 2014a; Bushnell, et al., 2014b; Ovbiagele, et al., 2013).

Second, older women have some distinct biological factors that place them more at risk for stroke. The AHA/ ASA also formed an interdisciplinary writing group to address stroke risks that were sex specific and/or more common in women, stating that addressing the needs of stroke in women is “vitally important” (Bushnell, et al., 2014a). In addition, for the first time, specific guidelines were developed for stroke

prevention in women (Bushnell, et al., 2014a). Physiological risk factors that are sex-specific and impact older women include postmenopausal hormone use and change in hormonal status (Bushnell, et al., 2014a). Other researchers note that in the 10 years after menopause, stroke risk doubles for women (Lisabeth & Bushnell, 2012). The AHA/ ASA writing group (Bushnell, et al., 2014a) also described sex-specific risk factors that are stronger or more prevalent in women: migraine with aura, atrial fibrillation, diabetes mellitus, and hypertension.

Third, in addition to physiological factors, older women have some distinct psychological and sociodemographic factors that may make them more vulnerable to negative outcomes after stroke. The AHA/ ASA writing group (Bushnell, et al., 2014a) identified depression and psychosocial stress as risk factors that were stronger or more prevalent in women, with these factors having the potential to impact stroke risk as well as outcomes after stroke. Furthermore, older women are more than twice as likely to live alone (9.2 million) as compared to older men (4.1 million), and there are more than three times as many widows (8.8 million) as widowers (2.4 million) (Administration on Aging, 2015). Living arrangements, marital status, and/or widowhood, are all factors that may have an impact on availability of practical and social support and overall health status; these factors are therefore significant in consideration of recovery outcomes (Whitson, et al., 2010). Older women also have a higher poverty rate (12.1%) as compared to older men (7.4%) (Administration on Aging, 2015). In addition, minority women are even more disadvantaged in dealing with needs after a stroke, with poverty rates of 20.9% for black women and 19.6% for Hispanic women age 65 and older (Cubanski, Casillas, & Damico, 2015; Eichner &

Robbins, 2015). Women stroke survivors who are living in poverty would likely have limitations in accessing resources that may be factors in prevention, treatment, and recovery.

Fourth, although stroke in women has been identified as a significant public health issue in the United States, it has not been adequately addressed, and, as of 2014, there were no mechanisms in place for a coordinated research agenda (Bushnell, 2014a). According to the AHA/ ASA interdisciplinary writing group (Bushnell, 2014a):

*Because the United States lacks a national surveillance system for cardiovascular disease (CVD), and sex-specific or age-and sex- specific stroke incidence data have not been routinely reported in published studies, there are important gaps in our understanding of sex differences in incident, recurrent stroke events, temporal patterns of stroke events, and outcomes after stroke (p. 2).*

Furthermore, the majority of research that is done on women and stroke is quantitative and uses objective measures of functional recovery (Fukuda, Kanda, Kamide, Akutsu, & Sakai, 2009; Gargano & Reeves, 2007). Less is known about subjective information related to women's recovery.

Fifth, women stroke survivors have worse physical and psychosocial outcomes than men. Differences in physical outcomes include women having poorer functional outcomes, greater disability, and lower likelihood of regaining independence (found in studies among those ages 65+) (Fukuda, Kanda, Kamide, Akutsu, & Sakai, 2009; Gargano & Reeves, 2007; Persky, Turtzo, & McCullough,

2010; Petrea, et. al., 2009; Reeves, et al., 2008; Whitson, et al., 2010). Differences in psychosocial outcomes include women being more likely to suffer post stroke depression, report lower quality of life, and face challenges related to gender-based social roles (i.e., mother, caregiver) (Eilertsen, Kirkevold & Bjord, 2010; Gargano & Reeves, 2007; Kvigne, Kirkevold & Gjengedal, 2004; Reeves, et al., 2008). There is disagreement as to why these differences in outcomes exist. Some researchers attribute differences to women being older at first ever stroke, and having more pre-morbid health conditions (Petrea, et. al., 2009). Others have noted that, after controlling for factors like stroke severity, premorbid factors, and age, outcomes are still worse for women (Gargano & Reeves, 2007). The reason for poorer physical, cognitive, and psychosocial outcomes is not well understood, and most researchers agree that additional studies are needed.

Finally, examining the recovery experience of older women stroke survivors is also important in regard to understanding the concept of “recovery” itself; traditional outcome measures do not capture the complexities of the experience of recovery (Dowswell, et al., 2000). Objective measures of physical or cognitive function that are commonly used in the rehabilitation setting do not address the subjective experience of the stroke survivor (Lai, Duncan, Dew, & Keighley, 2005). According to Dowswell, et al, (2000), these measures are simplistic and over-generalized, whereas, recovery is complex and multidimensional, including important psychosocial and self-identity elements. This variation in definition of recovery is reflected in disagreements in the assessment of recovery between the survivor and healthcare professionals (Bendz, 2003; Gerlacher, et al., 2013; Dowswell, et al., 2000;

Lai, Duncan, Dew, & Keighley, 2005). Furthermore, even survivors who have been identified as having “mild” strokes, based on objective assessment, may still report significant change in self-perceived health and social functioning (Taule, & Råheim, 2014).

### 1.2. Research Questions and Aims

This dissertation was designed to address this research question: “*What is the experience of stroke recovery for community dwelling women age 60 or older?*”

The following aims were developed:

- 1) To describe women’s experiences of recovery after stroke
- 2) To determine how women experience self during the stroke recovery process
- 3) To establish how women define normal life before and after stroke

### 1.3. Conceptual Framework

The nature of stroke involves a sudden and potentially-major change that can impact physical appearance, physical function, cognition, communication, as well as social status and interactions with others (Anderson & Whitfield, 2012; Charmaz, 1995).

Kaufman (1988), argued that a phenomenological approach was necessary in studying the life altering experience of stroke for 3 reasons: 1) stroke assaults the sense of self, 2) stroke has no cure, and 3) the prognosis is uncertain, because it is unknown if deficits will disappear or persist for an indefinite amount of time. For these reasons, a phenomenological approach is suitable for the study at hand. In a phenomenological approach, the investigator examines the lived experiences of

several individuals in order to identify common meanings and themes that represent the “essence” or essential meaning of the shared phenomenon or concept (Creswell, 2013; Patton, 2002; Richards, & Morse, 2007). Phenomenology is applied in this research to thoroughly capture and describe how the participants make sense of their experience with life before and after stroke.

In a qualitative study, theory may emerge from the data as a result of the analysis (Creswell, 2013; Patton, 2002; Richards, & Morse, 2007); however, there are several theories that were useful in developing the research question and aims, as well as in creating the framework for this study. Theoretical concepts of self and social identity are intertwined; they include not only how we see ourselves, but how we present ourselves to others, and perceive how others see us (de Medeiros, 2005, 2014). The abrupt nature of the changes arising from stroke may even include having a change in appearance and an altered body (Charmaz, 1995). Thus, self and identity are especially vulnerable due to stroke, and loss or change in identity is common (Anderson & Whitfield, 2012; Kaufman, 1999). These concepts are addressed in this research in the second aim, and influenced the formulation of questions for the interview guide.

Other related concepts that are pertinent to this study are biographical disruption and continuity theories (Becker, 1993, 1997). The abrupt nature of stroke causes a disruption in the expectation of self across the life course, and can create inner chaos and uncertainty during recovery (Becker, 1993, 1997). The recovery process may well include a desire to re-create order and continuity of self and attempts to reconcile changes in self (Becker, 1993, 1997; Bury, 1982). Being able to

continue with life, envision moving forward, and setting and achieving goals is the process of continuity (Secrest & Zeller, 2007). These concepts are addressed in the third aim, and influenced formulation of questions for the interview guide, as participants are asked to reflect on their perception of “normal,” and how it relates to current life.

#### 1.4. Summary of Chapter 1

This dissertation examines the intersecting issues of stroke recovery experience, aging, continuity of self-identity, and female gender to better understand the meaning of recovery and “normal” life from the participants’ perspective. This study fills a gap in knowledge as to how women experience stroke recovery and in identifying subjective factors that may explain why women have poorer psychosocial outcomes than men. Findings may improve understanding of how women recover and shed light on factors that may be important in developing recommendations for changes in resources, policies, or services pertinent to women’s needs.

Research focus on women and stroke has been identified as a critical issue, given the increasing numbers of older women stroke survivors, yet, there is still limited research in this area. Poorer outcomes for women stroke survivors are well documented, but not clearly understood. Most research about stroke recovery is quantitative, resulting in a need for additional, qualitative research to provide more subjective information. This dissertation examines the recovery experiences of women stroke survivors age 60 and older, using qualitative methods, and a phenomenological approach. Data collection includes in-depth semi-structured interviewing and use of auto-photography. Addressing the research questions and

aims, this study fills a gap in research in knowing more about how older women recover from stroke, how self is affected, and how participants view themselves in relation to “normal.”



## **Chapter 2: Literature Review**

### **2.1. Introduction**

This literature review provides background information on stroke and its' significance to society, then discusses the distinct challenges of women stroke survivors, and how researchers are approaching this issue. Next, there is a discussion on recovery and how it is defined and measured. Finally, there is a review of theoretical concepts pertinent to the research question, including applications of both identity and continuity theories as they might apply to women stroke survivors.

### **2.2. Significance of Stroke as a Health Problem**

#### **2.2.1. Overview**

Stroke is one of the leading causes of death and disability in the United States. It not only places personal burden on the individual and family members, but also places tremendous strain on the healthcare system and the overall economy (Mozaffarian, et al., 2016; Ovbiagele, et al., 2013). Every 40 seconds, on average, someone has a stroke in the United States (Mozaffarian, et al., 2016). Stroke deaths declined from the third to the fifth cause of death in the general population over the past few decades, and there has been a decline in incidence of ischemic stroke (i.e. blockage of cerebral blood flow), but these declines are variable based on age, gender and ethnicity (Kleindorfer, et al., 2009; Lackland, et al., 2014; Mozaffarian, et al., 2016; Towfighi & Saver, 2011). Ischemic stroke is the most common type of stroke (87%), most frequently presented in epidemiological studies, and more likely to be

reduced through control of preventable risk factors (i.e. smoking, diet, and exercise) (Bushnell, et al., 2014a). There has been no significant decrease in stroke prevalence (ischemic or hemorrhagic) for the past several years (Kleindorfer, et al., 2009; Lackland, et al., 2014; Mozaffarian, et al., 2016; Towfighi & Saver, 2011). There are 6.8 million Americans (age 20 or older) who have ever had a stroke, and an estimated 795,000 new or recurrent strokes occur each year (Lackland, et al., 2014; Mozaffarian, et al., 2016; Ovbiagele, et al., 2013).

Given that the U.S. population is aging and findings that the risk of stroke doubles with each decade over age 55, the number of stroke survivors will continue to increase, and the impact of stroke on our society is projected to increase dramatically (Ovbiagele, et al., 2013). With Americans having longer life expectancies, it is predicted that by the year 2030, stroke prevalence for individuals over 18 years old will increase from 3.2% (based on 2012 data), to nearly 4% of the U.S. population (Ovbiagele, et al., 2013). Women, older adults, and minorities are especially harder hit. In 2012, the overall prevalence of stroke was 3.22% for the general population (age 18 and older), but higher for older adults at 9.02% for ages 65-79, and 15.41% for adults 80 years and older. Black women (4.55%), white non-Hispanic women (3.84%), and black men (3.33%) also had higher prevalence rates than white non-Hispanic men (2.94%) (Ovbiagele, et al., 2013). By the year 2030, the overall prevalence is projected to increase by 20.5% as compared to rates in 2012, and the total projected annual cost of stroke (direct and indirect) is projected to increase by 129% at an annual cost of 240.67 billion dollars (Mozaffarian, et al., 2016; Ovbiagele, et al., 2013).

The majority of strokes (ischemic) are caused by a disruption in blood flow commonly due to cardiovascular disease and associated with such risk factors as hypertension, diabetes, disorders of heart rhythm, high cholesterol, smoking, poor nutrition, sedentary lifestyle, genetics and family history (Mozaffarian, et al., 2016). In hemorrhagic strokes the disruption of blood flow is due to bleeding from a ruptured blood vessel (Mozaffarian, et al., 2016). In either case, the disruption of blood flow causes damage to brain tissue in the affected area of the brain. Some strokes are mild and recovery may be complete, as in transient ischemic attacks (TIAs) and “silent” strokes, but these are also potential precursors for a more significant stroke event (Mozaffarian, et al., 2016). When there are residual deficits, survivors may never regain pre-stroke performance and function. Deficits after stroke affect not only physical function, but can also affect communication, cognition, emotional, and psychosocial status (Bushnell, et al., 2014B; Mozaffarian, et al., 2016; Northcott & Hilari, 2011; Robison, et al., 2009). These types of deficits can be just as significant as physical deficits in affecting recovery, return to active life, and overall quality of life (Bushnell, et al., 2014B; Robison, et al., 2009).

#### 2.2.2. Physiological deficits after stroke

A report from the U.S. Burden of Disease Collaborators (2013), listed stroke in the top 18 diseases for years lived with disability (YLD), based on data from 1990 to 2010. The authors also noted that stroke is one of 15 in a complex mixture of cardiovascular diseases that contribute to leading causes of health loss, as represented by “disability-adjusted life years” (DALYs). Based on data from the Framingham Study, a large longitudinal community-based cohort study, in a representative sample

of 108 stroke survivors over age 65, deficits seen on examination at six months after first-ever ischemic stroke were numerous. Approximately 50% had some hemiparesis (i.e. weakness on one side of the body), 30% were unable to walk without assistance, 46% had cognitive deficits, and 26% were dependent in activities of daily living (Kelly-Hayes, Beiser, Kase, Scaramucci, D'Agostino & Wolf, 2003).

*Depression.* Depression may occur as a physiological effect of stroke, due to the changes in brain tissue and function (Bour, 2010; Cramer, 2008). In most cases, post-stroke depression is a reactive response, and is therefore discussed below as a psychological issue.

*Communication deficits.* Communication disorders after stroke includes deficits such as aphasia, dysarthria and apraxia (Brookshire, 2007). Aphasia is a communication disorder that results from damage to the language areas of the brain, typically in the left hemisphere (Brookshire, 2007). Individuals with aphasia may have difficulty with expressing and understanding language, including speaking, listening, reading, and writing; however, the level of deficit varies from person to person, ranging from very mild to very severe (Brookshire, 2007). Stroke is the most common cause of aphasia, and it occurs in an estimated 19% of stroke survivors (Brookshire, 2007; Kelly-Hayes, Beiser, Kase, Scaramucci, D'Agostino & Wolf, 2003). Dysarthria and apraxia are motor speech disorders and less common than aphasia (Brookshire, 2007). In these conditions, language is intact, but speech intelligibility is reduced with varying degrees of severity across individuals (Brookshire, 2007). In dysarthria, intelligibility is reduced (e.g. slurred speech, low volume, breathy voice) due to muscle weakness or incoordination (Brookshire, 2007).

In apraxia, intelligibility is reduced due to a motor programming deficit, in which muscle function is intact, but volitional speech is affected, and there is difficulty sequencing speech sounds and words (Brookshire, 2007). Communication is essential in every aspect of daily life. Deficits in communication have a significant impact on outcomes, such as social interactions, role fulfillment and quality of life (Brookshire, 2007; Northcott & Hilari, 2011).

### 2.2.3. Psychological changes after stroke

*Depression.* Post stroke reactive depression can have a potentially negative impact on recovery, including limiting participation by the stroke survivor in the rehabilitation process, as well as return to active life (Bour, et al., 2010; Go, et al, 2014; Hackett, Yapa, Parag, & Anderson, 2005). In a systematic review of 51 studies, Hackett, Yapa, Parag, & Anderson (2005) found variability in frequency of depression clinical diagnosis (per article authors, included major depression and dysthymia - minor depression) across studies, but determined a pooled estimate of 33% of cases across samples experienced depression. Bour and colleagues (2010) followed 190 first-ever stroke patients for one year and found that post stroke depression most often develops in the first month, typically resolves in the first three months, but may also develop at other times during the first year. As a result, the recovery process is not linear, and depression could continue to have an impact on motivation, as well as physical function, psychological status, emotional status, as well as social activities and interactions (Bour, 2010).

*Quality of life and life satisfaction.* Quality of life (QOL) is a multidimensional construct that includes the individual's objective perception of both

physical health and psychological state, as well as, level of independence, social relationships, personal beliefs, and associated feelings of well-being (Carod-Artal, & Egido, 2009; Ellis, Grubaugh, & Egede, 2013; Gargano & Reeves, 2007; WHO, 1995). Health related quality of life (HRQOL) refers to aspects of QOL affected by disease (Sturm, et al., 2004). Numerous studies have shown some decline in life satisfaction and quality of life (QOL) after stroke (Bujick, et al., 2014; Bushnell, et al., 2014b; Carod-Artal, & Egido, 2009; Clarke & Black, 2005; Ellis, Grubaugh, & Egede, 2013; Sturm, et al., 2004). The World Health Organization (WHO) defines QOL as:

*... individuals' perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns (World Health Organization (WHO), 1995, p. 1406).*

Hopman & Verner (2003) assessed HRQOL for 85 stroke survivors (mean age 69.9; range 33- 92 years old) during and after 6 months inpatient rehabilitation. The authors found that, in the period from admission to discharge, there was statistically significant improvement in how survivors rated themselves on 5 domains: physical functioning, mental health, social functioning, bodily pain, and general health perceptions. In contrast, 6 months after discharge, there were 5 domains that showed statistically significant decline: role emotional (rating of how they felt emotions affected their roles), mental health, social functioning, bodily pain, and general health perceptions. Consequently, quality of life after stroke is dependent on many factors,

and may both improve and decline during the recovery process along several dimensions.

It is also important to note that there is not always a clear one-to-one correlation between functional disability and quality of life (Bujick, et al., 2014; Clarke, & Black, 2005). Bujick and colleagues (2014) interviewed 84 community-dwelling stroke survivors (mean age 78) three months after completing rehabilitation. The authors used the RAND 36 Health Survey (RAND-36) to assess QOL, and found that QOL ratings ranged from 48 to 85 (scale 0 – 100; higher score represents higher QOL). Higher QOL scores were generally associated with better functional status, and fewer neuropsychiatric symptoms and depressive complaints. Some individuals had relatively high QOL scores, despite lower physical function domain score. This discrepancy has been described as the disability paradox, and also referred to as resilience, but highlights the potential for good quality of life despite disability (Bujick, et al, 2014; Clarke & Black, 2005). Researchers have pointed out the need to explore the complexities of this paradox that are not readily discernible in QOL questionnaires (Bujick, et al, 2014; Clarke & Black, 2005).

*Self-identity and self-concept.* Given the abrupt and disruptive nature of stroke, the survivor may face challenges to self-identity and self-concept (Anderson & Whitfield, 2012; Ellis-Hill & Horn, 2000). Ellis-Hill & Horn (2000) compared twenty-six first time stroke survivors (mean age 71; SD 8.4; 4 – 24 months post stroke) and age matched peers (mean age 71.0; SD 8.0). The researchers found that stroke survivors rated present self-concept as the same or more negative than past self-concept, and the difference was statistically significant. They viewed themselves

as less capable, independent, and in control; survivors also said they were less satisfied, interested, active, confident, and of less value (Ellis-Hill & Horn, 2000). Stroke survivors still perceived themselves as friendly, calm, caring, hopeful and talkative. In contrast, the comparison group rated themselves highly in both past and present periods on the same elements of self-concept (Ellis & Horn, 2000). Further discussion on self-identify and self-concept is described elsewhere in this dissertation as it pertains to theoretical considerations.

#### 2.2.4. Social effects of stroke

In addition to the physiological and psychological effects, stroke may also impact social factors, which in turn, may contribute to changes in roles and social relationships, social participation, quality of life, life satisfaction, and self-identity (Becker, 1993, 1998; Gargano, & Reeves, 2007; Go, et al, 2014; Robison, et. al., 2009).

*Social roles.* Stroke survivors may experience a loss in their roles as providers, parents, employees, bosses or community leaders (Hopman & Verner, 2002; McKenna, Liddle, Brown, Lee, & Gustafsson, 2009). McKenna et al. (2009) compared time use, role participation, and life satisfaction of community-dwelling stroke survivors age 65 or older (n=23, mean age 74.2), with older adults without stroke (n= 195, mean age 75). Older adults with stroke engaged in a mean of 4.3 roles, and reported a mean loss of 3.8 roles; as compared to older adults without stroke who engaged in a mean of 6 roles, and reported a mean loss of 1.9 roles (McKenna, et al., 2009). Researchers asked the non-stroke older adults to compare role loss over a similar time period as the matched stroke participant (McKenna, et



al., 2009). Loss of or changes in intimate roles (i.e. spouse, parent), roles associated with household finances, and community social status may create additional social and economic stress for the stroke survivor and family (Daniel, Wolfe, Busch & McKevitt, 2009; Lynch, et al., 2008). Unwanted changes in social roles can cause anger, frustration, depression or withdrawal for the stroke survivor, as well as the caregiver (Hopman & Verner, 2002; Lynch, et al., 2008; McKenna, Brown, Lee, & Gustafsson, 2009).

*Social participation and social engagement.* Interpersonal interactions and involvement in activities that include others incorporates social participation and social engagement (Levasseur, Richard, Gauvin & Raymond, 2010; WHO, 2002). These concepts are important in healthy aging because they have been linked to positive health outcomes and are modifiable health determinants (Levasseur, et al., 2010). Whereas higher levels of social participation and social engagement have been associated with decreased mortality, lower levels have been associated with loneliness, withdrawal and feelings of depression (Amarshi & Reid, 2006; Derosiers et al., 2005; O'Connell et al., 2001; Thomas, 2012). Social participation may decline after stroke due to changes in supportive social ties, cognitive changes, depression, limited mobility, and lower endurance (Becker, 1993; Derosiers et al., 2005; Hammel, Jones, Gossett & Morgan, 2006; Northcott & Hilari, 2011; Robison, et al., 2009; Roger, et al. 2012).

Stroke survivors may have barriers or facilitators to participation at various levels, (e.g., limited financial resources at personal level, limited accessible transportation at system level) (Derosiers et al., 2005; Hammel, et al., 2006). While

physical disability often creates challenges to participation, there is no single deficit (e.g., communication deficit, cognitive changes, physical function, or mobility), but rather a combination of any of these factors that may reduce social participation (Becker, 1993; Derosiers et al., 2005; Robison, et al., 2009). Robison and colleagues (2009) conducted semi-structured interviews with 19 stroke survivors and eight stroke caregivers, at 12 months post-stroke. and found that factors that influenced outcomes for returning to participation after stroke included physical or cognitive disability, environmental factors, individual adaptability, support from significant others, and availability of professional help. The authors noted that social and psychological factors, such as, loss of confidence in themselves and their bodies, and reluctance to undertake activities in public due to worry as to how others might view them also inhibit social activity.

*Social networks and social ties.* Aging adults in general may experience a reduction in social network due to a number of reasons, including loss of friends through death, widowhood, and geographic distance of family (Connidis, 2010; Pillemer & Glasgow, 2000). Social networks may also shrink as a result of reduced social roles and social participation, but stroke survivors also report that they lose friends after stroke. Northcott & Hilari (2011) interviewed 29 stroke survivors (including 10 who had aphasia) and found that common reasons for lost friends were loss of shared activities, reduced energy levels, poor mobility, unhelpful responses of others, environmental barriers, aphasia, and changing social desires of the survivor (i.e. the stroke survivor did not want to socialize). Loss of friendships may be important in recovery, as it is associated with increased risk of depression, loneliness,

social isolation, and failure to resume social activities (Haun, Rittman, & Sberna, 2008; Hinojosa, Haun, Hinojosa, & Rittman, 2011).

#### 2.2.5. Interrelationship of multiple factors after stroke

As noted above, the impact of stroke can be significant across physical, psychological, and social aspects of life. All of these factors do not occur in a vacuum and are not only interrelated but often difficult to tease out. One of the many challenges in measuring recovery is assessing only physical function, and not considering the impact of psychological and social factors. This highlights the need for measures and research methods that are not only objective, but subjective and comprehensive as well.

### 2.3. Distinct Challenges of Stroke for Women

#### 2.3.1. Higher burden of stroke

Stroke in women was largely neglected in the past as an important health concern, because research focused primarily on males. Gender issues were not addressed, and women were underrepresented in studies (Bousser, 1999, Kurth & Bousser, 2009). This gap in the research has been recently acknowledged as a major public health issue, and plans to more comprehensively overcome this issue are being put into place (Bousser, 1999; Bushnell, 2014a; Kurth & Bousser, 2009). Researchers in the United States, Italy, Japan, and many European Countries have found that women have a higher burden of stroke (Bousser, 1999; Fukuda, Kanda, Kamide, Akutsu, & Sakai, 2009; Paolucci, et al., 2006; Persky, Turtzo & McCullough, 2010). By burden, researchers mean that stroke outcomes over time are generally more

severe for women as compared to men. Burden includes both physical function, and psychosocial concerns, which will be described in greater detail below (Bushnell et al, 2014a; Bushnell et al, 2014b; Ovbiagele, et al, 2013).

In 2014, a multidisciplinary writing group for the American Heart Association/ American Stroke Association developed guidelines for the first time that specifically addressed the prevention of stroke in women, based on factors that were unique to or more common among women as compared to men (Bushnell, et al., 2014a). Stroke risk factors that are unique to women include, pregnancy, preeclampsia, gestational diabetes, oral contraceptive use, postmenopausal hormone use, and change in hormonal status (Bushnell, et al., 2014a). Stroke risk factors that are stronger or more prevalent in women include migraine with aura, atrial fibrillation, diabetes mellitus, hypertension, depression, and psychosocial issues (Bushnell, et al., 2014a). In the United States, of the estimated 6.8 million stroke survivors, 3.8 million of them are women (Bushnell, et al., 2014a). As life expectancies in the United States continue to increase, older women will continue to outnumber men and the prevalence of people living with stroke is projected to increase, especially in older women (Bushnell, et al., 2014a; Ovbiagele, et al, 2013). Projections are that by the year 2050, women will make up 60% of stroke survivors, as compared to 55.8% in 2012 (Ovbiagele, et al, 2013).

In the U.S., approximately 55,000 more women than men suffer a stroke each year. Although stroke has declined to the fifth leading cause of death for men, it remains the third leading cause of death for women (Bushnell, et al., 2014a; Mozaffarian, et al., 2016). However, some researchers have reported that it is the

second cause of death for women (Lackland, et al., 2014; Ovbiagele, et al, 2013).

Although younger men have a higher risk of stroke than younger women, the gender association reverses with advancing age (Carandang, et al., 2006; Mozaffarian, et al., 2016). In addition, women have a higher lifetime risk of stroke (ranging from 20% to 21% based on data compiled by AHA) than men (ranging from 14% to 17%) (Mozaffarian, et al., 2016). Women also are typically older than men at a first ever stroke (estimated average at age 75 for women versus 71 for men) (Mozaffarian, et al., 2016). Given increasing longevity, there will be increasing numbers of women stroke survivors living with post stroke outcomes, with estimates of approximately 200,000 more women than men (Bushnell, et al, 2014a). Older women have greater longevity, but may also have more comorbidities than men that could impact their health and recovery from stroke (Davidson, Digiacomio, & McGrath, 2011; Kelly-Hayes, et al., 2003). Whitson and colleagues (2010) analyzed cross-sectional data from 5888 community dwelling older men and women (mean age 72.8) in the Cardiovascular Health Study (CHS) and found that, although men in the sample were more likely to have a stroke, women had a greater rate of disability after a stroke occurred. Older women have many differences that lead to more vulnerability to less favorable outcomes after stroke

### 2.3.2. Stroke outcomes in older women

Women and men differ in their recovery patterns and outcomes, with women having poorer functional outcomes, greater disability, and lower likelihood of regaining prior levels of independence (ages 65+) (Fukuda, Kanda, Kamide, Akutsu,

& Sakai, 2009; Gargano & Reeves, 2007; Persky, Turtzo, & McCullough, 2010; Petrea, et. al., 2009; Reeves, et al., 2008; Whitson, et al., 2010).

*Functional outcomes.* Fukuda et al. (2009) followed 997 patients in Japan (343 women, 654 men) for five years after first time stroke. The mean age in the sample for men was 67.2 (SD= 11 yrs.) and 66.7 (SD = 13.4 yrs.) for women. The authors found that gender was a determinant for long-term functional outcomes, while subtype of stroke was not (i.e. ischemic vs. hemorrhagic). Women had significantly worse locomotor activity than men at both one and five years post-stroke, and the survival rate was significantly higher for men at both of these time points. Furthermore, Fukuda and colleagues noted that the reason for the gender differences reported in their study were unclear, because they could not be attributed to differences in age, known risk factors for stroke, or sex-related features of stroke subtype.

Petrea et al., (2009) examined data for 1136 stroke occurrences (638 women/ 498 men) from the Framingham Heart Study. These authors did not observe a significant difference in stroke severity or case fatality between men and women. However, they did report that women were more disabled than men at 3 and 6 months follow-ups, and that the women were almost four times more likely to be institutionalized. In another analysis, Gargano & Reeves (2007) reported results based on data from the Michigan Acute Stroke Care Outcomes and Treatment Surveillance System (MASCOTS). (The MASCOTS is part of the Paul Coverdell National Acute Stroke Registry (PCNASR), a large study developed to monitor the quality of stroke care in the United States). After collecting data on 2566 consecutive

acute stroke admissions from 15 Michigan Hospitals, they identified 373 eligible participants (including 210 women) and completed surveys by phone. The authors reported that women were significantly less likely to achieve ADL independence, and had lower self-rated quality of life based on the Stroke-Specific Quality of Life scale (SS-QOL); however, the differences between women and men were not attributable to greater age at stroke, or other demographic or clinical factors differentiating the groups.

For additional studies (not including those discussed above) regarding functional outcomes based on gender after stroke, see Table 1. Of the eight large studies listed there, six showed significantly poorer outcomes for women, with the time period post stroke ranging from initial discharge to one year; the remaining two studies show no differences by gender.

**Table 1.** Summary of Studies in Functional Outcome after Stroke

Author (Published Year)	Subjects	Follow- up Period	Worse outcome M or W	Results
Appelros (2003)	377 first ever stroke (169 men, 208 women)	1 year	No difference	mRS $\geq 3$ in M OR 1.1; 95% CI, 0.7-1.8
Di Carlo (2003)	4,999 first ever acute stroke (2,239 men, 2,260 women)	3 months	W	BI: 16.6 in M, 14.7 in W (p <0.001) mRS: 2.2 in M; 2.6 in W (p <0.001)
Roquer (2003)	1,581 first ever acute stroke (809 men, 772 women)	At discharge	W	mRS: $\geq 3$ : 24.2% in men, 36.1% in W (p < 0.001)
Glader (2003)	19,547 acute stroke (9,881 men, 9,666 women)	3 months	W	Independent ADL: 67% in M, 53% in W (OR 0.71; 95% CI, 0.66-0.76)
Kapral (2005)	3,323 first ever stroke (1796, 1,527)	At discharge	No difference	mRS >4: 26% in M, 30% in women (p< 0.1)
		6 months	W	SIS-16 score, median: 92.2 in M; 85.9 in W (p < 0.0001)
Paolucci (2006)	440 first ever acute ischemic (220 M, 220 W)	At discharge	W	ADL autonomy: 27.6 in M, 14.87% in W (p <0.01)
Gray (2007)	1,268 acute first-ever ischemic stroke (846 men, 445 women)	6 months	W	mRS (median); 2 in M, 3 in W (p < 0.01) BI: 95 in M, 90 in W (p< 0.0001)
Fukuda (2008)	1,291 acute first-ever ischemic stroke	At discharge	W	Unaided walk: 70.4% in M, 56.4% in W (p< 0.001)

Key: M, men; W, women; mRS, modified Rankin Scale; OR, odds ratio; 95% CI, 95% confidence interval; BI, Barthel Index; ADL, activity of daily living; SIS-16, Stroke Impact Scale-16. Source: Fukuda, et al., 2009



*Psychosocial outcomes.* In contrast to the numerous studies examining gender differences in functional outcomes, studies that examine psychosocial outcomes beyond depression are less common. Although there are several studies that report on QOL and HRQOL, many of these studies use questions that are related to physical function, as opposed to factors like friendships, social roles, social support, social participation, and self-concept/ self-identity. Less is known about which psychosocial factors play a role in the recovery process for women. In addition, this researcher has noted that many studies addressing these issues are conducted outside of the United States, including Australia (McKenna et al., 2009), United Kingdom, (Northcott & Hillari, 2011), Canada (Anderson & Whitfield, 2010; Levasseur et al., 2010), and Norway (Eilertsen, et al., 2010; Kvigne et al., 2004).

### 2.3.3. Age and gender risk in relation to stroke

Stroke is an important health issue for both sexes, but there are several reasons why increased scrutiny is warranted in regard to women and for older women in particular. Older women have certain sociodemographic characteristics that impact their health and may negatively impact recovery from stroke. Davidson, Digiacomo, & McGrath (2011) conducted an integrative literature review of 79 articles and policy documents to examine the feminization of aging. This is the phenomenon in which, as the population has increasing longevity, more women are living longer and therefore becoming a larger majority (Davidson, Digiacomo, & McGrath, 2011). Davidson and colleagues argue that, although population aging is well recognized, feminization of aging is less acknowledged but critical in consideration of health care practices and

policies. Apart from stroke, older women have several factors that make them more vulnerable to unfavorable post-stroke outcomes.

*Aging women and poverty.* Older women have higher poverty rate and fewer economic resources as compared to men (Cubanski, Casillas & Damico, 2015; Davidson, Digiacomio, & McGrath, 2011; DeNavas-Walt, & Proctor, 2014; Kosiak, Sangl, & Correa-de-Araujo, 2006). Based on U.S. Census data from 2014 Current Population Survey (CPS) Annual Social and Economic Supplement (ASEC), the poverty rate for women over 65 was significantly higher, at 11.6%, as compared to men at 6.8% (DeNavas-Walt, & Proctor, 2014). Based on the Supplemental Poverty Level (SPL), the gap increases for individuals over age 80, with rate of poverty at 23% for women, as compared to 14% for men (Cubanski, Casillas & Damico, 2015). Implications for being in poverty include limited access to quality health care (including preventative screenings, medications, and treatment), poorer quality housing, and fewer options for transportation (Davidson, Digiacomio, & McGrath, 2011).

*Aging women and depression.* Depression is known to be more common in older women in general, as well as for those women who have suffered a stroke (Appelros, Stegmayr, Terent, 2010; Poynter, Shuman, Diaz-Granados, Kapral, Grace, & Stewart, 2009). Illness, disability, poverty, limitations in activities of daily living (ADL), and decreased social participation, are all risk factors for depression in older adults (Kim, Richardson, Park, & Park, 2013). Kim and colleagues (2013) analyzed data for 2614 participants (45% women) from the Health and Retirement Study (HRS) who were over age 65, in order to determine the relationship between poverty

status, depression, and older age. The researchers found that older women were more often depressed and had other factors that increased their likelihood of depression, such as, greater risk of poverty, higher likelihood of living alone, less education, lower perception of control, and, among married women, less support from spouses. The association between poverty and depression was only statistically significant for women. Furthermore, education, health, sense of control, and support from spouse had significant main effects on depression in women (Kim, Richardson, Park, & Park, 2013). On the other hand, impoverished women who had strong support from friends were less likely to be depressed, as this served as an important buffer against depression (Kim, et al., 2013).

*Aging women and social roles.* Stroke survivors, as noted previously, may experience change in roles; however, women may face additional challenges when adjusting to changes in gender-based social roles (Eilertsen, Kirkevold & Bjord, 2010; Kvigne, Kirkevold & Gjengedal, 2004). Kvigne, Kirkevold, and Gjengedal (2004) completed a longitudinal phenomenological study with 25 first-time Norwegian women stroke survivors. The women were interviewed 3 times during the year and half post stroke period (20 completed all 3 interviews). Age range was 37 – 78, but the majority were 71-80 years old (15 women), married or widowed (14 and 7 respectively), and receiving a state pension (19). Kvigne and colleagues found the women in their sample highly valued their traditional roles and responsibilities as mothers, wives, grandmothers, and housewives, and struggled to resume these roles, even as they were going through their own rehabilitation.

*Marital status and living arrangements.* The link between marriage and benefits to health status has been well established in the literature (Moen, et al., 2000). Older women in general are more vulnerable to social isolation because they are more likely to be living alone, without a spouse, and/or widowed (Davidson, Digiacomio, & McGrath, 2011; Moen, et al., 2000). These are potential threats to reduced social support, as well as social and economic resources.

*Aging women, social ties and social support.* From childhood to adulthood, social ties are formed as individual's lives become linked to other people and we live interdependently (Connidis, 2010). Although not all ties are supportive, supportive ties can provide a variety of essential resources, including, emotional support, companionship, financial support, small services (errands), and large services (personal care) (Wellman & Wortley, 1990). Aging women may experience a reduction in social network due to several reasons, including loss of friends through death, widowhood, and geographic distance of family (Connidis, 2010; Pillemer & Glasgow, 2000). Loss of perceived social support, as well as a reduction in the quality and quantity of social ties, can lead to loneliness and isolation (Hinojosa, et al., 2011; Tomaka, Thompson, Palacios, 2006), which are associated with negative health outcomes in older adults (Gargano & Reeves, 2007; Pillemer & Glasgow, 2000). Kvigne et al (2004) found that the older women in their qualitative study reported that friends were important, and that, for those who experienced loss of friends, establishing new friends, especially other stroke survivors, was beneficial.

#### 2.3.4. Gaps in research for stroke and women.

Although there is now recognition of important gender-specific differences in stroke outcomes, research knowledge is lacking in several ways. According to the AHA/ ASA writing group (Bushnell, et al., 2014a), the U. S. does not have a national program for the surveillance for cardiovascular disease, and there is no routine reporting of sex specific or age and sex specific stroke incidence. Additionally, the authors state that there are important gaps in understanding gender differences in first and recurrent stroke events, temporal patterns of stroke events, and outcomes of stroke. As noted in this literature review, outcome measures used to report differences in recovery are largely quantitative and based on health/physical dimensions and therefore less is known about some of the reasons for sex-based differences in recovery.

### 2.4. Recovery

#### 2.4.1. Defining recovery

Stroke survivors experience a range of physical as well as psychosocial challenges after stroke, so the recovery process has both subjective and objective components (Becker, 1998; Gargano, & Reeves, 2007; Mozaffarian, et al., 2016). There is some ambiguity in the literature as to what recovery means and how it is defined and measured (Bennet, Breeze, & Nielsen, 2014; Collier, 2010). Recovery can be viewed from at least 2 different perspectives: 1) a “medical” model of recovery, and 2) a more holistic personal recovery framework model (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011).

#### 2.4.2. Medical model

The first perspective on recovery refers specifically to cure from illness and regaining physical and cognitive function (Bennett, Breeze, Neilson, 2014; Jacobson & Greeley, 2001). In the case of stroke, this would include regaining ability to walk a certain distance, regaining arm function, completing activities of daily living, speaking, swallowing, etc. This is the primary focus of recovery in rehabilitation medicine, and measures of recovery and treatment success are based almost exclusively on physical cure and functioning (Lai, Duncan, Dew, & Keighley, 2005). Consequently, recovery and treatment success for stroke are often assessed by scales that measure physical function, such as the NIH Stroke Scale, Barthel ADL Index, Stroke Impact Scale and the Functional Independence Measure (FIM) scale. (Gargano & Reeves, 2007; Lai, Duncan, Dew, & Keighley, 2005).

Although these scales attempt to include some measures of social function, they are largely insensitive to or insufficient in measuring the psychosocial aspects of recovery including, social function and quality of life (Doyle, 2002). Doyle (2002) noted that, despite the prevalence and persistence of communication and cognition deficits in stroke, many commonly used health assessment scales neglected to include these areas, and focused solely on measurement of physical function. As a result, Doyle developed the Burden of Stroke Scale (BOSS), a self-assessment measure that includes well-being based on physical, emotional and cognitive burden (Doyle, 2000). Although the BOSS presents some items that may be more critical to stroke recovery, the personal perception of recovery or return to normal life may still extend

beyond these objective measures, and the underlying meaning of the recovery experience cannot be obtained from these types of measures. Recovery is also an individual psychological and social process, and should be described subjectively as well as objectively in research. People are deemed cured to a certain extent and discharged home after a stroke, but may still be feeling inadequate, diminished or unsuccessful in terms of their subjective views of the meaning of a full recovery (Bendz, 2003; Wiles, Ashburn, Payne, & Murphy, 2002).

Some researchers in rehabilitation have begun to document the inadequacy of this medical/physical approach to recovery as the only focus. Several studies have concluded that there is a mismatch in how healthcare professionals measure recovery as compared to how stroke survivors see it (Bendz, 2003; Gerlacher, et al., 2013; Medved, 2011). In addition, there is some evidence that survivors have been denied an active role in goal setting and assessment of their post-stroke “recovery” (Bendz, 2003; Gerlacher, et al., 2013; Medved, 2011). Bendz (2003) interviewed 15 stroke patients and listened to recordings from the health care professionals who treated them. An analysis of the transcripts revealed that stroke survivors were concerned with the social context of recovery, such as regaining control over their lives, and viewed therapy as an opportunity to regain a former social position or adapt to another social position. In contrast, healthcare professionals were concerned with these patients’ reduced physical and cognitive function, and saw therapy was a means to regain that function. Although healthcare professionals’ expectations were consistent with the existing medical standard of practice, there was no acknowledgement of the concerns that were expressed by the patients. Bendz noted

that the perspective of the health care professionals was almost exclusively biomedical, whereas the patients' perspective was a combination of biomedical, social, and psychological concerns.

#### 2.4.3. Personal recovery framework

Several researchers in the field of mental health have promoted models that are more holistic and individualized than the medical model. Although stroke is not synonymous with mental illness, the more holistic and person-centered approach derived from a focus on mental illness better addresses some of the shortcomings noted in a purely medical model. Jacobson and Greeley (2001) describe the life recovery model, which considers both internal and external factors. The internal factors in this model of life recovery are ones that are most relevant to stroke recovery. The authors include internal factors such as hope (a belief that recovery is possible), healing (having a sense of self outside of the illness), empowerment, and connections (Jacobson and Greeley, 2001).

In more recent research, Leamy, Bird, Le Boutillier, Williams, & Slade (2011) developed an empirically based personal recovery framework based on a synthesis of 97 studies. Leamy and colleagues (2011) identified five recovery processes represented by the acronym CHIME: connectedness, hope and optimism, identity, meaning in life, and empowerment. This framework also identified 12 characteristics of the recovery journey, highlighting recovery as an active process that is unique and multidimensional. Recovery is viewed as a journey rather than an outcome or an endpoint. For stroke survivors who may face lifelong changes in function rather than a cure, this perspective of recovery may be more applicable. Bennett, Breeze &



Neilson (2014) have also proposed using a more personalized recovery model based on mental health in the physical rehabilitation setting. They noted that it would be beneficial due to its focus from the perspective of the service user, rather than the professional, and that psychological components, like hope and empowerment, were essential in reaping the maximum benefits of rehabilitation.

### 2.5. Theoretical Concepts

Theories related to self, social identity, and disruption and continuity may be useful for the examination of stroke recovery, particularly given the abrupt nature of stroke and the chronic nature of residual deficits. There is a degree of uncertainty that survivors have to face when a stroke occurs, as well as the question of whether they will ever recover and be “normal” again (Clarke & Black, 2005).

#### 2.5.1. Self and social identity

Definitions of “self” vary according to disciplines from a number of fields, including anthropology, psychology, medicine, psychiatry, sociology, philosophy, linguistics and literature (de Medeiros, 2005, 2014). According to Herzog and Markus (1999), “self can be defined as a multifaceted, dynamic system of interpretive structures that regulates and mediates behavior” (p. 228), and is seen as both interpreter and mediator of behavior existing within cultural influences (de Medeiros, 2005). This definition will be used for the purpose of this paper, as de Medeiros (2005, 2014) pointed out its usefulness and applicability in narrative gerontology. De Medeiros, (2014) notes that the concept of self can be represented through three questions:

1) Who am I? 2) How do I know who I am? and 3) How do you know who I am?

“Self” and “identity” are intertwined. The last 2 questions relate specifically to identity, as it is shaped by how an individual identifies themselves in relation to others around them (de Medeiros, 2014).

Social identity after stroke is vulnerable for several reasons. There is abrupt change in many areas, including appearance, physical ability, health status, and ability to fulfill social roles (Anderson & Whitfield, 2012; Becker, 1997; Charmaz, 1995). When stroke survivors look in the mirror, they may see someone who is barely recognizable. Others may see them that way as well. In addition, they may not even sound the same or be able to communicate in the same way. Threats to identity due to loss of control, uncertainty about the future, perception of self and identity, as well as how as others view them, are all possible effects of stroke (Anderson & Whitfield, 2012; Becker, 1997; Haslam, et al., 2008). As women in this dissertation reflect on their lived experience, they may have to define who they are to the interviewer. They are encouraged to reflect on the concept of “normal” and how that concept applies to their life, before and after stroke. Will a survivor feel that she is the same, or somehow an altered self?

#### 2.5.2. Continuity theory and biographical disruption

The idealized view of aging, particularly in Western culture, is that life is a linear process (Becker, 1997). There is an expectation of continuity of self across the life course. When the life course is disrupted by a chronic illness such as stroke, there is an inner chaos and a desire to re-create order and continuity of self (Becker, 1993, 1997; Bury, 1982). The sudden nature of stroke creates discontinuity and uncertainty

during the recovery process (Satink, et al., 2014). How one views self and self-concept, and the ability to reconcile self with what is happening now is necessary for re-establishing continuity (Becker, 1993, 1997).

The ability to continue on with life successfully, and the capacity to envision how life will proceed allows a person to move forward with life, set goals and work toward achieving those goals (Secrest & Zeller, 2007). The concept of recovery may be tied to discontinuity and continuity as women reflect on their lived experience. Do they see themselves moving forward, standing still, or moving, but on a different path? Recovery may be seen as something that is ongoing, or with a definite endpoint, or even as an unattainable goal. In addition, the concept of “normal” may be tied to their view of life as it continues. In some individuals who are recovering from various medical conditions, they speak of a new normal. As women share their lived experiences after stroke, they have an opportunity to reflect on this concept, as it may apply to them.

## 2.6. Summary Chapter 2

This literature review provided evidence as to the significant impact of stroke on society, including many physiological as well as psychosocial challenges. Furthermore, it has shown how the gender differences seen in stroke and stroke recovery, including the specific challenges and vulnerabilities for older women, are related to post-stroke status and recovery. The concept of recovery was highlighted, and it was illustrated that reliance on a medical model definition exclusively does overlook the thorough and appropriate consideration of the individual’s lived experience after stroke. In contrast, a personal recovery framework model considers

holistic and individualized factors such as connectedness, hope, identity, and empowerment, based on an individual's own terms and definition of recovery. Finally, this review highlighted two theoretical areas that may be informative in examining the recovery experiences of older women. However, given the phenomenological nature of this dissertation, interpretation will remain open to what the data reveal. This dissertation study will add to the literature in stroke recovery in women, as there is to date only one other qualitative study on women stroke survivors age 60 and older in the United States (Hilton, 2002), and a few studies in other countries have studied younger women (Leahy, et al, 2016).

## Chapter 3: Methodology

### 3.1. Introduction

This chapter outlines the study design and methods by first describing the rationale for the methods used. Then it describes the participant sample, recruitment process, data collection, and data analysis. Next, there is a description of a pilot study that was completed to examine the use of auto-photography with women stroke survivors. Finally, there is a discussion of limitations and strengths of the study design.

### 3.2. Research Design Overview

This study was designed to fill gaps in knowledge of a) how women experience stroke recovery and b) subjective factors that may be important elements relating to women's stroke recovery. Qualitative methods were used to explore the lived experiences of female stroke survivors and gain a better understanding of their subjective experience of the recovery process. Methodology included integrated use of in-depth, semi-structured interviewing and auto photography as techniques to allow participants to share their personal experiences (Harper, 2002). To reiterate the research question, "*What is the experience of stroke recovery for community dwelling women age 60 or older?*"

Specific aims of this study were:

- 1) To describe women's experiences of recovery after stroke;
- 2) To determine how women experience self during the stroke recovery process; and

- 3) To establish how women define normal life before and after stroke

### 3.3. Rationale for Use of Qualitative Methods

Qualitative research provides “a means of accessing unquantifiable facts” about human beings (Berg, 2009, p. 8). Qualitative investigators seek answers to their research questions by studying how individuals derive meaning and make sense of their lived experiences (Berg, 2009; Creswell, 2013; Richards, & Morse, 2007). Creswell (2013) states that qualitative research is useful when: a) a new problem needs to be explored, b) if variables of interest are not easily measured, and c) when there is a need to understand the complexity of an issue. Additionally, qualitative research empowers individuals who may not otherwise have an opportunity to be heard and to share their own experiences on their own terms (Creswell, 2013). Qualitative research may also be used to identify the direction of further inquiry (i.e., hypothesis-generating), and /or to support the development of theory regarding phenomena being studied (Berg, 2009; Creswell, 2013; Patton, 2002). Qualitative methods provide more insight about the “why” of a phenomenon than some other approaches and are particularly important in studying the aging population, because it is composed of individuals whose lives are widely diverse and complex (Schoenberg & Rowles, 2002b).

Qualitative approaches are well suited to an examination of the recovery experiences of women stroke survivors age 60 or older for several reasons. First, the medical community has admitted that stroke in women has been neglected in research and requires a closer look (Bushnell, et al., 2014a; Ovbigele, et al., 2013). Older women as a group are typically underrepresented in health research (Bushnell, et al.,

2014a; Davidson, Digiacomio & McGrath, 2011). Second, Reeves et al. (2008) reviewed research on thousands of stroke cases internationally, finding different outcomes by sex. They concluded that, even with adjustments for variables such as age, stroke subtype, and stroke severity, women had poorer outcomes, including higher probabilities of being institutionalized, poorer functional outcomes, and lower reported quality of life after stroke than men. The existing literature provides only limited clues regarding these gender differences, making this a complex and poorly understood problem where traditional quantitative approaches may not suffice. Third, use of qualitative methods provides the potential to uncover insights that may improve lives, increase awareness regarding gender-based inequalities, and inform policy (Schoenberg & Rowles, 2002a).

#### 3.4. Phenomenological Approach

In a phenomenological approach the investigator examines the lived experiences of individuals in order to identify common meanings and themes that represent the “essence” of the phenomenon or concept (Creswell, 2013; Patton, 2002; Richards, & Morse, 2007). Although there are different phenomenological approaches, the underlying objective here is:

... thoroughly capturing and describing how people experience some phenomenon - how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others. (Patton, 2002, p. 104).

This investigator sought to capture how older women experienced their lives as directly as possible through in-depth interviewing (Patton, 2002). Patton states

that, in an effort to capture “an essence or essences to shared experiences,” (p. 106), the researcher becomes immersed in the data, explicates patterns and meanings, and finds commonalities or differences across participants (Creswell, 2013; Patton, 2002; Richards, & Morse, 2007). The experiences shared by individuals can then be bracketed, analyzed and compared, and a common essence can be identified (Creswell, 2013; Miller & Crabtree, 1999; Patton, 2002). In this process, the researcher must become immersed in the data and use explication and creative synthesis to show patterns and relationships.

In a seminal article Kaufman (1988) argued that a phenomenological approach was necessary in studying the life altering experience of stroke for 3 reasons: 1) stroke assaults the sense of self, 2) stroke has no cure, and 3) the prognosis is uncertain, because it is unknown if deficits will disappear or persist for an indefinite amount of time. For these reasons, a phenomenological approach is suitable for the study at hand.

### 3.5. Visual Methods and Photo Elicitation

According to Harper (1988), visual research methods were established in the field of anthropology in the 1940s. Visual methods employed in the social sciences may include a variety of techniques (Harper, 1988). These techniques vary depending on the needs of the study (Shenk & Schmid, 2002). The photographs themselves may be generated by the investigator, drawn from an existing collection of participant photos, or taken by the participant at the time of the study (Harper, 1988). The photographs can be used as data and analyzed for their content, or they may be incorporated into the interviewing process (Shenk & Schmid, 2002).



Several terms have been used to identify variations in the process in which participants themselves take photographs for research purposes (Clark, 1999; Harper, 2002; Kohon & Carder, 2014; Oliffe & Bottorff, 2007; Phoenix, 2010; Rush, Murphy, & Kozak, 2012). Variations of these techniques have also been used for many years in participatory action research to study social problems (Harper, 2002). The term auto-photography is used in this study to make it clear that the participants took pictures themselves to represent their personal experience of stroke and stroke recovery. These participants' pictures were then used as an elicitation technique during the interview process to stimulate or enhance discussion of participants' meanings relating to their personal experience of recovery from stroke.

*3.5.1. Auto-photography.* Auto-photography is one such photo elicitation technique that has been used in gerontology and aging studies addressing various topics, including: experiences of recovery and self-identity in cancer survivors (Balmer, Griffiths, & Dunn, 2014; Oliffe & Bottorff, 2007), health, housing and identity of low income older adults (Kohon & Carder, 2014), identity in older adult bodybuilders (Phoenix, 2010), and older adults' conceptualizations of risk-taking and risk avoidance in daily life (Rush, Murphy & Kozak, 2012). The technique's effectiveness in older adult participants is well-established (Harper, 2002; Kohon & Carder, 2014; Phoenix, 2010). Using auto-photography as a communication facilitator in the interview process may be particularly helpful to persons recovering from stroke who have aphasia or other difficulties with word-finding or memory (Clark, 1999; Harper, 1988; Harper, 2002).

### 3.6. Sample and Participant Recruitment

#### 3.6.1. Sample

In a phenomenological approach, it is necessary to include participants who have had the relevant experience under study. Therefore, purposeful sampling was used here with the goal to recruit 10 to 15 community dwelling women, currently age 60 and older, whose strokes occurred after age 55 and who were at least three months post stroke. The rationale for smaller number of participants in qualitative research utilizing purposeful sampling is in selecting information-rich cases (Patton, 2002).

#### 3.6.2. Rationale for sample criteria and eligibility

Sampling of women age 60 and older (at the time of the study) was selected because: 1) older women are at higher risk for stroke and are typically underrepresented in health research (Bushnell, et al., 2014a; Davidson, Digiacomo & McGrath, 2011); 2) while the aging population is diverse, women over age 60 may share some life experiences related to age cohort that may differ from stroke related experiences for a younger cohort. The inclusion criteria also required that the stroke occurred at age 55 or older in an attempt to broadly group women who experienced stroke in the context of similar age-related experiences (i.e. possibly ending a career, having grandchildren or having aging parents or spouse). There was no upper limit on the age of participants.

Time since stroke was at least three months but with no upper limit. The lower limit of three months was selected because of the many changes in emotional, medical, physical, and social status that occur in the earlier months after a stroke

event (Bour, et al., Cramer, 2008; 2010; Hackett, Yapa, Parag, & Anderson, 2005; Taule, & Råheim, 2014). In addition, there is greater likelihood of post stroke depression in the first six months after stroke, especially for women, which typically resolves in three to six months (Bour, et al., 2010; Hackett, Yapa, Parag, & Anderson, 2005; Poynter, et al., 2009). The first three months also may be a busier time, due to rehabilitation, medical appointments, adjusting household responsibilities, and/ or living arrangements, etc. Waiting beyond this acute stage allowed an opportunity for these initial, acute changes and transitions to occur and also permitted time for reflection on recovery status.

Eligibility was determined by the age/stroke timing parameters listed above. In addition, given the likelihood of communication, cognitive, and / or motor deficits in this population (Kelly-Hayes, Beiser, Kase, Scaramucci, D'Agostino & Wolf, 2003), several additional performance screenings were used at the first session to assure participants' capacity to effectively participate, as described below.

### *3.6.3. Sample size*

There are many factors that contribute to estimation of sample size in qualitative studies: the scope and nature of the topic, number of interviews required per participant, and overall study methods (Morse, 2000). Morse (2000) suggests 6 to 10 participants in a phenomenological study involving multiple interviews. He also recommends overestimating the number at the start of the study, so that additional time and resources are already built in if the lower number is insufficient in meeting data needs. Patton (2002) states that there are no rules for sample size, and that the focus instead should be on purpose, usefulness, budget, credibility, and depth.

Data saturation is a key concept in determining sample size in qualitative research (Fusch & Ness, 2015; Morse, 2000). Fusch & Ness (2015) noted that, although data saturation is hard to define, it is generally reached when there is enough information to replicate the study, no new information is being obtained, and further coding is no longer feasible. These authors further recommend that investigators focus on designing the study to gather data that is both thick in quantity and rich in quality (i.e. many layered, detailed, nuanced, etc.). Thick and rich data can best be obtained through in-depth interviewing (Fusch & Ness, 2015; Patton, 2008).

For this study, it was determined that saturation had been reached after 10 participants. The data analysis process, which includes the determination of saturation, is described more fully below. Had saturation not been achieved at that point, additional participants would have been sought. Determination as to whether saturation was achieved was made in consultation with the dissertation committee chair.

#### 3.6.4. Screenings

*Cognitive screening.* To assure adequate cognitive skills for this study, The St. Louis University Mental Status Exam (SLUMS) (Tariq, Tumosa, Chibnall, Perry, & Morley, 2006) was administered prior to the initial interview. The SLUMS is a brief cognitive screening tool with good sensitivity and specificity in detecting mild neurocognitive disorder and dementia (Tariq et al., 2006). It is a 30 point questionnaire that screens for orientation, memory, attention, and executive function. Participants had to meet cut-off scores, based on education level to rule out dementia

(e.g., 21 for high school education, and 20 for less than high school education). A copy of the SLUMS is included in Appendix A.

*Communication screening.* Language needed to be sufficient to participate effectively in the interview. During the initial session, a picture description task from a formal aphasia assessment was used to establish sufficient, spontaneous speech content. The picture description task of the *Western Aphasia Battery-Revised* (WAB-R) (Kertesz, 2006), designed to elicit spontaneous speech, was used for this study. A pictured scene (see figure 1) was presented, and each participant was asked to describe the scene in detail. Criteria for inclusion was the mention of at least 10 people, objects, or actions. The WAB-R is a commonly used assessment for aphasia, and is useful as a measure of functional language performance (Bakheit, Carrington, Griffiths, & Searle, 2005). The investigator is a certified speech language pathologist and qualified to assess language competency.

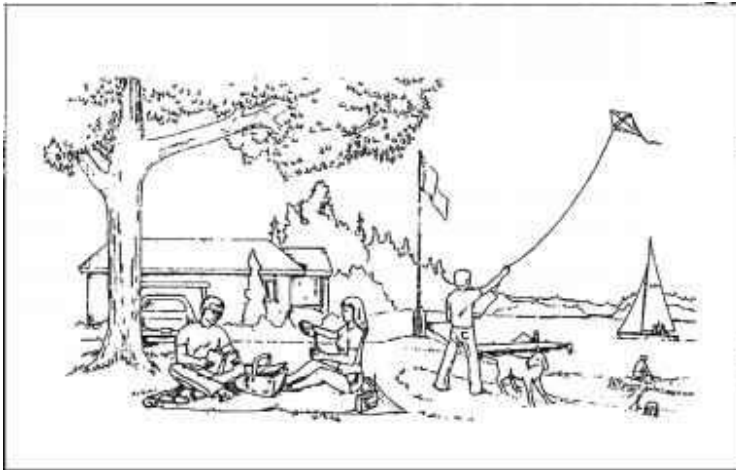


Figure 1: Western Aphasia Battery - Revised Picture Description task for language content.

*Screening motor function and vision for use of the camera.* Prior to the initial session, during a pre-session telephone call, the participant was asked if she would be able to use a camera to take pictures. During the first session, the client was given a camera and the investigator demonstrated adaptive use for one handed operation, as needed. The participant was then required to demonstrate use and take some sample pictures to pass this screening.

### 3.6.5. Recruitment

A goal of sampling was to recruit 10-15 diverse participants (i.e. representation of white and black women in the sample) across the Baltimore - Washington metropolitan area. Given the scope of this sample, it was determined that including a broader representation of other racial ethnic groups would be impractical. Including black women in the study was important, as noted previously, because they have a higher prevalence of stroke (4.7%) than white women (2.7%) (Mozaffarian, et. al., 2016; Ovbigele, et al., 2013). In addition, Beal (2014) conducted qualitative research through focus groups with black women (n=48), and results suggested that these women felt that they had limited knowledge of stroke, and that health professionals did not readily offer them adequate information on stroke, or stroke risk factors in general. For these reasons, the researcher made an effort to recruit a diverse sample.

One recruitment approach utilized the network of stroke support groups in the area. Lists of these groups are publicly available through national stroke organizations, such as the American Stroke Association, and the National Stroke Association. There is a possibility that support group joiners may have some

characteristics that differ from non-joiners, but it is not clear if there is any difference in subjective recovery experience between joiners and non-joiners. Researchers have identified stroke support groups as an important factor in coping with the effects of stroke and connecting with others who have had similar experiences (Ch'ng, French, & Mclean, 2008; Sarre, et al., 2014). Given that stroke group joiners may have more positive experiences, efforts were made to use this resource sparingly. However, this researcher has observed that those active in stroke groups come seeking information and are generally open to participation in stroke related studies.

In order to recruit a diverse group of participants, the investigator used a combination of the following methods to engage with potential participants and/or to distribute print information inviting participation in the study:

- Contacted major local outpatient rehabilitation providers, including local university clinics, and provided flyers for distribution and posting.
- Contacted 4 large local African American churches/clergy groups and provided flyers for distribution and posting. Distributing information through African American churches is well established as a source for screenings and health promotion activities for the African American community (Beal, 2014; Butler-Ajibade, Booth, & Burwell, 2012).
- Contacted local stroke support group leaders and requested that the study information be passed on to female stroke survivors.
- Spoke to two local stroke support groups about the project during their meetings.

- Distributed information to work colleagues and alumni in the investigator's own university setting.
- Posted information on personal social media pages on Facebook and Twitter.

Flyers and other notices about the study instructed interested individuals to contact the investigator. Responses were monitored on a weekly basis, and additional recruiting steps were repeated with the approaches noted above, as needed. Initial email distribution to personal and professional contacts were repeated and/ or followed by phone calls when recruitment was low.

### 3.7. Protection of Human Subjects

The proposal was initially approved by expedited review by the UMBC Institutional Review Board (IRB) on June 21, 2016 and identified as protocol #Y16LM21259. The IRB was renewed twice, through June 25, 2019. The approval and renewal documents are included in Appendix B.

#### 3.7.1. Vulnerable populations

As previously mentioned, some stroke survivors have cognitive-communication deficits that may raise a question as to whether they are members of a vulnerable population. Institutional Review Board (IRB) committees often automatically classify people with aphasia as belonging to a “vulnerable population” (Maher, 2002). Loss of decision-making capacity (DMC) may occur when aphasia is very severe; however, competence and DMC are intact for many individuals who have aphasia. The criterion used here to identify vulnerable subjects is the ability to



make decisions (Shamoo & Resnik, 2009). Research suggests that studies should not automatically assume impaired DMC in individuals who have aphasia (Brady, Fredrick, and Williams, 2013). The most common concern is whether possible communication and/ or cognitive deficits would interfere with ability to understand information that is presented. In this study, the communication and cognitive screening measures, as well as facilitating communication strategies were designed to assure selection of appropriate participants.

### 3.7.2. Facilitating communication in the consent process

The standard method of obtaining informed consent relies heavily on effective exchanges of written and verbal information (Brady, Frederick & Williams, 2013). To compensate for any communication or cognitive challenges in the consent process for this study, adjustments were made in the way information was presented, as well as in how comprehension was confirmed. This study used evidence-based methods of simplified written language in the informed consent form, which included: increased white space, larger sans serif font (between 14 and 18), and a Flesch – Kincaid readability level of 5 or lower (Brennan, Worrall, and McKenna, 2005; Stroke Association, 2012).

Comprehension of verbal instructions was facilitated by use of a slower speech rate, allowing for additional response time, and checking for comprehension during the consent discussion. Participants were encouraged to ask questions, as needed. These communication facilitation techniques were used throughout interactions with the participants.

### 3.7.3. Consent procedures

Informed consent was obtained by the investigator at the beginning of the initial visit (see Appendix B). Participants were informed of the number of interviews, length of those meetings, and instructed in the auto-photography task. Participants were asked to consent to audio voice recordings of interviews for the purpose of verbatim transcription. The consent process contained an option to prohibit use of either voice recording or photographs taken by participants in academic presentations. Participants were informed that there were no significant risks associated with this research, and that others may potentially benefit from the findings.

Confidentiality measures were explained to them, including: 1) the use of pseudonyms, 2) investigator-only access to the research records, and 3) that participation was voluntary and could be discontinued at any time. Since participants needed sufficient motor skills to operate the camera, a signed consent or mark was required.

### 3.8. Data Management and Confidentiality

Participant interviews were recorded on a personal digital audio recording device. Audio files were identified by pseudonyms only and saved on the investigator's secured (password protected) laptop. Files were transcribed verbatim, by a professional transcriptionist. Photographs that the participants took for the study were captured on the investigator's digital cameras loaned to participants for this purpose. After the photographs were used for the interview and analysis, the picture files were transferred to the investigator's secured laptop, and a password protected

flash drive, and were also erased from the camera's sim card. Participants were asked if they wanted to keep any pictures, but no one wanted them. The investigator was the only person who had a list of the participants and their associated pseudonyms. That information was kept in a password protected computer file and on paper in a locked office.

### 3.9. Data Collection Procedures

#### 3.9.1. Pre-screening questionnaire

When a potential participant expressed interest, the investigator called her to provide additional information about the study and its requirements. During this phone call the participant also answered the *Pre-Screening Inclusion Questionnaire*, included in Appendix C. This established whether the participant met the age and stroke timing requirements and indicated willingness to be interviewed. The initial interview included a more in-depth screening for communication capabilities, cognition, and camera operation (as described above). The telephone screening was helpful in identifying approximately four individuals who did not meet the eligibility requirements and had no further contact regarding the study. However, there were two participants who indicated that they met criteria during the phone call but were younger than 55 at the time of their stroke (ages 50 and 51). This discrepancy was not discovered until the initial interview and after the consent. Both participants were over age 60 and passed the screenings. The interview proceeded and the participants continued with the study. The discrepancy was discussed with the dissertation advisor and reported to the IRB committee. By the completion of interviews for 10 participants, the decision was made to keep these two participants (Rosemary and

Evelyn) in the study. This decision was based on analysis of their narratives which showed consistencies in themes and subthemes with the other participants.

### 3.9.2. Interviews

Each participant was seen for two interviews and given the choice of their home or another location in which they felt comfortable (Rubin & Rubin, 2011). Nine participants were interviewed at home, and one (Lydia) chose her local community senior center. Lydia stated that her home would be too hot due to lack of central air conditioning, and she made arrangements for an empty room at the center. Each session lasted approximately 60 – 90 minutes, depending on the length of the client's participation.

*First Interview.* In this meeting, the investigator first explained the purpose of the study and obtained informed consent to participate. Once consent was obtained, the investigator conducted the more detailed screenings for communication and cognition and for capacity to use the camera. There were two women who agreed to participate and went through the consent process but were excluded from the study because they were not able to pass the screenings. One did not pass the cognitive screening (and had difficulty with the camera), and the other did not pass the communication screening. In these two cases, the researcher informed the participants that they were not eligible to continue, and they were thanked for their time. When a participant passed all screenings, the investigator continued the session by providing both written and oral instruction in use of the camera for auto-photography. The investigator gave each participant a camera to use during the study. The session proceeded with an initial, semi-structured interview to obtain information about background and stroke recovery experience (see Appendices C and D for cognitive screening

and interview guides). Before the session ended, the investigator confirmed comprehension of the task by asking the participant to describe the instructions for the auto-photography project as she understood them. A follow-up appointment was set, giving participants at least 2 weeks to take pictures. See Appendix D: *Interview Guide for Session 1*

*Second interview.* This session focused on perceptions and meanings related to stroke recovery, self, and “normality.” During this session, participants shared the photographs taken and explained why they selected those pictures. The photographs were useful in eliciting further narrative regarding the concepts of interest. Participants were also asked to provide feedback on the process of auto-photography. This information was collected to determine the ease and effectiveness of this method for participants in this study. See Appendix D: *Interview Guide for Session 2*.

### 3.9.3. Field notes

Berg (2007) describes 4 elements for field notes, including cryptic jottings, detailed descriptions, analytic notes, and subjective reflections of the interviewer. Notes that directly describe what happened in the setting, (e.g. the participant said she was joking, but expression remained serious) are useful in analysis. The investigator made field notes after each session. These notes included general details about the session, including the setting, as well as the mood, emotions, and demeanor of the participant. In addition, the investigator used the notes throughout the study to reflect on any general observations about the session, logistical issues, and or thoughts regarding methodology or analysis (Patton, 2002). The purpose of these notes was two-fold: 1) as part of an ongoing reflective process for the investigator, and 2) to preserve memories of subjective information including unusual occurrences or facts.

In the latter instance, these notes were sometimes incorporated in the description of the clients.

### 3.10. Data Analysis

#### 3.10.1. Analytical process

The process of collecting data, transcription, review and analysis was an ongoing process for this qualitative research. The data analysis process began with a review of the audio file and field notes soon after the initial interview. This initial review was done to get a sense of the whole (Creswell, 2013). Field notes provided a supplemental point of reference (i.e., setting, mood and demeanor of the participant, etc.) (Patton, 2002). The researcher made any additional notes as to any initial impressions about the cases. Notes were also used to indicate things like emotional responses or other events that may not have been readily apparent from the finished transcript. As an example, during Lydia's first interview her husband sat in the room, and it was noted that she seemed quite reserved, and perhaps not forthcoming in answering some questions. It was unknown as to whether this was due to the presence of her husband, or if this was just her personality. In contrast, on the second visit Lydia's husband was not present and she was noticeably more animated and mentioned the tension that existed between the two of them.

Next, the audio files were transcribed by a professional transcriptionist. The researcher read through the transcripts while listening to the audio files again and made any additional notes regarding her impressions. Transcripts were uploaded to the NVivo Pro 12 Qualitative Research software program (QSR International, 2018). The Nvivo software was used to facilitate organization of the written transcripts.

While software can be useful, it is important that the investigator tease out shades of meaning and nuance, and not rely on the software to drive the analysis (Creswell, 2013; Patton, 2002; Rubin & Rubin, 2012). Constructivist inquiry guided the data analysis (Miller & Crabtree, 1999). Using a phenomenological approach and constructivist inquiry involves an iterative process of reviewing the data, identifying significant statements, meaning units, and themes, and then going back to the data for re-reading, following an inductive, cyclical pattern (Creswell, 2013; Miller & Crabtree, 1999; Patton, 2002).

As additional participant transcripts became available, the researcher began to look across cases for patterns and variations, and to identify potential codes. Using phenomenological reduction, codes were then grouped into meaning units or themes (Creswell & Maietta, 2002; Richards & Morse, 2007). These themes were reviewed and the investigator looked for connections across emergent themes to identify the essence of the shared experience of the sample (Smith, Flowers, & Larkin, 2009). The essence includes textural description, which explains “what happened,” and structural description which explains “how the phenomenon was experienced” across the group (Creswell, 2013). This process was repeated for each case as additional transcripts were reviewed and additional codes emerged and were also grouped. The researcher next went back to the data to test whether these codes were substantively consistent across cases, and sometimes items were re-coded as divergent patterns became more apparent across cases. Some early codes were not grouped into the final themes if they were not strong across the sample. For example, references about aging came up, and, while it seemed that this might be an appropriate theme, it was only mentioned

by two participants. It was therefore not supported by the data from this sample and was dropped. After completion of the analysis, the essence of the phenomenon was described in narrative with some supporting verbatim examples and is presented in chapter (Rubin & Rubin, 2012).

#### 3.10.2. Mentored meetings and debriefings

Meetings were held with a research mentor, the dissertation chair. The purpose of these meetings was to review the interview guide and identify the potential need for modifications based on ongoing interpretations and findings. Later meetings were used to review the data, and discuss emerging codes, patterns and themes. This confirmation of analysis occurred initially for four cases (on both first and second interviews). There was overall good agreement on the results of this analysis, and the investigator continued to test these ideas with the remaining cases, using the cyclical process of reviewing the data, developing codes, grouping into themes, testing the analysis against the data, revising as necessary, and repeating the steps.

#### 3.10.3. Soundness of the qualitative data

Lincoln and Guba (1985) identified four criteria to determine trustworthiness in qualitative research: credibility, transferability, dependability, and confirmability. Shenton (2004) described techniques to satisfy each one and noted that the four categories overlap at times. Some of these elements have been incorporated into this research to assure soundness of the findings.



Credibility is the extent to which the findings are congruent with reality. This can be achieved by adopting research methods that are well established, conducting debriefing meetings between the researcher and mentors, and collecting thick, rich descriptions of the phenomenon under study (Lincoln & Guba, 1985; Shenton, 2004). Dependability of the study can be determined by the fact the study process is described in detail, so that another investigator could repeat a similar study (Patton, 2002; Shenton, 2004). Dependability also relies on the researcher's care in describing the research process as it actually operated in the field. The third concept, confirmability refers to the extent to which the findings are shaped by the participants and not by the investigator's predispositions and biases (Lincoln & Guba, 1985; Patton, 2002). Reflexivity, one technique for confirmability, was included in this study (Patton, 2002). The investigator identified and conveyed information about her own background, experiences, and biases, and included ongoing reflection as to how these might shape interpretation (Creswell, 2013; Patton, 2002; Lincoln & Guba, 1985).

### 3.11. Pilot Study

Although auto-photography is used in several studies in the field of gerontology, it is not widely used nor had it been used with stroke survivors. Consequently, a pilot study was conducted to test the methodology in a small sample of somewhat younger women stroke survivors.

### 3.11.1. Pilot study research question and aims

The pilot study was approved by expedited review by the UMBC Institutional Review Board (IRB) on August 27, 2015 (protocol # Y16LM21013). Participant (N=5) interviews were completed between September and December, 2015. The purpose of the pilot study was to evaluate the integrated use of auto-photography and in-depth interviewing as a methodology to explore the lived experiences of women as they recover from stroke. The pilot study collected stories from the participants using the combination of interview and auto-photography in order to evaluate the ease of use of photography with participants and to determine the effectiveness of photos in facilitating a subsequent interview. It was also used to gauge participants' comfort with the auto-photography task and to test and finalize procedures for the full study.

### 3.11.2. Pilot study methodology

*Sample and participant recruitment.* Eligibility requirements were: adult women stroke survivors, living at home (i.e. not in a care facility), ages 30 – 59, 6 months to 10 years post stroke, with communication and cognitive skills sufficient to participate in in-depth interviewing, and with sufficient visual and motor skills to operate a digital camera. The two exclusion criteria were that women were not in the process of recovery from other co-morbid medical conditions that overshadowed stroke recovery experience, or concurrently participating in cancer treatment, because of possible cognitive implications. The researcher realized it was redundant to retain this second exclusion in the larger study, since participants must pass a cognitive screening in all cases.

Purposive, snowball sampling was used to recruit participants who met the eligibility requirements, using some of the same techniques intended for the full study. There was an effort to recruit diverse participants in terms of race, ethnicity, and geographic location (within the Baltimore –Washington metropolitan region). The researcher was not able to recruit a diverse study for this small sample; with only one African American woman expressing interest. She was over age 60 and could not participate in the pilot study.

Consenting and data collection procedures were the same as those described for the main study, with a few logistical changes that are listed below as “lessons learned.” First interviews were conducted as described above. During the second interview, the participants were asked first to talk about life after stroke and then describe the pictures they took. After describing the pictures, they were asked to respond to the words “normal” and “recovery.” Finally, they were asked questions about the auto-photography process and asked to rate it as a research tool.

### 3.11.3. Summary of pilot study results

All participants in the pilot study were able to take pictures and to effectively describe their meanings attached to the. One of the participants did not like to take the camera with her on outings. She felt that it was bulky and was afraid she might drop it, especially when she went sailing. At her request, we agreed that she could to use her iPhone to take pictures instead. One participant, an experienced photographer, asked to take only the investigator’s sim card so that she could use her own, sophisticated camera. Participants reported that the photography process was “easy” to accomplish. Four of the participants stated that they enjoyed taking the pictures,

and they thought it was a good way to talk about their stroke recovery experience. The other participant expressed that she found the pictures ineffective in telling her story. Overall, rich, thick data were collected during this pilot study while employing the photographs to elicit responses. Multiple participants noted that the process of taking the pictures was helpful in reflecting on their experience of recovery at a deeper level. After talking about pictures related to daily housekeeping tasks and taking care of her family (including the dog), participant #1 stated that, these tasks were “*routine*” before the stroke, but “*now I realize that’s who I am.*” She began to cry as she reflected on her inability to do these things initially after her stroke, and how important it was for her to be able to do resume doing these tasks again.

#### 3.11.4. Lessons learned from pilot study

Based on this pilot study, auto-photography was supported as a useful tool in qualitative interviewing with women stroke survivors. Three methodology logistics were identified as “lessons learned.” First, participants were typically eager to share their pictures. The second session started with an interview and delayed the picture description. Some of this information was sometimes also discussed during picture description and was therefore redundant. It was concluded that starting the second interview with the description of pictures would be more efficient and would allow participants to take the lead in discussing what they deemed most important. As a result, some of the questions about life before stroke and stroke event were moved to the first interview.

Second, participants were told that only 10 – 12 pictures would be selected for the study. This number was chosen based on two other studies where a number was

indicated. There was no supporting evidence from those studies that this number was meaningful. The number of pictures taken by pilot study participants ranged from 21 to 60 (an average of 40), but this number did not necessarily reflect any difference in the amount of information that they shared. The participant who took 60 pictures had many duplicates and also grouped several together in relating one idea of experience (e.g. household chores, going to the gym). Across the participants a single picture might elicit just a few words, or several minutes of reflection; therefore, the number of pictures was not an important factor. In sum, the auto-photography technique seemed to work well in female stroke survivors of slightly younger ages relative to the proposed sample.

### 3.12. Limitations and Strengths of the Study Design

There are several potential limitations for this study. First, there were challenges in recruiting a diverse group of participants, particularly for women who are more isolated and less active in the community. As such, participants who volunteered for this study may be more active in social and treatment environments, so that findings may not represent those who face greater health, financial or related challenges.

Secondly, using a camera may exclude two potential groups: those who have significant visual or motor deficits, and those who don't want to take pictures. The idea of using a camera might have prevented some women from agreeing to participate. Both of these factors may cause limits to what is learned about the phenomenon of recovery from this study.

There are also several strengths in the study design. First, older women and women who are stroke survivors are both underrepresented groups in research. This research provided an opportunity to add to knowledge about the experiences of these groups. Second, findings provide additional knowledge about the recovery experience, an area that is not well understood. Another consideration is that stroke survivors with aphasia are often automatically excluded from research. Use of aphasia friendly communication strategies and auto-photography in this study enhanced shared communication and provided access to participants who may have been excluded from other studies. Finally, this study presents an innovative use of qualitative methods, by combining use of auto-photography and in-depth interviews, which has not yet been published as a methodology with this group.

### 3.13. Summary of Methods Chapter

The methods for this study were qualitative and based on a phenomenological approach and social constructivism. This approach, and the related procedures, were a good fit for this study of sample of women stroke survivors ages 60 or older. The procedures permitted them to share their personal experiences of recovery from their personal perspectives. In addition, this study used a unique combination of auto-photography and in-depth interviewing to collect thick, rich data. The investigator conducted a pilot study to test the logistics of the procedures and found that they were effective for eliciting the data required for the study. Finally, the methodology and procedures for this study were constructed to reflect rigor in qualitative methods by employing such techniques as purposeful sampling, mentored meetings, collection of rich thick data, and investigator reflexivity.

## Chapter 4: Results

### 4.1. Introduction

This chapter shares the results of the study by first describing the researcher's role and the study's participants. It then turns to outlining and providing narrative support for the themes and subthemes that emerged from the analysis of the data. The chapter concludes with a discussion of methodological findings relating to the challenges and benefits of utilizing auto-photography with stroke survivors in support of telling their stories of the understanding of that event and its aftermath.

### 4.2 Researcher Role and Bias

In qualitative research, when a story is told, the listener/ researcher is in an active role. Therefore, the unique background and experiences of the researcher are not separate from the research process (Creswell, 2013; de Medeiros, 2014). Continuous self-reflection, or “reflexivity,” generates awareness of what the researcher brings to the table in terms of characteristics and experiences. This researcher reflected on her role as well as her background and experiences throughout the process and remained conscious of how those elements might shape her interactions and interpretations of the narrative data. Disclosure of potential bias is included in the reflexive process, which, in turn, provides transparency and improves credibility in qualitative work (Darawsheh, 2014). As discussed elsewhere in this dissertation, this process of “reflexivity” is also considered a form of confirmability, and, as such, important in maintaining the soundness of the qualitative data (Creswell,

2013; Patton, 2002; Lincoln & Guba, 1985). As part of this dimension, a description of the researcher's characteristics and background is described below.

The researcher is a middle-aged, African American female with both professional and personal interests in the topic of stroke. Professionally, she is a medical speech language pathologist, a clinical faculty member at a local university, and a coordinator for a community-based stroke survivor group (serving both survivors and caregivers). In these roles, the researcher has been in contact with many stroke survivors over the past 30 years in both individual and group encounters, and in clinical and social settings. She has also given presentations on a range of stroke-related topics at other local support groups and at both local and national professional conferences. As a speech language pathologist, she is skilled in interacting with individuals who have aphasia or other communication deficits. In her faculty role, she also supervises in a clinical program for stroke survivors. Given the researcher's professional network and visibility, much of the outreach for recruitment of participants for this study came through established professional contacts.

On a personal level, both the researcher's grandmother and mother had strokes. In addition, her mother, as a stroke survivor, experienced years of physical disability as a result of multiple strokes and passed away during the course of this project. The researcher was also the family caregiver for her mother for over 12 years. Research on stroke survivors had been an ongoing interest based on work as a clinician and support group leader. The focus on women stroke survivors occurred through the more recent discovery of literature that indicated a difference in overall outcomes based on gender. In addition, this researcher was further motivated by the



fact that historically, women have been underrepresented in stroke studies and recent efforts are just beginning to address this. (Bousser, 1999; Bushnell, 2014a; Kurth & Bousser, 2009).

These life experiences have served as both motivation and preparation for deep engagement with participants, as well as providing distinct skills for utilizing a qualitative approach.

#### 4. 3. Participant Information

Ten women participated in the study. The names used here are all pseudonyms and Table 2 shows the demographics for the sample. Participants' ages ranged from 60 to 78, and the time since their stroke ranged from 4 months to 15 years. The majority had college degrees, and all had worked outside of the home before the stroke occurred. Occupations varied and examples included, chief administrative officer, teacher, dog walker, accountant (who was also a farmer), and human resources professional. Most participants lived with a spouse or other family member, and two lived with and were caregivers for their mothers. Two of the women moved after the stroke to live with their daughters, and one moved to be near her daughter. One participant lived in a rural area, whereas three lived in a city, and six were in suburban communities.

Eight participants were referred by another healthcare professionals (stroke support group leaders, therapist, physician), or knew the researcher in her professional role. One woman's daughter saw the recruitment flyer when she was at her own therapy appointment and contacted the researcher on her mother's behalf. Another participant referred her next-door neighbor (Rosemary). At the first

appointment with Rosemary, both the researcher and participant realized they knew each. Rosemary had participated in a previous study with the researcher about 7 years ago and was enthusiastic about participating in this project as well.

Recruitment was more challenging than expected. The original goal was to recruit up to 15 participants, but there were challenges with potential participants who did not follow through. Two women scheduled, rescheduled, and did not follow up with rescheduling appointments, and a third asked to call back to set up an appointment but never scheduled. As noted previously, there were also two women who were seen and went through the consent process but did not pass the screenings. Nonetheless, the researcher believes that the sample is sufficient to achieve saturation (Fusch & Ness, 2015; Morse, 2000). Sample characteristics are described in Table 2.

Table 2: Participant Demographics

Pseudonyms	Age	Race	Time post stroke	Marital Status	Lives alone	Education
Georgia	65	B	3 years	D	N	College degree
Abby	69	W	4 years	D	Y	High school
Rosemary	60	B	10 years	S	N	High school
Delores	70	B	4 years	D	N	College degree
Joan	78	W	4 months	D	Y	College degree
Evelyn	64	W	15 years	M	N	College degree
Lydia	78	W	7 years	M	N	College degree
Maryann	78	W	3 years	M	N	College courses
Daphne	63	A	8 months	M	N	High school
Florence	67	B	10 years	D	N	College degree
<b>Median age 69.2</b>						

Key: W, white; B, black; A, Asian; M, married, D, divorced

#### 4.4 Themes and Subthemes

Participants were interviewed twice, with two weeks to two months in between to take their photos. Each of the two interviews lasted from 60 to 90 minutes and were, with the participant's permission, audio recorded. These narrative interviews were later transcribed verbatim. The transcripts were the primary data source. The researcher also took field notes (written and/ or audiotaped) just after the interviews. These notes were subjective as well as descriptive and reflective in nature. They were used to note any observations that appeared pertinent to the setting and/ or

participant, reflect on the methods (including the interview process and questions), and reflect on any patterns or themes that could be emerging across participants.

Photographs taken by the study participants and researcher field notes were utilized as supporting data. Although all participants were instructed to take pictures of their “*stroke and life after stroke*,” to share and discuss during the second interview, two chose not to do so. Their reasons are discussed later in this chapter. All (including the 2 who did not take any pictures) were additionally asked, “Are there any (other) pictures you would have taken to describe your stroke experience, including life after stroke?” The photographs, however, were not intended to be a data source, but served as additional prompts in the interview process. The value of photographs to elicit information, especially for individuals who may have communication or memory deficits, is supported in research and described in detail elsewhere in this dissertation.

The data analysis process was outlined in the previous chapter. Themes and subthemes emerged from the narrative transcripts and are described below. Four major themes, each with multiple sub-themes, emerged from the data: 1) the stroke event, 2) a new chapter, 3) meaning and process of recovery, and 4) self-identity.

The aims of the study were: 1) To describe women’s experiences of recovery after stroke, 2) To determine how women experience self during the stroke recovery process, and 3) To establish how women define normal life before and after stroke. Considerations relating to the aims are discussed as they apply to the derived themes described below.

#### 4.4. 1. Theme 1: The Stroke Event

Each participant was asked to tell the story of her stroke, and many provided detailed accounts of factual information about the event, as well as their own interpretations of the psychological, social and other dimensions of the event and its aftermath. Across the full-set of interview narratives, three common subthemes relating to the stroke event that emerged were: 1) the abrupt nature of the stroke, 2) being faced with the unknown, and, 3) the timeliness of treatment. The findings relating to this theme address aim 1, in describing the pivotal period of time that marks the stroke event and the inception of the process of recovery. Aim 3 is also reflected here, as participants were not always aware or ready to acknowledge that their “normal” lives, as they knew them, were changing.

##### *Stroke was abrupt*

The views of the participants reflect the nature of stroke as it is understood medically. All participants described stroke as an unexpected event that occurs on a “typical day” in one’s life. One participant, Lydia, had, five years before her stroke, experienced a transient ischemic attack (TIA) that caused no residual disability. However, the onset of her major stroke during a typical day was still quite sudden.

*And then the stroke... I had [it] at work. I went to work Monday morning. I felt fine, and boom. I passed out. – Lydia*

In contrast, Daphne was engaged in a strenuous physical activity that was part of her routine of outdoor holiday decorations. She was preparing to hang Christmas lights on the roof of her house.

*Actually, 15 minutes before my stroke I was up on this roof. We were cleaning out the rain gutters, my daughter and I. And, thank goodness, I came down to unravel the hose so we could wash the rain gutters, and that's when I fell over and lost my balance. - Daphne*

Rosemary experienced a headache, and her first response, getting a pain reliever, might be typical for anyone. Even though her stroke was 10 years ago, she stated that she had vivid memories of the onset.

*I remember that day like it was yesterday. I was - actually, I was washing clothes. Had a real bad headache. On the top of those stairs [pointing] - the hamper was at the top of the stairs. I was separating the clothes. Walked down the steps. Walked down the steps - went to the corner store on my block. Bought a aspirin, put the aspirin in my pocket, walked back to the house, walked up to the top of the steps. And then I got to the top of the steps, then I collapsed. - Rosemary*

Although the stroke was also sudden for Joan, she was one of only two women in the study who concurrently suspected that she might be having a stroke. The American Stroke Association has been trying to raise public awareness for stroke through ads that depict symptoms. The acronym FAST refers to face drooping, arm weakness, speech difficulties, and the need for timely intervention. Joan had seen these ads and it did influence her reaction. Joan took a picture of the Starbucks shop.

*I was in Starbucks and my arm went numb. So, I'm like, huh... I had a shoulder bag, and then I thought, well maybe I carried the shoulder bag wrong. So, I kinda stood around in there for a while, and then I went out in*

*the street, you know? And I remember seeing ads for a stroke, you know? If [you] can put your hands above your head then you were okay. [Interviewer: Right.] ... So, I put my hands above my head. \*laughs\* Oh, I must be fine. And could I say my name? So, I said my name to... nobody, except me. But still, this arm was not good. - Joan*

Stroke occurred for many of the participants in the course of a “normal day” and was usually a surprise. This event, which generated varied outcomes for the women in the study, reflected both the onset of a health condition that would require some recovery (Aim 1), as well as becoming the beginning of a reshaping of the concept of “normal” in their lives (Aim 3).

### ***Stroke was an unknown***

For eight of the participants, stroke was not only abrupt, but also an unknown. They did not recognize what was happening to them, and often outsiders and family members involved in the event were unaware as well. In two cases, others thought that the participant had been drinking.

Abby was working as a dog walker and about to take a dog out when she realized she was having trouble with the leash. A bystander noticed and offered to help her put the leash on the dog.

*And the girl who did it [helped with the leash], she says, “Maybe she’s - I think she’s drunk”. [Interviewer: Oh, no.] Yeah. But she knew that I don’t do alcohol. [Abby is a recovered alcoholic]. So she’s [the bystander said] “oh, no. Something’s wrong.” So, she called [911] right away. And by the time [of the call], I almost fell. - Abby*

While Evelyn was having stroke symptoms, she prepared some food. However, when her husband questioned her about the food, they were both puzzled by her response, which didn't make sense to either of them. Fifteen years after her stroke, some of the unusual things that happened that day stood out in her memory.

*I said to my husband "Do you like these vegetables?" and he said "Yea. What are they?" and I said, "They're arranged blue cheese," and he looked at me quite startled and said, "Have you been drinking?" and I said, "No, I haven't. I don't know why I said that." and he said, "Maybe you'd better go back to bed." - Evelyn*

Evelyn's symptoms had started when she was at the hairdresser's earlier that day.

*I was at the hairdresser getting my hair cut and I noticed... I was looking in the mirror, and I noticed that my smile was sort of lopsided, and I got very, very sleepy and umm... my hair dresser said, "Are you okay?" and I said, "Yea I'm just sleepy." And he said, "Are you sure you're okay?" and I said "Yes" and he said, "Do... do you want help getting home?" and I said, "No I'm okay." – Evelyn*

Despite the fact that both Evelyn and her hairdresser saw that she had developed a facial droop, this did not signal a red flag to either of them, and she proceeded to drive home. She shared a picture of the road she took that day:

*Yea, I drove home. I drove home when I had the stroke. I wasn't driving here in this picture, but I drove home, and I was all over the road. And I didn't realize anything was wrong. – Evelyn*



In contrast, Maryann knew that something was wrong with her, but she and her husband didn't associate her symptoms with a stroke.

*I wasn't very knowledgeable, about strokes. No one had really told me much about it. And I was expecting that you'd have pain, and I had absolutely no pain. ... I started dragging my right leg, and I still didn't think of a stroke, and neither did my husband. Then I was holding onto the wall, because I was knocking pictures down and everything, but neither one of us thought it was stroke. - Maryanne*

A family member was waiting for Delores to come downstairs so that they could go out, but when she went looking for her, she found her just sitting.

*I was sort of in a daze. I didn't know what to do. I knew something was wrong, but I didn't know I'd had a stroke. .... And I was sitting on the side of the bed, and she [her aunt] said, "Are you all right?" I said, "No. I'm not all right." I didn't know what was wrong with me. She said, "Well, I'm gonna take you to the emergency room." - Delores*

Although stroke is one of the most common causes of disability in the United States, and there have been efforts to raise awareness, most of the women interviewed, as well as many around them, appeared to have no frame of reference for the symptoms that they experienced. In addition, there was often a tendency to even ignore physical symptoms and continue with daily routines and responsibilities. This tendency to continue with "business as usual," as seen above with Evelyn and Maryann, ties to aim 3 and reflects the desire to continue the pre-stroke version of "normal life."

### *Timeliness of treatment*

One of the challenges in administering effective medical treatment after stroke is the issue of receiving care in a timely manner, specifically in the first four and a half hours (recently increased from the initial guideline of three hours), when there is chance of restoring blood flow in an ischemic stroke (Faiz, Sundseth, Thommessen, & Rønning, 2014; Teuschl & Brainin, 2010). Researchers have attempted to identify whether women were more likely than men to delay treatment, but the majority of studies have found no difference by gender in timely response (Bushnell, et al., 2018; Faiz, Sundseth, Thommessen, & Rønning, 2014; Teuschl & Brainin, 2010). Only Joan immediately recognized her symptoms and sought early medical treatment. For four of the women, there was a notable delay in seeking treatment, which, in three cases, was related to not recognizing the symptoms of stroke. Evelyn and Georgia both delayed treatment overnight. As discussed above, Evelyn saw that her mouth was drooping, and had mixed up her words when talking to her husband. But she still decided to see if going to bed would make things better.

*So, I went to bed. Slept for twelve hours, cause I got up the next morning [and] it was around 8 o'clock and... He [her husband] came down and he said, "How do you feel this morning?" and I looked up at him and I smiled and he said, "Let's go to [local urgent care]." And I said, "What are we, what are we doing that?" and he says "Well, I think you ought a see somebody there." – Evelyn*

Georgia, who was aware that she might be having a stroke, felt obligated to go to work early in the morning to finish some work tasks. She had weakness on one side and noticed that her speech was different, but still decided to delay treatment.

*But I noticed something was different. So when I got home I noticed it even more. And the thing is, I knew what was happening. You know, because I'm in the medical field. I said, damn, you know? I wasn't just quite ready to be hospitalized at that time, so what I did was take a lot of aspirin... - Georgia*

Since Georgia worked at a hospital, she went to work the next day, expecting that she would be admitted before the day was over. In the interview, she described her rationale for delaying treatment. She felt that her work responsibilities and obligations to others came before her condition and attempted to quickly do as many work tasks as she could before going to the emergency room.

*Anybody I told that to [describing her delay] would think, you weren't too bright, you know? Jobs will continue after you....I don't regret what I did. - Georgia*

Rosemary also tried to ignore her symptoms, and continue her household chores, until she was no longer able to do so. In addition, her family eventually intervened. She had collapsed on the landing of the stairs. In recalling the experience from ten years ago, she recognized the significance of the delay.

*With me being so stubborn, I heard my mother say, "You OK?" I said, "I'm fine." I'm trying to get up. Trying to roll myself - body over to get up. Couldn't get up. My cousin stopped over. "Rosemary want - want me to help you up?" "No, I'm fine. I'm fine"...because I'm always used to doing things on my own.*

*I can get up by myself. Now I know, all this time being wasted. Then my nephew came by to help me get off this floor. He picked me up. He said, "...you're like a little ragdoll." Then ....they called 911. - Rosemary*

Maryann initially tried to continue preparing for a planned trip until the symptoms became too obvious to ignore. She had no idea that she was having a stroke. But looking back, she realized that when she did seek help, the medical professionals did not respond in a timely manner. She went to an urgent care center and they called an ambulance.

*[The ambulance] took their good old time. I went to [local hospital], and they were not in any rush, they didn't put any sirens on, anything, and I felt fine. - Maryann*

Once she got to the hospital, several hours passed before an MRI was performed.

*I've heard that if you get there within three hours, you know, they can reverse it, but no way could I have made that. - Maryann*

Joan was the only participant who was both aware of time and sought timely intervention. Yet, she admits that there was an urge to avoid medical care. Her stroke occurred near a source of assistance. She took pictures of the Starbucks where she noticed her symptoms and the clinic that was on the same street. As she looked back over the pictures, she described her experience with prompt intervention, which turned out well, in her view.

*... and I'm standing in front of a -- clinic... on the corner of [name of street] where my doctor is.... So, I'm debating this with myself, you know. I really want to run away and go home. But I... how could I do that? So, I walked into*

*her office and I said you know, my arm hurts and my arm is pa.... feels paralyzed ...*

*..... You know it was so beautiful. It was an ideal stroke story, because they then took me to [Hospital]. Walked in there. They were all over me, you know? The whole team and whatever and whatever. – Joan*

The delay in timeliness of the response to seek treatment was, in some instances, related to lack of recognition of stroke symptoms, but Georgia was aware and deliberately delayed medical care. Only Joan made a conscious effort to seek medical help in a timely manner. Bystanders and family members were also helpful in seeking medical care, but again, not always in a timely manner. As in the previous subtheme, delay sometimes occurred when participants were seemingly more compelled to carry on with their lives as usual (Aim 3).

#### *Summary of theme 1*

The stroke event theme emerged as participants described the stories of their strokes. Their narratives reflected the concept of discontinuity and biographical disruption (Becker, 1993, 1997; Bury, 1982). There is a natural tendency to want to keep going with normal activities of life, and the sudden nature of stroke creates a challenge to order and a need to restore order (Becker, 1993, 1997; Bury, 1982; Satink, et al., 2014). It was a pivotal point in their lives, in which a major event unfolded that was both sudden and unknown.

Their narratives also reflected a common public health issue. There is limited awareness of stroke symptoms in the community, including lack of awareness of seriousness of the symptoms, and often delayed treatment. As discussed elsewhere in

this dissertation, literature indicates that women have overall worse outcomes from stroke than men. One of the concerns regarding stroke outcomes is prompt medical intervention. Georgia was the only participant who worked in the medical field (dental hygienist and educator) but still significantly delayed seeking treatment. Only Joan reported being keenly aware of symptoms and the need for prompt treatment because of public health advertising. She was also the only one who indicated that she received tissue plasminogen activator (tPA). tPA can dissolve the blood clot in an ischemic stroke and restore blood flow, thereby restoring function and minimizing deficits. As a result of this treatment, her symptoms were resolved quickly, her hospitalization was very short, and residual deficits were minimized. tPA treatment may not be appropriate in all cases, but prompt medical intervention at least provides an opportunity for a better outcome.

The stroke event theme and subthemes supported Aim 1 by illustrating the very beginning of a major event that would require recovery and Aim 3 as participants realized at that time that normal life was disrupted and on the precipice of changing.

#### 4.4.2. Theme 2: A New Chapter

Participants were asked two questions about how they saw their lives after stroke. “Thinking about your life, do you divide it into times before the stroke and since the stroke?” and “Has your recovery had different phases or chapters?” Most of the women discussed how the stroke divided their lives into phases, or saw different phases in their recovery. Their narratives focused on both the changes that occurred just after the stroke and over time. These changes focused in several areas: A)

physical or functional abilities, B) changes in lifestyle, and C) impacts on interpersonal relationships.

While physical and functional changes are widely known by professionals and the public at large as stroke outcomes, more impactful, perhaps, due to being less expected, were the lifestyle and relationship changes. Aim 3, defining normal life before and after stroke, is reflected in this theme, as the women experienced and described changes in many areas of their lives.

*I mean and that's that kind of your life... your whole life has changed by this event. - Joan*

#### ***Changes in physical and/or functional abilities***

The physical disabilities pursuant to stroke are well known. Others can typically see or hear that something has happened to the stroke survivor. Impairments in walking, speaking, swallowing, and performing daily tasks are common after stroke (Bushnell, et al., 2014B; Robison, et al., 2009), and they sometimes become permanent. The women who participated in the study discussed how they found that they needed to adjust and adapt on various levels to limitations in their bodies and in performance of functional tasks. Rosemary was typical of those noting this type of post-stroke outcome.

*You know the things you did before, you can't do those same things the same way. – Rosemary*

Joan walked out of the hospital in two days but was shocked when she realized how much her daily routine was initially disrupted.

*I mean the biggest... the biggest absolutely the biggest thing to me was that I couldn't ke... when I got home is that I couldn't keyboard with that hand. So, that was horrifying ... 'cause I'm on the computer a lot... - Joan*

Joan initially experienced difficulty using both her phone and the computer, and she realized how much these were a part of her every day routines, as well as an important connection with others, especially since she lived alone.

Abby had more deficits with her stroke than Joan, but she was walking independently when I interviewed her at about 4 years after the event. However, she shared her continuing frustrations with seemingly simple daily tasks.

*But my whole - my right side is all still screwed up because of the stroke. ..*

*But even my hair - I can't do a blow dryer with that [she was holding out her weaker hand]. I can't do that. You know. There's certain things – this [pointing to her hand] is all screwed up. – Abby*

Rosemary was nearly in tears as she described how worried she was when she found out that she was going to be a grandmother. She felt as if her deficits would interfere in building a bond with the newborn.

*But when I found out that they [her son and his girlfriend] was having a baby, I felt so bad because my arm - how I'm going to hold this baby? You know how they say that children can feel fear? She's [the baby] going to know that - she's going to feel something because I can't hold her the way I really want to. - Rosemary*

She went on to describe her relief when the family found a way for her to hold the baby securely.



*So, when the baby came, I remember holding her for the first time. They put this thing around my waist, like a donut, and I held her. - Rosemary*

Most of the participants had trouble with communicating at some point in their recoveries. Abby, Evelyn, and Lydia all experienced some degree of aphasia, and Joan reported that she was still working with a speech pathologist to help with word-finding skills. Evelyn communicated well during the interview, but spoke about her mixed success with music therapy early in her recovery.

*I was really excited that I.. that music therapy worked ..... and that I was talking. So... I... I... I'd talk a whole bunch. I mean I'd talk non-stop. So I was talking and talking and talking, but...then I found that I was calling things by the wrong name. - Evelyn*

Georgia, Florence, and Rosemary also reported changes in voice or tone that had, in their views, negatively impacted their communications with others. Right after her stroke, Georgia was unaware of the change in her appearance until she noticed her daughter's reaction.

[In response to a question about speech therapy] *I didn't think my face had changed a lot, but I think it did. And my daughter looked at me and started crying and all that stuff. So in speech therapy, I was just doing the things to get my facial muscles back into sync. I thought I spoke clearly, okay, but I think it was my facial muscles, and maybe I didn't speak clearly. - Georgia*

Other participants noted some changes in thinking or memory that improved over time. As Evelyn described one of her pictures, she recalled a scary episode that happened when she first came home from the hospital.

*That was a bathtub and I took a... bath during the first week I was home from the stroke. And I had candles on the edge of the tub, and I finished the bath and dried off and I came down stairs. And I was sitting... down stairs, and my husband came home from work, and he heard a noise. He said, "What's that?" and I said, "I don't know". It sounded like glass breaking. He went up and the fire... the... the tub was on fire. - Evelyn*

Evelyn had left candles burning around the tub (large Jacuzzi-type) and the glass jars broke so that there were small fires on the ledge around the tub. Her husband was able to put the fires out, but there was damage that had to be repaired. They were both grateful that he was home and heard the noise, so that he could put it out before it became a larger fire.

Two of the single women discussed their concerns about intimacy after stroke in relation to functional changes. Georgia, who was single but interested in seeking a partner, felt that she could not even pursue a relationship. Rosemary had a newly found relationship but brought up the failure of professionals and support groups in providing information about intimacy and sex after stroke.

*What they don't talk about is intimate relationship. They don't talk about that much. And they need to talk about that more, because at one point, I went through a period of wanting to open - to open to something. But it never happened. How do people get to talk about intimacy after stroke? – Rosemary*

While people in general know that changes happen post stroke, they may not understand the range of changes or be able to imagine how it would impact their daily lives. What was normal before stroke has now changed (Aim 3). The range of

physical or functional issues of interest to the study participants was broad and included how their disability might impact a relationship with a newborn or being able to safely enjoy using scented candles. In some instances, there was a perceived lack of information or preparedness that might have been expected to come from healthcare professionals.

### *Changes in lifestyle*

In addition to physical and functional changes, women also experienced a range of changes in lifestyles, including impacts arising from necessary post-stroke relocation or financial challenges. These more secondary outcomes may not be widely understood or anticipated, based on our highly medicalized approach to stroke treatment. But, nonetheless, they may be significant to stroke survivors in adapting to the ongoing consequences of a stroke. These changes in lifestyle also supported aim 3, in redefining the meaning of “normal” after stroke.

By the time of her interview, and because of her stroke, Abby had already needed to move to two different states from where she originally resided. Her moves were linked to living near her only daughter. At the time of our interviews, she was preparing to move again, but this time it was to a smaller unit within the same senior citizen apartment building and due to financial reasons. She expressed frustration both about her living situation and her financial concerns. She took many photographs in her apartment building to show unsatisfactory conditions, including rodent droppings in one area, inadequate snow removal, and a stacked washer/ dryer combination that was not easy for her and other residents (especially those in wheelchairs) to reach.

*And I hate this. I don't like this place. I'm not - I'm elderly, but I wanted just a neighborhood with kids and dogs and things. But that - in [the previous city], I could do that. So I wasn't depressed even though I moved. Here [where she lives currently], I'm off and on about depressed. ... I don't like apartment buildings. - Abby*

Both Florence and Delores had a change in living arrangements, and possibly some loss of personal agency in their activities around the home. Florence moved from another state to live with her daughter and grandchildren after her stroke.

*After rehab my children brought me down here. They wouldn't let me stay in [previous state] at home by myself. I've been here since.... My daughter forbids me to be in the kitchen cooking. I can't cook nothing. – Florence*

Delores's daughter relocated to the state where her mother was living after the stroke and bought a house for the two of them.

*But since I've been living here with my daughter, she doesn't let me cook. She does it. She really does look out for me. - Delores*

Both Lydia and Maryanne talked about not being able to keep their houses in order after the stroke. For Lydia this continued to be an issue, and she stated that she didn't take any pictures inside her house because, "the picture would have been an absolute disaster." Her husband had his own medical issues but did not share in helping to keep the house in order; although she indicated that he was able to do some tasks. Maryanne, in contrast, was proud that she was eventually able to resume some household chores.

*At first, he (husband) did all the laundry, everything. I had to lower my standards considerably, but now I do all the cooking and all the laundry. -*

*Maryanne*

Driving was an issue that came up frequently with participants. Their concerns focused on not just the physical act of driving, but the level of independence that driving represented in the life of an adult.

*"Well why would I need to drive?" Well a sense of freedom. Not that I need to go anywhere, because I think it'll be difficult for me to try to get in and out of the car and trying to get the wheelchair or whatever. The changes, sometimes that it's hard to accept. - Daphne*

Lydia was able to drive, but it was limited. She previously enjoyed being able to jump in the car and drive through the countryside to visit her daughter in another state whenever she wanted to. Now that “do it yourself” option was gone, requiring her to rely on others.

*[The drive] is about four and a half hours, plus stopping. I did them myself. But now I have to rely on him [her husband] to take me there. And then I stay for a couple weeks, and then they come and get me. - Lydia*

Daphne also expressed some frustration in lifestyle changes that were limiting to her former autonomy and lifestyle. She was highly organized and kept craft, holiday decorations, and all-occasion gifts neatly stored in her basement. She took a picture of the stairway and talked about her frustrations. Due to her stroke, she was “forbidden” (by her family) to go down there because of the steep steps.

*They [husband and son] had cleaned the basement, so my son can move back down there. A lot of stuff had been moved or thrown away, so I don't know what's down there. Actually, I kind of do and it's kind of upsetting because a lot of it's gone. I actually did cheat one day. - Daphne*

Daphne “cheated” one day by going downstairs when she was home alone. She managed to get back upstairs, but couldn’t stand up, and had to call a neighbor to come help her. She eventually “confessed” to her husband and was told not to do it again. There was frustration, not only of physical limitations of one’s own body, but of loved ones who placed restrictions with good intentions.

In contrast, Florence anticipated that she would lose out on doing something that she enjoyed, traveling. But she was pleasantly surprised that she was able to continue her passion to travel. Continued travel was enabled by moving in with her daughter, who initially compensated for any functional or physical challenges Florence had. Her first trip after stroke was with her daughter, but she eventually began to travel with a group of friends. Many of the pictures that she shared and described were from a cruise she took between the interviews.

*I thought that [the stroke] would be the end of my traveling but has not been.*

*It's been way more. I've been traveling quite a bit since then. – Florence*

Changes in lifestyle, in some instances, included increased family presence and support. However, “support” was also restrictive at times. It was noted that several participants used words and phrases such as “forbidden,” “banned,” and not “allowed,” suggesting that these changes represented some frustrations and challenges to independence and autonomy. These changes in normal routines (Aim 3)

were sometimes quite drastic, such as moving from state to state. But even seemingly minor changes, like not being able to access a certain part of the home, were all significant in the lives of the participants.

### ***Impact on family and friend relationships***

The impact of the stroke on interpersonal relationships was evident across the sample. In relationships with parents, children, spouses, and friends, roles sometimes changed or became strained. Social ties were sometimes strengthened or weakened, and positive or negative relationships sometimes were altered in the lives of the women participants. Once again, there was often a shift in what was normal (Aim 3), and this subtheme reflected how relationships were impacted.

The women in this study generally reported good support from family and friends after their strokes. Sometimes they even seemed surprised at how much others did for them.

### ***Family***

For example, Evelyn's husband didn't initially recognize the signs of her stroke, but he became her strong supporter and advocate during recovery. His support was very meaningful to her.

*And my husband was fabulous. I mean, I can't believe he... he knew what to do because we... neither one of us had any connection with stroke whatsoever... - Evelyn*

Daphne became emotional as she recalled how much her family sacrificed to support and take care of her during her hospitalization and recovery.

*My son actually moved back home from the West Coast to take care of me ...my husband took all his PTOs, his time off and his vacation, so he could come to the hospital every day [started to cry]. - Daphne*

Delores and Florence both moved in with their daughters, and saw roles reversed as their daughters took care of them. Florence felt that she was capable of doing some things in the kitchen, but also admitted that she needed her grandchildren to assist with lifting and reaching things. When she tried to prepare something on her own and cut herself, she was embarrassed and tried to hide it from her daughter.

*... I cut myself, but I didn't tell her and I had my finger wrapped up. I had one of the fingers wrapped up or something, and she happened to see the blood in the paper. ... She had a fit! - Florence*

Florence did not openly express anger or frustration at being “banned” from cooking and chuckled a little as she told the story. She told the researcher that she was on blood thinners, which indicated that she understood her daughter’s concern about the cut and her overall well-being.

There were also changes in relationships that were not as positive. For example, after Delores stated that her daughter and mother provided positive support, she compared that to the actions of her aunt. She mentioned that her aunt was previously “like a mother” to her but became distant right after she had her stroke. In answering a question about how the relationship changed, she said:

*Although my aunt was sort of, I think, upset because I wasn't what I used to be, I kind of felt like we became apart during that time. But we've always been close. But something happened during that time. I don't know what. I guess*



*because I wasn't able to take care of my, do for myself like I should have. And I was living with her [at the time of her stroke]. - Delores*

Rosemary also had some negative experiences with family relationships. She felt hurt by the awkward reactions of her siblings. They criticized her, assuming that she could do more than she was able and apparently did not understand the range of physical and functional outcomes of stroke. Ironically, despite Rosemary's physical disabilities, she continued as the sole caregiver for her mother who has dementia.

*They [siblings] really didn't know how to - I guess they didn't know how to react to me. Some of them say, won't you try to do certain things? They don't know how hard I'm trying to do certain things. - Rosemary*

Evelyn and Lydia described how the stroke changed their marriages. They both stated that they remained married because of the stroke, but for different reasons.

For Evelyn, stroke changed the course of her marriage. She explained that prior to her stroke, she was driven by and focused her attention primarily on her career. The marriage had been struggling, and she was about to get a major promotion. But, after her stroke, she lost her career, and her life and marriage took a different path.

*I think if I hadn't had a stroke I'd be divorced now. [Interviewer: Umm, wow. Okay.] Because I was so hard... hard driving, hard charging. And I had taken a step back. [Interviewer: Umm. Okay. That's a good thing? To take a step back?] Yes I... I think it... it... it's a good thing for my health. - Evelyn*

Lydia also indicated that stroke may have changed the course of her marriage. She had bought a "very nice, very lovely" mobile home without her husband's

knowledge out in the country. She used it as an occasional “getaway.” However, she had been planning to move there on a permanent basis, leaving her husband. After the stroke, Lydia felt that she could no longer do that because of her post-stroke disabilities. She was reflective but resigned as she described the disruption in her plans.

*I bought a mobile home in [rural area] about five miles from my daughter and it's very nice, very lovely. All my things in it. And that was my getaway. But then of course in 2010, I had a stroke. [Interviewer: Right] And that changed everything. ...To move to there [now], I don't think I'll ever make it, because I can't leave [my husband]. Because we take care of each other. – Lydia*

### ***Friends***

In response to the question: *Tell me about how your friends responded to your stroke?* Overall, participants reported good support of friends, especially right after the stroke occurred. A number of participants also noted that “good friends” were there for them after the stroke. In some cases, they viewed friends’ supportive reactions to their condition as identifying “true friends.”

The role of friends was especially important to Joan, because she did not have any immediate family. She was very fortunate and appreciative of the strong support she received from her neighbors in her condominium, and friends near and far. She was also surprised at the extent to which others provided her with help. Speaking of one, she said:

*... [we] have been friends for 30 years, she came, she flew in. She's a lawyer and she said, "I can work from anywhere." She just packed herself up, flew*

*herself in here and stayed here and cooked for me and took care of things and stuff. ... I have more of a support network than I may have even ever been conscious of. And there are people I can count on, and I'm very grateful for that. - Joan*

Daphne, who had a large network of friends and was very active before her stroke, was worried that her wheelchair was a burden for others and was pleasantly surprised at the support she received. She stated that she was “blessed” with good friends.

*A lot of my friends do not mind my wheelchair, they don't mind putting that in the car or truck and taking me places...*

*They call up and take me out to lunch or they invite me to someplace, food festivals, somewhere; so I've got a lot of great friends. - Daphne*

Maryanne was pleased with the response of her friends when she first had the stroke, and that those relationships continued.

*Oh, they were wonderful. I got a big box of cards this big. I've kept them all. I never go back and look at them, but sometimes I think I will. But a lot of them came to visit me, and I thought that was nice. – Maryann*

Lydia noted that her friends were there initially, but since she was less mobile after the stroke, there was gradually less contact in person, and more contact by phone.

*They were all there. They'd come and see me, or they'd call. Most of them called, because it wasn't much to see. We called a lot. – Lydia*

Georgia also reported that her friends were supportive, but they initially treated her as if she were fragile. Once they realized she was going to be all right, they treated her as they always had.

*I think they were probably a little bit more, what you call it, what you call it, um helpful, or just kind of weary, I mean not weary, leery of doing anything that would hurt me. You know so they were just very careful, just treated me a little bit more fragile in the beginning, now they know that I can do it, they say tough [laughs]. - Georgia*

Daphne talked about one friend who did not seem to understand the effects of the stroke and made comments that were hurtful to her rather than helpful.

*...one of these days I'm going to have to call her out. She's the one that [said], "Oh come on, you can do that." No! I can't, I can't do this. I have limitations here. And she just sometimes makes me feel like a failure. Like I'm not doing enough. I'm just lazy or something. - Daphne*

Rosemary, Abby, and Florence, also described new friendships they had established after the stroke due to new connections with other stroke survivors. Abby and Florence had also moved to different states, which necessitated new friendships. For them the stroke did not seem to have any negative impact on making new friends in these new surroundings.

*I've been doing a lot, and then with the girls that I met at the stroke group. They're very supportive, and I've met a lot of new friends from there and they're committed to you. ... That's besides the meeting at [local hospital]. I've met a lot of friends there and a lot of friends at the church here. - Florence*

The subtheme of impact on relationships with family and friends reflected the complexities of social ties and relationships after stroke. Social ties may or may not be supportive, but in this sample, most reported supportive social ties with family and friends. There were a few social ties that were not supportive, but this was not the norm for this sample. In addition, continued friendships were common with these participants.

### *Summary of theme 2*

Overall, the beginning of a new chapter emerged as a major theme across the sample of participants. This theme related to Aim 3, which was seeking to describe how these women define normal life before and after stroke. For the participants, there clearly was a transition from what was normal life before to something different, something new. While physical changes were somewhat expected, participants were often surprised by the disruption in everyday functional activities like ability to express needs clearly to others, access a computer to connect socially or access information online, or even relax at home without safety concerns (i.e., the candle fire). Some experienced significant changes in lifestyle related to living situation and finances, and a sense of uncertainty about the future. Social roles within relationships were subject to change in positive and negative ways. In the cases where the stroke survivor was the parent, roles were often reversed. And while this may have been a necessity at the onset of stroke, the continuation of this reversal caused some frustration. In marriages, the more dominant role of the caregiving spouse was also a source of frustration. As these roles shifted (parent/ child, as well as spouses),

well-meaning significant others placed restrictions and contributed to a sense of loss in personal autonomy and agency.

On the other hand, this sample overall reported receiving a good amount of support, and there were no instances of abandonment or neglect from family or friends. Participants were often surprised and grateful at the sacrifices of family and friends. The impact of stroke was significant enough to change the course of marriages for two participants. There were challenges as well as benefits, as survivors adapted and adjusted in this new chapter of life after stroke.

#### 4.4.3. Theme 3: Meaning and Process of Recovery

All of the participants in the study discussed recovery as a process that occurred over time. They were asked several questions related to recovery, including: “Would you describe your improvements from stroke as a process of recovery or would you describe it some other way?” and “How do you think about yourself in terms of recovery?” All specifically described how they saw themselves in the recovery process and identified whether they felt they had achieved recovery and to what extent. There were differences among the participants in how they both described and experienced the process of recovery. In terms of speed of recovery, answers varied, as responses were fast, slow, steady or a combination of speeds. When asked if recovery had different phases or chapters, eight agreed. Florence’s answer was a definite yes:

*Yes, yes, yes. There's a point when you can't do anything, and then there's the point where you have to learn to try and do these things. You don't want help from other people, but you have to have help from other people. You're in*

*denial for a period of time, until you come out of that denial to keep moving on. There are chapters that you go through. - Florence*

Among key points in their comments, they noted that recovery has no definitive time period and is an individualized experience. Delores, at four years post stroke, felt that her recovery was still an ongoing process for her. So did Rosemary, at 10 years after that event. In contrast, both Georgia at 3 years and Evelyn at 15 years felt that they had recovered as much as they could. Such variations in participants' perspectives on what recovery means, and when it is reached, point out the complexity of this concept in the narrative data. As discussed elsewhere in this document, definitions of recovery are somewhat ambiguous in the literature, and have been described as including both subjective and objective components. In line with those findings, the complexity of recovery as a concept was evident across the narratives. Elements of Aim 1, describing women's experience of recovery, were addressed by this theme and its subthemes.

As the women described their recovery status and experiences, several subthemes emerged: A) challenges to participants in defining their recovery status or stage, B) the discrepancy in recovery time participants perceived that they needed vs. time allowed by professionals, C) the self-proclaimed importance to those interviewed of hard work and determination, and D) the goal of "getting back out there."

### ***Defining recovery status/stage***

The responses in regard to the question of whether or not they had "recovered" were interesting and diverse, and addressed Aim 1. When initially asked

the questions noted above, five women quantified their recovery in terms of a percentage ranging from 80 to 99%, and two (Florence and Delores) simply stated that they were fully recovered. These percentages appeared to be based on a comparison of what they used to be able to do before the stroke, and participants who described their recovery this way generally did so without being asked specifically to make that comparison.

Joan, who received prompt medical intervention, was treated with tPA (clot busting medication), which quickly restored a great deal of function. She was discharged after only 2 days in the hospital and with only mild residual deficits. At four months after stroke, she described her recovery as 85 – 90%. Evelyn, who required hospitalization as well as inpatient and outpatient rehabilitation, said that she slowly made progress over time. At 15 years after her stroke, Evelyn felt that she had recovered 99%.

*I... don't think there is any more recovery. I think I have recovered as much as I will. Umm... But, I'm satisfied with... with the recovery. – Evelyn*

Maryanne, at three years post stroke, described herself as already being 85 – 90% recovered. She had spent several months in inpatient rehabilitation, and received therapy at home as well.

*Well, I think I've made a good recovery and everybody says the same thing. They think it was a miracle, because they saw me when I had, had the stroke, during that period. - Maryanne*



Georgia (3 years after stroke) also described her recovery as a noteworthy 80%. She felt that she would not recover any further. She explained that her focus was on doing what she could to avoid another stroke.

*I think it's just I recovered significantly, but I think I've reached a plateau. And I think now, what I have to do is make sure that it never happens again; by trying to get my body in control, with the problems that I had before I had the stroke [obesity and high blood pressure] to not existing again. - Georgia*

Rosemary had significant deficits at the time of her stroke and required extensive hospitalization, as well as inpatient and outpatient rehabilitation. At the time of the interview, physical deficits in her arm and leg remained obvious. Ten years after the event, Rosemary still considered herself in the midst of stroke recovery. She had also participated in numerous stroke studies in the area, and was active in stroke support groups. As a result, she felt that she was continuing to benefit from the recovery resources that were available to her in the community. Rosemary did not use a percentage, but she stated that she was “in a good place” when describing her recovery.

*It's still in process, because you're always learning different things, different ways of doing things. - Rosemary*

Recovery was also described as periods of progress that were ongoing for some and cyclical for others. Participants noted periods of improvement in function, and some noted emotional changes as well. Notably, no one talked about losing any ground or a reversal in their progress post-stroke.

Daphne felt that, with her recovery, it was sometimes hard to see her progress from day to day, and she said it was “too hard” to quantify her recovery. Nonetheless, she realized that even small, positive changes were important. She also felt that recognition of one’s progress was important in building confidence and hope to keep going.

*Yeah, so it's little stages in just recognizing each little thing is a celebration that you're recovering, making progress.....Take baby steps for recovery, that's how you're going to feel better-- just a little added confidence. - Daphne*

Georgia also described a more continuous yet incremental progression as her way of thinking about recovery. When asked, “*Has your recovery had different phases or chapters?*”

*No, I think it's been a continuous slope. Just, you could walk a little bit more, a little bit longer, and you are more steadier. You could handle things a little bit more, you had more strength, your face appeared normal to people after a while. But it was just like a gradual..... climb. - Georgia*

Some women felt that being emotional or feeling depressed was, in itself, a phase in the process of recovery.

*[Recovery] was emotional in the beginning. When I used to sit here and just cry all the time, and, if somebody said something to me, I can cry. Sometimes it gets emotional when I have to talk about it, because at one point there when I was talking to you, I could feel myself getting filled up. But I had to bring it [emotion] back down. - Florence*

Most of the participants talked more about being on the “other side” of their emotional reactions to the stroke by the time they were interviewed. Rosemary was the only one who used the word “grieve” to describe this emotional response, but emotion and/or depression were common responses to stroke, as reflected in others’ reactions.

*There could be some times you have to - first of all, you have to grieve. To me, it's like a grieving (unintelligible) you go through. What happened to you before - get past that. Life goes on. Takes a while to get through that. That's why I say sometimes, you will be depressed. Go ahead and cry, and be done with it. -Rosemary*

Daphne shared an encounter that she had with a man who was concerned about his wife being depressed after stroke, and her lack of recovery. He complimented Daphne, because he saw her making progress and told her that she looked like she was doing well in her recovery. She explained to him how she had handled feeling depressed and was able to continue to move forward in her recovery.

*I felt like saying, Well I'm faking it kind of. [She laughed.] It's like, "Well no, there's a lot more to that." I said, "You can really embrace that depression and see how bad you're off, or else try to look at other avenues." - Daphne*

Defining recovery status and progression was variable and individualized for each person in the sample. Researchers have also noted that recovery is individualized and subjective (Bendz, 2003; Wiles, Ashburn, Payne, & Murphy, 2002), yet recognition of these individualized trajectories is often not taken into consideration in the healthcare community. Participants used a variety of elements in

describing what recovery meant to them. In contrast, the biomedical model has a narrower focus, creating a mismatch between what healthcare professionals acknowledge as progress and what survivors perceive or desire for better understanding of their experiences. Participants' ability to believe that progress was possible, regardless of a specific time frame was also significant in their ability to have hope for further recovery. Internal factors like hope and healing were reflective of the personal recovery framework, which, in contrast to the biomedical model, allows for more holistic aspects of recovery (Bennett, Breeze & Nielson, 2014; Jacobson & Greeley, 2001).

#### **Discrepancy in recovery time needed vs. time allowed by professionals**

Anger, surprise, and frustration were among the reactions interviewees expressed regarding the time allotted for recovery, as defined by health care professionals and the insurance companies. Women participating in this study believed that additional time was needed to support recovery. Being told that certain goals were met, plateaus were reached, or that insurance had run out was very difficult for a number of these participants to hear or understand, especially when they were still struggling with the deficits and disabilities of their strokes.

Georgia was faced with health insurance limitations on coverage for her stay while she was still an inpatient in a rehabilitation facility. She had to fight with the insurance company for a longer stay.

*... Because after a week they wanted to send me home.... I had to appeal. So, I didn't want to go home, because I knew I was going home to my mother, I*

*didn't want to go home and be dependent.....So I was able to stay there for a month. But it was ridiculous that I had to fight to stay that long. - Georgia*

Abby, because of her aphasia, often struggled in the interviews to find the right word. She also has difficulty with reading and dealing with numbers but continues to live independently and handles her own finances. She was disappointed that she was no longer able to get coverage for speech therapy.

*So it's hard - it's a process to do - there's a - the speech. I'm very frustrated with this. That's why I want to do it, but it takes money. So I need a place that is free to do this [provide speech therapy]. So that part of it - because I do my exercises. I can do my balance. I can do that. But the speech is the hardest for me, and I would love to get a job - even a little one [to have money to pay for therapy out of pocket]. Abby*

Abby was dependent on Medicare for health coverage, and given that her stroke was four years old, she was no longer eligible to receive speech therapy given the time post-stroke.

Daphne, who was still using a wheelchair at the time of our interview, was also very frustrated with the limits placed by insurance coverage. She was even told by the insurers that she should not bother to appeal, because the number of covered sessions was a hard number, and she would be denied.

*So somebody is sitting at a desk, doesn't realize that if you stop my therapy that you're stopping my progress. I'm going to start slipping back unless I do something else. And I don't think that's right! I don't think insurance has that right to tell me when ... You gotta wait until I'm recovered! I have a little more*

*progress before you can say, 'okay stop going.' So that was one frustrating part is that. - Daphne*

Evelyn was in her early fifties when she had her stroke. She was told by her therapists that therapy had come to an end.

*The [outpatient rehabilitation therapy] program was very good. Umm... I liked all... all the therapies, speech, occupational, physical. Had wonderful success there. So, one day I went in and umm... the girl said, "Well you're finished." I said, "What do you mean I'm finished." she said, "You did everything you were supposed to do. You're finished." I said, "But I'm not back to normal." And she said, "You've done as much as we could do for you." - Evelyn*

Evelyn tried to return to an executive position at her company, but failed because of her aphasia, and was fired. She wanted to continue working and found a minimum wage job that she could do to enable her to continue regaining her speech through interacting with others. She eventually began working as an accountant but did not have to talk much on the job. She found that working at a major department store during the holiday season allowed more practice with her speech.

*I think that [working at the major department store] more than anything helped with the aphasia and the speech... because I had to talk to customers.*

*– Evelyn*

Across the sample, participants discovered that their recovery process often extended beyond what traditional medical coverage allowed. Health insurance companies set limits on coverage that are, at times, based solely on number of

sessions or dollar amounts, and not on the individual needs of the survivor.

Participants in this study also indicated that rehabilitation professionals may have not been in tune with their own perceptions of recovery. This is consistent with researchers (Bendz, 2003) who found that when addressing goals, healthcare professionals focused almost exclusively on biomedical concerns, whereas stroke survivors were concerned with a combination of their medical needs as well as psychological and social concerns.

### ***Hard work and determination***

Each participant described herself as taking an active role in her recovery. They often explained how they pushed themselves and felt that their actions made the difference in the progress they made. Many continued to do whatever they felt was necessary to keep making progress, maintain health, or even prevent another stroke or other illness in the future. These data address Aim 1, relating to perceptions of recovery, but also supported Aim 2, in showing how these participants defined self after stroke.

Ten years after her stroke, Rosemary had worked hard to regain some of her physical function, and continued to do so. She got up 4:30 a.m. so that she could get ready to go to the gym, “almost every day of the week.” She used a city public transportation service for disabled individuals that was available at a reduced fee and provided door-to-door service. Rosemary also belonged to a gym that specialized in providing services for people with special needs. As she explained it, staying healthy was “her job.”

*I have to get up ... 4:30 in the morning, every morning, to get my bus that picks me up at 5:30 to get me to ... to the [specialized gym for people with disabilities] ...Because for me, it's a job. My job is to stay healthy. Because I had a stroke once, it's easy for me to have another stroke. - Rosemary*

Rosemary also explained that she was back home by 8:30a.m. to go on with the rest of day, which included taking care of her mother, who had dementia.

Several women used the word “determination,” and other words that conjured images of strength in their interviews when discussing recovery. Lydia described herself as “feisty.” She continued to exercise and participate at the Senior Center, and explained that, even though she felt her right arm and hand would not return to full function, she had to keep going.

*It's a couple days? of, "Oh God I just feel like doing nothing." But then I think, "Well, no gotta get out there. Gotta get out there." Try again. ... But then I got determined it wasn't gonna keep me down, so I just proceeded, and did what I could. The best I could. – Lydia*

When Maryann was about to be discharged from the rehabilitation facility, she knew she’d rather not have to use the wheelchair, so she took the walker that was sitting in the corner of her room (on her own) and walked the perimeter of the facility to prove to the staff that she didn’t need the wheelchair.

*I was trying to get up my nerve to use it [the walker], because I'm like, "They don't trust me," ... Yeah, I was determined, and if somebody told me I couldn't do something, it made me want to do it that much more. - Maryann*



Daphne used the word “stubborn” in describing how she pushed herself to keep going even when challenged. She fell down at home on four different occasions but described each event and the lesson learned so that she would not make the same mistake. Instead of beating herself up, she focused on the lessons learned.

*A lot of it is just the challenge every day is not to give up or even when you see the smallest improvement is an improvement. Now, like I said, I had fallen four times and every time was a stupid mistake. .... just become more stubborn, a little stronger. - Daphne*

Abby still has trouble spelling and coming up with exact words that she wants to use when she is writing 4 years after her stroke. Although it is a challenge, she continues to try hard. She was disturbed that the elevator in her building was not working for several days. She and a few other residents were able to use the stairs, but she found a tripping hazard on the stairs and wanted to warn others. We discussed a picture she had taken of a homemade sign that she had made and placed on the steps in her building.

*[Interviewer: So you made... did you write this sign?] Yeah. I put this here, and I wanted a "caution" for other people. [Interviewer: Oh. It's a plastic strip on the step, and it's broken.] ... So the thing about this, that because of the stroke, I can't spell. It took me a half an hour to go use the... dictionary. 'Cause I can't spell it right, you know. I can say 'caution,' but I can't do... I can't write it down. So finally, I had two dictionaries to do this. One's little and one's big. But finally I found it! - Abby*

Florence, as well as some others, reported pushing themselves to improve, so that they wouldn't be as much of a burden on their family members.

*No. I remember crying all the time, but I would tell myself that I had to get up from that chair, and I had to walk. I had to learn how to talk and write. I had to do all these things for myself, because I refused to be a dependent on my daughter. That's a lot of stuff to put on one person. ...I was a fighter, okay. I was determined. – Florence*

Determined, feisty, strong, stubborn, and fighter were a few of the adjectives that participants used to describe what it took for them to continue to make progress during recovery. Being able to adjust while pushing forward, despite disability or a life-altering event is also consistent with the concept of resilience (Sarre, et al., 2014). In addition to resilience, the sample illustrated some aspects of recovery as defined by the personal recovery framework (Leamy, Bird, Le Boutillier, Williams & Slade, 2011). That model includes concepts such as hope, which is the belief that recovery is possible, and empowerment, which includes being in charge of life and not being a victim. These internal factors were clearly apparent in this sample of survivors.

### ***Getting back out there***

In discussing their lives before stroke, participants described lives that were either busy or very busy. They were largely involved, active and socially engaged with others. Evelyn was the only one who stated that her life was consumed by her job, and that she had very little time for friends or social activities. Everyone else talked about an array of social activities, which included volunteer work based on their interests, as well as time out with friends and family. Social participation and

social engagement are important concepts in aging and stroke recovery, and are often linked with recovery outcomes, and overall well-being (Amarshi & Reid, 2006; Derosiers et al., 2005; O'Connell et al., 2001; Thomas, 2012). Where the participants saw themselves in terms of being socially active and engaged was something that they wanted to share in their interviews. They were initially asked to “tell me the story of your life,” and this often elicited rich, thick, data. Later in the interview, they were asked: “Thinking about your life, what things about it have changed since the stroke?” As such, the question from the interview guide typically encouraged some comparison of activity level before and after stroke. This subtheme also addressed aim 1, on understanding and defining recovery, but also spoke to Aim 3, defining normal life before and after stroke.

Daphne led a very busy life before her stroke and participated in many activities with a large network of friends. She was well known and liked in her community, and even stated that her morning walks were often disrupted, because so many people wanted to stop and talk to her. She took a picture of a sidewalk that was repaired in her neighborhood since her stroke and described with longing how she could not wait to walk on the new surface. Daphne described the challenges of getting back out there after stroke. Beyond the physical challenges, it was an emotional hurdle as well.

*And really, I think a lot of it too is just to suck it up and go out in public and do things, because people aren't going to feel sorry for you being in a wheelchair. - Daphne*

Daphne did get back to social activities out in the community with friends, and even went from avoiding phone calls to connecting with people on the phone and online to plan for involvement in events.

Being able to participate in church activities was very important to Delores, Florence, Maryann, and Rosemary, and they were happy to be able to return to engaging and, sometimes, contributing after stroke. Mobility issues often presented barriers, but ones that could be overcome. Rosemary now catches the mobility bus “every Sunday,” to go to church, and takes her mother with her. Initially, Maryann couldn’t get to her own church since she could no longer drive. But she was able to resume that activity when a friend volunteered to take her to his church.

*So I went to his church, and I adjusted miraculously. I like it. It's smaller and it's very different, but that's worked quite good. And they have activities sometimes, too. – Maryann*

Both Delores and Florence not only attended church but were also involved in work and leadership roles at their churches after stroke. Most of Delores’ pictures were of her church activities and her leadership roles. She not only returned to driving after stroke, but sometimes drove the church van to transport others. She was involved in several activities for children and adults, taking several pictures to describe these experiences. Pride and happiness were evident as she described all that she was involved in. As she shared pictures about a church group activity for older adults, she was asked: “Is that something that you also organize or you just attend?”

*As a matter of fact, I'm the, is it the president? (Laughs) I don't know how I get to be this stuff [in all of these activities]. No, the pastor, the pastor*

*organizes it. And when we first organized it, we only had about six people.*

*Now we have almost 40. - Delores*

Since Florence had relocated to a new state, all of her local social activities and connections were made after she had her stroke. In her new state, Florence did volunteer work in her church as part of the food SHARE program and had several pictures to show her involvement in helping to organize and distribute food to participants. She also participated in groups at her senior center, and local stroke support group. Between interviews for this project, she went on a cruise with a group of women who she socializes with in her community and shared pictures to describe the ship and her trip. Prior to the trip, she took a picture of the group of women who would travel together.

*We went there to have a greet and meet. She organized all our travel plans and everything. And a couple of ladies we did not ... I didn't know. To make sure that we all knew each other before we set sail, that Saturday before, we all went to her house. She had cooked this great big meal. - Florence*

Although Abby did not like living in her apartment building, she actively engaged with her neighbors, participated in social activities, and did volunteer work to help others. Abby took pictures of the communal dining area and a weekly event in which she helped to distribute food. She admitted that she rarely ate it herself because it was “cheaper” food” catered for “seniors.”

*They have volunteers pick up bread and stuff, and they drop it off [here]. So I volunteer for this, and they get bags, boxes and boxes of bread, and all other*

*things, and we put it on the tables [in the apartment building dining room]  
where the dinner does (goes). - Abby*

Lydia seemed to be the most frustrated about her social participation. She talked about how active she was before her stroke, and how that changed drastically. Before she had stayed busy and was active with her friends and grandchildren. Not being able to drive places on her own made a big difference. Many of her pictures were taken from her front and back porches, where she now spends time sitting. She took pictures of hummingbirds, her cats, and Amish people riding by in their horse-drawn buggies. These pictures represented her daily activities, and she talked about how much things had changed for her. She lives in a rural community and was not able to independently “get up and go” to visit friends, grandchildren, or to regularly participate in social outings. Instead, since her stroke, she goes to the senior center three days a week at 8 am to exercise and participate in various classes. She took pictures of an art class which she talked about with some skepticism, based on her lack of skills, but stated:

*...so I do it left-handed (because of the stroke). And I stayed in the little line. But that's not so great. But at least I get out, and I get to meet people. And I just enjoy it. [Interviewer: Great, great. I was gonna ask you how you feel when you're participating in that.] I feel rather stupid because I can't do much. But she [the teacher] said, "Don't worry about it. Just do the best you can, and enjoy it." So I do! I do it. - Lydia*

Rosemary found a new social group among other stroke survivors.

Participants from a local stroke group developed a tradition of going out to eat, and the researcher realized that Florence had referred to this same group.

*I belong to a - I call a group - of us, we call the Lunch Bunch. Every month we go to a little different restaurant. We've been doing this for three years.*

*[Interviewer: Nice.] So it just gives you an outlet - getting out and meeting people - not just meeting people, but going out and learning how to be sociable again. Once you start that again, it gets you out the house.*

*- Rosemary*

Getting back out and socializing with others in the community after stroke was a challenge that most participants faced and overcame. In some instances, they had to adjust and adapt to new activities or doing things in a different way, which again, illustrated resilience in the sample.

### *Summary of theme 3*

The meaning and process of recovery emerged as the third theme presented here. However, subsequent subthemes provided overlapping evidence relating to all three aims, as described below. Aim 1, the experience of recovery, was well illustrated throughout the theme. Recovery is a complex concept and was individualized for each of the women. Half were able to report a percentage score that represented where they felt they were in terms of overall recovery, and most of those scores were fairly high. Two others claimed a full recovery. While some stated that recovery had ended, others strongly felt that the process was still ongoing or open-ended as they lived their lives.

One source of frustration and anger during recovery was the lack of understanding and coverage allowed by the healthcare system. What was allowed did not match up to the participants' perceived needs, and priorities of healthcare professionals may have differed from those of the stroke survivors.

Analysis of this theme also highlighted that recovery required hard work, and participants believed that doing the work and having the right attitude, (i.e. being determined, feisty, stubborn) would gain positive results. As this subtheme emerged, there was also evidence for Aim 1, and also for Aim 2, relating to self-identity. These participants saw themselves as strong and empowered in pursuing their goals relating to recovery and their future lives. In addition, their comments reflected elements of recovery as defined in the life recovery and personal recovery framework models, as will be discussed further in Chapter 5(?) (Bennet, Breeze, & Neilson, 2014; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011)

Finally, within this set of subthemes, the notion of being socially engaged and participating in activities with others was also widely desired and appeared to be another measure of progress in the recovery process (Aim 1) Additionally as participants set goals and made progress in "getting back out there" after stroke, this touched upon aim 3, which is to define normal life before and after stroke.

#### 4.4.4. Theme 4: Self Identity

Examining self-identity, and the influence of stroke on it, was another key goal of this study. The purpose of Aim 2 was to determine how women experience self during the stroke recovery process and Aim 3 explored how women define normal life before and after stroke. Both of those aims are addressed here under the



major theme of self-identity, which arose empirically from the narrative data. Several questions were asked in relation to this topic. For example, participants were asked: *“Thinking about your life, what things about it have changed since the stroke?”* and *“Sometimes people who have gone through a serious health crisis are described as survivors. Do you think of yourself as a survivor? Please explain”*.

From narrative data in response to these and other questions, four subthemes emerged within this theme: A) a new normal, B) defining and refining self-identity, C) how others see me, and D) survivor status.

### ***A new normal***

The third aim focused on how these participants defined normal life before and after their strokes. The idea of a “new normal” was widely voiced in the sample. In making this connection, women who were interviewed still identified with their lives before stroke and compared ways in which elements of that life were the same or different. Calling this a “new normal,” which was voiced by most of the women participating, indicated some acceptance of what life looked like for them at the moment. Sometimes this also reflected a recognition that the prior “normal” was now perhaps out of reach. But for those who felt that they were still in the process of recovering, it represented what they saw as a temporary state.

*I'm not normal in the respect that I used to be like.... It's a new normal.*

*[Interviewer: Right. It doesn't look like things did before?]*

*No. Because I was not one to sit still. And I was involved in everything...*

*- Lydia*

Daphne described her situation as “my normal for now.” She was only eight months post stroke and anticipating more recovery. While struggling with accepting her current status as normal, she said she still wanted her “old life.” She wanted to be realistic, yet hopeful and hardworking toward making more progress.

*...sometimes you question it [acceptance of a “new normal”] though, as, "Okay, [Daphne] are you insane? Because this is your normal now." But in my head saying, "No, I don't want this to be my normal." I think that's what it is. My resisting to that. This is my normal for now... For now. Temporarily my normal, but eventually it's going to be something else. - Daphne*

This mixed view of “normal for now” was also echoed by Lydia, at 7 years post stroke.

*I have to leave it a normal as it is today. Not what it used to be, because then I'd go crazy... Normal is...I guess my life is normal as normal can be. - Lydia*

Rosemary challenged the notion that her life would be called anything other than normal. She believed it was not appropriate for anyone else to judge her life.

*So I'm just as normal as anybody else. I just have a little bit of - a little deficit, but I can work with that. I would dare them [people who have not had a stroke] be in my shoes, see how they would react. Then they can tell me what is normal. I'm normal! – Rosemary*

Joan found that her new normal includes a more keen awareness of “the fragility of life.”

*It's that this is a new normal, which is a not normal. I'm much more conscious of what can happen and get a little ping of a pain and I think, whatever. My*

*awareness is different, I think, about my own body and the fragility of life, I think. I'm just much more aware of that. I'm taking it as a positive thing. I think there's a new consciousness, but I'm not sure what all that means at this point. I'm not getting anxious about it. I'm peaceful about it, but it's real.*

*- Joan*

Florence gave her definition of normal, and, surprisingly, also compared herself to other stroke survivors.

*Normal. Being able to get up in the morning and go about your daily way. Doing what you want to do and being with other people and communicating and travel. [Interviewer: Would you describe yourself as normal?] Yes. ... For me, I think my life is pretty normal compared to other people who have had strokes. - Florence*

Evelyn shared how her life course was altered, and how normal would have looked for her if she had not had the stroke.

*I think that I would have been like a CEO [if] I not had a stroke, and I probably would be divorced. So, it depends on what you evaluate as a good thing. Would it be good to be a CEO? Yea, you'll have tons of money umm... Would it be good to get divorced? No, but if you're a CEO maybe it's not so bad. ... So, you make the best of what you have to do. – Evelyn*

Whatever life adjustments occurred after stroke were incorporated into the participants' daily lives and expressed as "normal," whether for the moment or for the rest of their lives. The concept of normal appeared to be fluid to reflect life experiences, in particular, the changes brought about by stroke.

### *Defining and refining self-identity*

During the interview, participants were asked, “Do you feel that you are the same person you were before the stroke?” Seven stated emphatically that they were not the same and went on to describe how they had changed. In addition, these responses moved well beyond the physical dimension. Throughout the interviews there were also comments that reflected how they saw themselves before and after their strokes. This subtheme provided evidence for Aim 2, defining self-identity.

Delores, Joan, and Evelyn all described slowing down after stroke as a positive change in their lives. Evelyn described herself as being very driven, and a type-A personality before the stroke event, always doing ten things at once.

*I'm very different. [Interviewer: Ummm, can you explain that?]. .... I was very... fast. I was speedy. Now I am extremely slow in everything I do. And I am much more... able to get along with my husband, because I'm not as quick to judge. So, I... I feel like I'm a better person in that regard. - Evelyn*

Interestingly, Evelyn felt that her self-proclaimed type-A personality was also the key to her recovery.

*That... that is the one thing that I want to get across to you. My personality had ... everything to do with my recovery. [Interviewer: Can you describe that more? ...] I was type-A, I was driven. - Evelyn*

Joan also felt that she was a new person, and that change was necessary for her health overall.

*You know I ... I'll... I can't go back to being that person, because that person had too much stress, and too much this, and too much that. And I've got to*

*change the conditions that may have caused the stroke. Which we don't know what caused the stroke, but umm... So, it's kind of a negotiating with yourself and also with the people around you, I think. - Joan*

Delores initially stated that she was the same, but later stated that she believed the stroke had given her a “different outlook on life” and given her a “second chance:”

*It has given me a second chance. Chance to do things a different...differently. A chance to do things a different way. Whereas, before I had the stroke, I might not have thought about what I was doing. But since I've had the stroke, it has kind of calmed me down, somewhat. - Delores*

Rosemary also spoke about having a second chance and being a better mother. *I think of after the stroke and where I was before where I am now. I just think it's a blessing, because it gave me a chance to be a better mom to my - to my two sons. Before that I really wasn't ... But now have a second chance to be a good mom to my boys. Which I say, I know I have. - Rosemary*

Sobriety, which occurred after the stroke, was also a big turning point for Rosemary.

*Actually, other than the physical, I'm a better person. The physical, of course, I mean ... I can't use my arm the way I want to. I don't walk the same, I don't talk the same. I think differently. Before the stroke, I had used ... I've used drugs, I did. I'm not that person anymore. No. - Rosemary*

After stroke, some felt they were more patient, tolerant, empathetic, and more grateful towards others.

*I think I have more empathy for people... I'm a little more symp ... and a little more appreciative that people are actually very kind when you have a wheelchair. They open doors for you. There's a lot of kindnesses out there. No, I'm not the same person at all. I appreciate my family a lot more for all they've done. – Daphne*

Maryann stated that her perspective on others had changed.

*I've gotten more tolerant of things, and tried to be more understanding of people and what they ... Not everybody thinks alike. So, I do think it's changed me. Probably for the better. - Maryann*

Georgia described how she had changed and felt that it was a mixture of positive and negative qualities.

*I feel that I'm more abrupt, so I ... You know, and other things. And so, no I don't feel I'm exactly the same person. I feel that I'm more grateful, more appreciative, but also, more, as I said, impatient. Maybe sometimes even rude. - Georgia*

Lydia also described some changes in herself after stroke.

*I was just grouchy and temperamental. Short patience [since the stroke]. - Lydia*

There were other aspects of self that women mourned as a loss or were working hard to regain. During the interviews Abby often referred to herself as an “artsy person,” and took time to show the researcher projects that she had done in the past, as well as current work, and took pictures of her artwork. Even though she was lacking some fine motor skills in one hand after her stroke, she challenged herself by

learning zentangle, a craft which required drawing an intricate series of patterns to create art.

*And I've had a lot of... artsy stuff myself over the years, so I'm trying to see if I... I did basketry, felting. So I'm trying to do [see] if I can still do some of this. So I discovered that I can do certain things, you know, to do this [zentangle]. – Abby*

Daphne talked about how she was always fashionable and took a picture of her boots to share her thoughts on this aspect of self. She was always known for her boots, and she mourned the fact that she could no longer wear them or be “fashionable.”

*Oh my boots. I love wearing boots. I have all kinds of boots. Short, tall, whatever .....I miss wearing my boots, I really do, because I only can wear my tennis shoes... I miss wearing my boots. Being fashionable, because this is my fashion right now. Shorts and a t-shirt. – Daphne*

Georgia saw herself as being more vulnerable because of the stroke, and felt that this would be a barrier to having an intimate relationship.

*Well it's funny, I'm single, I wouldn't mind dating again, but it would not even occur to me to do that, because I felt that I would be very vulnerable. I couldn't really fight anybody off, I couldn't run away. So if I went somewhere out, and someone's interested in talking to me, I just wouldn't do it, because I didn't feel comfortable going out with a male person and not being able to take care of myself. – Georgia*

Researchers have noted that social identity is vulnerable in stroke due to the abrupt changes in appearance, function, social roles, and other changes (Anderson & Whitfield, 2012; Becker, 1997), with these changes being primarily negative. In this sample, the majority of the women stated that they were a different person after the stroke, but several noted positive changes. Some even talked about what they had gained, such as a new perspective on life or a better appreciation for others. There were also some losses, such as no longer feeling that the label of fashionable would fit or feeling too vulnerable with men to chance an intimate relationship.

### **How others see me**

Self-identity also includes how we think people see us or want others to see us. Several of those interviewed emphasized how it was important that other people realized they had changed. During the second interview, Joan described that she needed people to know that she was different, so that they would not continue to have the same expectations of her as extremely busy, driven, and overworked. She believed that letting people know her limitations would protect her from their unrealistic expectations and protect herself from falling into the same pattern of trying to do too much.

*I've... it... this is kind of a conflict in a way because people are... people see me and they... I look like myself ... and I'm busy trying to discourage them from thinking that I am the same person that I was. I mean in a self-defense way. - Joan*



Rosemary, who battled drug addiction before her stroke, wanted her family to see that she was stronger after the stroke and able to take care of both herself and her mother. She did not want them to pity her or tell her what to do with her life.

*I let them know exactly how I feel and why I'm feeling it. I guess they thought, because I had the stroke, you could beat up on me. But you can't do that. I'm just as strong - I'm stronger than I was before. I guess, I kind of shocked them so now they - they back off. - Rosemary*

Rosemary was also in a new relationship, the first since her stroke, and was both happy and empowered in knowing that her boyfriend looked beyond her disabilities. She had a huge smile as she explained how he saw her.

*I just have some deficits. But my friend [boyfriend] doesn't look at that. You know, he told me, I don't see this [pointing to her weak arm and leg]. I see what's in here [pointing to her heart] - Rosemary*

At one point, Evelyn, who had previously worked as a high-level executive, took a minimum wage job. As her communication and cognitive skills improved, she eventually began professional work again as a tax accountant. It was of great significance to her when her neurologist asked her to do her taxes, because Evelyn saw this as confirmation of her recovery. She shared this story with pride.

*That... that's [that means] a lot to me that she had... when I was telling her [the neurologist] that I was.... I had taken a job as a tax accountant, and she had this special umm... situation one year, and I thought it was really great that my stroke doctor asked me to do her taxes. - Evelyn*

Some participants were concerned that others would see them as a burden, not only to family members, but also friends or others in the community. For example, Daphne worried about the views of others who saw her taking too long to cross the parking lot or do her shopping.

*My son will take me to the grocery store once in a while, and I feel so badly because I have to walk across that walkway. But I'm delaying traffic, because it takes me forever to walk.....But I've gone to the mall in a wheelchair and stuff, and I feel like a lot of times, I feel like I'm imposing on that person that has to push my wheelchair. They don't mind, but I still feel bad. – Daphne*

Lydia wanted her daughters to see her as independent when she spent time alone at her mobile home retreat, which she had paid for and furnished before her stroke. She looked forward to being alone there, but both daughters would worry and check on her. She felt that they called too much.

*Yeah. All my daughters on the phone. My other daughter's on the phone, "Can I (you) just leave me alone please?" - Lydia*

Abby wanted people to see her as someone with aphasia and was assertive in letting them know. She was often frustrated that others still did not make considerations for her communication deficits when speaking to her. She tried to explain to her building manager that she had aphasia and wanted the manager to call her daughter to discuss her personal finance and business matters.

*...and I say, I have aphasia. But she would interrupt me, and say certain things... Can you just nicely say? [Abby wanted the manager to listen to her]*

*Can you [not] finish what I'm trying to say? But she wasn't doing that. [The manager wasn't listening to her]. - Abby*

How others viewed them was important and served as one of the elements of self-identity. Just as the participants had to re-define and refine their own sense of identity, they also were concerned about how family and friends viewed them, and often had to advocate for themselves. They wanted others to be aware of what they were capable of and, at times worried that others had misperceptions about their capabilities or wishes. This subtheme provides additional evidence in relation to Aim 2, self-identity.

### ***Survivor status***

Historically, the word “victim” was more commonly used to describe someone who has had a stroke. However, that term conjures up an image of someone in a passive, helpless situation. That passive status was more common for stroke in the past, when treatments were not as available or as successful. In contrast, the word “survivor” conveys a more positive image of overcoming adversity. The researcher asked each woman if she considered herself a survivor. All answered yes, and the discussion below reflects how they explained what that meant for them.

It is important to note that several of those saying “yes” accepted the survivor label, but with some reservations. A few used it in a very literal way. For example, Daphne said that she initially felt like a victim, and that accepting the status of survivor took her some time. Her responses also may have been influenced by the fact that both her mother and sister had died from strokes. She took a very “minimalist” view of survivorship.

*I guess [I am a] survivor, because you realize people do die from strokes. So somehow I survived that. So yeah, I consider myself a survivor. Yes. In the beginning I had a really hard time accepting that, because I felt like I was a victim. The stroke did this to me, look what I'm left with... So yeah, since I didn't die I survived that. – Daphne*

In further reflection on Daphne's response, her statement, "the stroke did this to me," has a suggestion of anger, and/ or other emotion. In light of the fact that stroke took two close family members, she may be reluctant to diminish the seriousness of the stroke diagnosis in any way.

Georgia's response to being asked if she described herself as a survivor was also quite minimalist.

*I guess so. I didn't die. I'm still functional. – Georgia*

Joan, who had also survived breast cancer, took a somewhat more positive tone. She said she preferred the word survivor to victim. However, she had some mixed feelings about the word "survivor" as well.

*Survivor ... feels more heroic than I feel about myself. You know I... I'll pat myself on the back for doing what people told me to do. I did the therapy that I was supposed to do, and now my arm is better. So that's good. I deserve credit for that, but I'm not, you know a hero. - Joan*

Narrative from other interviews indicated that some saw themselves as survivors in a way that was more empowering. When asked to explain what "survivor" meant, Delores replied:

*Well, to have gone through a stroke and to be able to come back, and do the things that I used to do. Maybe not in the same way, but being able to think about.... at least knowing that I have the ability to do the same thing I used to do. I think of myself as a survivor. – Delores*

Florence felt that being a survivor demonstrated how strong she was.

*I feel as though I am a survivor, because I was strong enough to fight to get myself out of the situation of not being able to talk [and] not being able to walk. – Florence*

Abby used the word survivor to describe herself before she was asked about it. She reflected on difficult life circumstances that she had come through. In addition to the stroke, she survived cancer, addiction, and a traumatic childhood.

*Because of the stroke and the struggle [health and other life issues], I'm better because of - my life was not good. So I'm a survivor, I guess. - Abby*

Evelyn, who had also survived major heart surgery years before her stroke reflected on being a survivor throughout her life. She defined being a survivor as:

*Taking whatever situation umm... presents itself and discovering ways to ... make that lifetime situation work for you in whatever it is that you're in. - Evelyn*

Being a survivor had various meaning for the participants in this sample. For some, it was a label that was empowering, and for others, it was a label that they accepted with reluctance or negativity attached. A few women reflected on various conditions that they survived over the life course and saw this as one other hurdle but not an impasse.

#### *Summary of theme 4*

The fourth theme, self-identity, and the many subthemes that emerged addressed dimensions of Aims 2 and 3 and provided more insight as to how this sample experienced self and faced a new normal. As participants adjusted to life after stroke and forged ahead, life had changed in minor or even major ways. As the women in this sample were generally pleased with the progress and trajectories of their recovery, they were able to adjust to their current situations and most still used the term “normal” to describe themselves and their lives. They took steps to define and refine who they were, as well as how they wanted others to see them. Finally, the term survivor was preferred over victim, but its meaning carried many nuanced variations.

#### 4.5. Auto-photography

Use of various visual elicitation methods, including auto-photography have been well established in gerontology and aging studies research (Balmer, Griffiths, & Dunn, 2014; Oliffe & Bottorff, 2007). It has also been shown to be useful in studying concepts such as, identity, and changes in self over time (Harper, 2002; Kohon & Carder, 2014; Phoenix, 2010). Participants are asked to take pictures to represent the phenomena that are being studied.

This researcher performed a successful pilot study, described earlier in this dissertation, in order to determine if this method seemed to be a good fit for this study and population. Auto-photography was used as a facilitator in the narrative data collection process, to augment the interview process, and to provide an opportunity to encourage communication triggered in a different, more expansive and personalized

way. Additional description of and the rationale for use of auto-photography was described in detail in the methodology chapter, but the results of its use in this project are outlined here.

In this study, participants were asked toward the end of the first interview to take pictures that helped them to tell their story about their stroke and recovery experiences, which could then be discussed during the second interview. The researcher also contacted participants by phone between the two interview visits to ask how the photo project was going and to see if additional time was needed to take pictures. In some instances, participants asked for additional time, and appointments were adjusted as needed. All participants received the same instructions and agreed to take pictures.

In the two instances where the women did not take pictures, they did not tell the researcher that they did not any take pictures until the researcher returned to their homes for interview two. Their reasons for not taking pictures differed. Georgia was not feeling well during that interval between sessions and rescheduled her second interview appointment. During the second interview, she explained that she “*wasn't really enthusiastic*” about taking the pictures, and decided, “*I just didn't see anything that I wanted to photograph.*” During her second interview, she talked about something that she could have photographed. Without a specific question from the researcher, she stated that she could have taken a picture of her car parked on the street. She then talked about driving, resuming driving, and what that meant to her. The other participant, Rosemary, also rescheduled her second interview appointment, so that the second visit was five weeks later. Her stated reason for not taking

photographs appeared to be worry in regards to taking the camera with her outside of her home. She wanted to take pictures at an outdoor track that she could not get to during the cold weather, and to the gym, where she went regularly, as these were important sites to her stroke and recovery story. In the second interview, when the researcher asked if there were any pictures she might have taken, Rosemary described several pictures that she could have taken, both outdoors, and at home, that would be meaningful to her experiences.

Georgia's lack of picture taking was not entirely a surprise, because she was somewhat hesitant in participating in the study at all. She originally said that she was not interested in being in the study but changed her mind. Her overall affect was rather flat, and she talked a lot about her negative emotions and resentment in having to take care of her mother, a situation that pre-dated her stroke. However, Rosemary's lack of pictures was surprising, because she was very enthusiastic about participating in the study and using the camera. On the first visit, she even told the researcher that she wanted to take a picture at the outdoor track, and that she was thinking of other pictures. In Georgia's case, her lack of enthusiasm for the project was likely a red flag. In getting her consent to participate, she certainly had an opportunity to stop then or at any time. In hindsight, I might have gotten a better result if I had talked to her more about her doubts and whether she felt that she would be able to complete the task.

These were the first and third participants. For subsequent participants, I made sure that during follow-up calls about the photography project, I was explicit in asking them about use of the camera and taking pictures between visits. As to the



reasons for why there was hesitancy, there does not seem to be a well-defined explanation, other than they chose not to do it. The majority of the sample took pictures, but this method may not be appealing to some as a matter of personal choice. In the pilot study preceding this dissertation, all 5 participants took pictures. In reviewing other studies that used auto-photography (Butowski & Buetow, 2010; Kohon & Carder, 2014) sometimes participants did not follow through with taking pictures, and no explanation was provided. For example, in a study by Kohon and Carder (2014), of 47 low income older adults participating in a study on housing, only 31 chose to do auto-photography and complete a second interview. In future studies with this methodology, it would be wise to encourage full participation with the auto-photography portion of the study. Researchers would need to make phone calls to give reminders, to check participants' statuses, and to expect that participation may be less than 100%.

Of the eight participants who took pictures, only one took pictures that were limited to the inside of her home. Everyone else took pictures both at home and in the larger community. Abby and Florence took the camera with them when they traveled and had pictures from their trips. They also took the most pictures; Abby took 93, and Florence took 51. Other participants took from 7 to 28 pictures. Abby and Lydia (28 pictures) had more difficulty with word-finding due to their aphasia as compared to the rest of the sample. Both would often search to find the words they wanted to say, and pictures helped them in getting their messages across. In addition, Abby was very concerned about the apartment building where she was living and took multiple pictures to show the poor conditions that were of concern to her.

Participants were asked to critique the use of auto-photography. All rated the process as easy and an appropriate research method to use for stroke survivors.

Evelyn thought that it would be best for people who had trouble communicating, but not as necessary for those who could talk without difficulty. Daphne felt that it was extremely useful in reflecting on how her life was before and after stroke, even though it was somewhat upsetting to her to see what she was no longer able to do.

*...and the whole picture taking thing, this whole project was bittersweet- in catch 22? Double edged sword? Whatever the cliché is. – Daphne*

Given that the narrative was the primary data for this project, the content of the pictures was not analyzed, but some observations were noted. The women generally took pictures of personal items, places in and around the home, places in the community (church, gym, senior center, coffee shop, doctor/therapy offices), participation in social activities, and traveling. Joan took a picture of the Starbucks where she was standing when she had her stroke, and the doctor's office that she walked to for help. A few took pictures of family and friends, and two (Abby and Joan) took pictures of their doctors/ therapists. Two women (Joan and Daphne) mentioned that they sat down and made a list of pictures they wanted to take, before getting started.

There is sufficient research that supports use of auto-photography as a methodological tool. As a researcher, I found that it was a beneficial tool, and that there was rich, thick data in the discussions surrounding the photographs that were taken. Although auto-photography was not a good fit for two of the participants, it was useful for those individuals who chose to use it. It seemed especially helpful for

people who had aphasia and was also useful in sharing concerns about living conditions. There are some people who will be automatically excluded from a study with auto-photography, given any motor or visual deficits, and it would be important to weigh whether to limit the sample to only participants who could operate the camera. It would also exclude participants who were put off by the task of taking pictures. Visual methods have also been used successfully with children and adolescents, so it is not necessarily difficult, but may require a certain degree of creativity and abstract thinking in using pictures to convey uncomfortable information. Consequently, as a researcher, I would use auto-photography in future research studies, with the knowledge that being selective and careful in matching the method to the desired sample and study goals is key.

#### 4.6. Summary of Chapter 4

This chapter began by describing the role and background of the researcher and acknowledged unique aspects of her background that were relevant to the study, In addition, it acknowledged her role as an active participant in the interview and described use of the reflexive process to maintain the soundness of the data. Then participant information and demographics were provided, along with a brief review of the interview process.

Themes and subthemes that emerged from the interviews were described in detail and illustrated by the words of the participants from the sample. Stroke was sudden and disruptive to normal life. At the time of stroke, there was often a desire to continue life as usual, and, in some instances, even waiting overnight before seeking medical care. Results reflected a common public health problem in the overall lack of

recognition of stroke symptoms by participants, families and friends. The onset of stroke also signaled a new chapter in life, in which changes occurred not only in physical appearance and function, but in lifestyle and relationships as well. Having to move or face financial difficulties were challenging, but being restricted in normal, everyday activities was a source of frustration and anger as well. In this sample there was generally good support of family and friends. However, role reversals (parent/child; dominant spouse) and loss of autonomy and personal agency sometimes occurred as the result of a well-meaning loved one.

The concept of recovery was complex and individualized for participants. Multiple factors including time, comparison to pre-stroke function and current activity level were of importance to participants in their subjective definitions of recovery. However, it was problematic to them that health insurers and healthcare professionals were often not on the same page as survivors in terms of conceptualizing recovery or meeting treatment needs. Most participants felt empowered and believed in their ability to make progress and recover through hard work and determination. They were further motivated to become socially active and engaged, and also saw this as a component of the recovery process. Finally, women found it necessary to refine and redefine who they were, and how others saw themselves. This often required self-advocacy in informing others, letting go of some aspects of former life and embracing a “new normal.”

The method of auto-photography was reviewed and found to be a good tool in facilitating rich, thick, data during participant interviews. Although two participants

chose not to use photographs, they still provided some insight into their recovery experiences.

## **Chapter 5: Discussion**

### **5.1. Introduction**

This study used a qualitative phenomenological approach to learn more about the experience of recovery after stroke for women age 60 and older. In this chapter, there is a brief review of findings for each of the three aims, based on the narrative data that was described in detail in chapter 4. These reviews are followed by a discussion of findings in relation to the literature and theoretical perspectives of the study. In addition, other factors not identified by the aims are identified and linked to literature. Next, limitations and strengths of this research are discussed. Finally, there is a section discussing implications and recommendations for stroke rehabilitation practices, public policy, and future research.

### **5.2. Review of Findings and Related Literature**

#### **5.2.1. Aim 1: Recovery**

*To describe women's experiences of recovery after stroke.*

Recovery began at the pivotal point during the onset of stroke and continued as a process that had ended for some and was open-ended for others. The women's assessments regarding completion of recovery were not clearly tied to the amount of time since the stroke. Many participants readily compared their current statuses to their capabilities and actions before the stroke and came up with a percentage of recovery achieved or another subjective description to denote their perception of progress toward that goal. Notably, there was a mismatch between what the healthcare system allowed for care and services to recover from stroke and these

survivor's perceived needs for care. These narratives also emphasized hard work, determination, and getting back to an active life as components that the sample identified as keys to recovery. The subjective views of recovery, as described by study participants, were misaligned with those of the healthcare system, which utilizes primarily a limited biomedical model.

According to the literature, recovery, as it applies to stroke, has both subjective and objective components (Becker, 1998; Gargano, & Reeves, 2007; Mozaffarian, et al., 2016). There is ambiguity in the literature in defining the concept of recovery (Bennet, Breeze, & Nielsen, 2014; Collier, 2010; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Results of this study confirm the complexity of recovery as it was experienced by the women in this sample. From the medical perspective, recovery is fairly straight-forward, and is measured in terms of cure from illness and restoration of physical and cognitive function (Lai, Duncan, Dew, & Keighley, 2005). Recovery is also viewed under the medical approach as an outcome or an endpoint. However, the criteria used in the medical model has been seen by some as inadequate in addressing the complexities of recovery as defined by individuals (Bendz, 2003; Doyle, 2002; Wiles, Ashburn, Payne, & Murphy, 2002). Based on the narratives from the women in this study, recovery has many layers and is somewhat individualized in terms of time, trajectory, and personal factors. Participants also viewed recovery as a process, rather than simply as an outcome.

The literature provides another approach to recovery. In contrast to the medical model, the field of mental health has promoted models of recovery that are more holistic and individualized in focus. Although stroke is not a mental health

condition, other researchers (Bennet, Breeze, & Neilson, 2014) have proposed use of a mental health recovery model in rehabilitation as more suitable for use with individuals who have long-term health conditions, such as those resulting from stroke. Leamy and colleagues (2011) developed an empirically based conceptual framework of personal recovery based on a synthesis of 97 papers. This personal recovery framework provides a more holistic approach to defining recovering and would seem, based on findings here, to be suitable for recovery from stroke. The framework identifies recovery as a journey with 13 characteristics. It also names 5 recovery processes, which uses the acronym CHIME: connectedness, hope and optimism about the future, identity, meaning in life, and empowerment.

Participant narratives in this study aligned well with the personal recovery framework in several ways. First, connectedness, which included peer and support groups, support from others, relationships, and being part of a community, was well represented by this sample. “Getting back out there” to participate in being part of a community was an important goal for participants in the study, and most were involved in some community social activities (stroke support groups, senior centers, church, apartment housing activities, or travel groups). Support and relationships from family and friends were significant in the narratives as well.

Second, hope and optimism about the future was well represented in these data. Some participants expressed hope in their expectations for continued recovery, and several women, including Rosemary who was 10 years post stroke, believed that recovery for her was an open-ended process. Hope was also echoed by Daphne, as she noted that she had a ways to go, but even her “baby steps” were a source of



“celebration,” as she moved toward recovery. Third, findings from this study were consistent with the process of rebuilding positive identity, which is included in the CHIME framework. Further discussion on identity appears later in this chapter.

Fourth, the framework referred to the process of meaning, which included spirituality, meaningful social roles and social goals, and rebuilding life. Evidence of the process of meaning in this study included participants’ discussion of social roles and goals, as well as some reflection on spirituality. Daphne and Maryann specifically mentioned healing:

*I prayed that I'd be able to walk again. Then, I didn't worry about it. I just decided that it was in God's hands and that was the best way to handle it. I didn't worry at all, and I didn't get depressed. - Maryann*

Fifth, the importance of empowerment was consistent with the findings of this study. Participants saw themselves as active agents in recovery and perceived that their hard work and personal characteristics, such as, determination, feistiness, and strength, were essential components in the recovery process. Overall, findings from the current study were consistent with many of the characteristics of recovery as described by the personal recovery framework. In particular: recovery was seen as an active process, individual and unique, and as a life-changing experience that can occur without professional intervention. The last point about professional intervention is especially powerful, because in stroke recovery the interaction with professionals may occur soon after the stroke event and then stop, even though the survivor is still recovering. This was consistent with the experiences of many women in the current study.

In addition to the mismatch in defining recovery, the findings of this study also highlighted the divergent views regarding the recovery time allowed by professionals and the healthcare system vs. the perceived time needed by survivors. Participants expressed in their interviews their frustration and anger when services ended or were denied in the face of survivors' perceived unmet needs. Their sense of not always being empowered in the rehabilitation setting was consistent with other research that indicated that survivors are often denied an active role in goal setting and assessment of recovery after stroke (Bendz, 2003; Gerlacher, et al., 2013; Medved, 2011). After being dismissed from formal rehabilitation services, participants in this study often developed their own ways of working on deficit areas. Examples included Evelyn, a former executive working a minimum wage job to continue work on her speech skills, and Rosemary, using a fitness gym for the disabled to continue working on her weakened limbs.

Dismissal from rehabilitation services is not always based on the judgement and discretion of the therapist, but instead based on the rules of the health insurers. This remains an area of frustration and concern for the participants in this study, as well as across the healthcare system. Survivors are left to depend on their own resources but many lack adequate resources or know how to best address their ongoing needs.

#### 5.2.2. Aim 2: Self-Identity

*To determine how women experience self during the stroke recovery process.*

Sense of self and social identity are often studied in stroke survivors, because survivors are vulnerable to change, given the abrupt and sometimes life-altering

impact of stroke. Individuals may have sudden changes in appearance, physical abilities, communication and/or cognitive skills. In addition, they may lose independence, as well as important social roles, and suffer fear and uncertainty about the future (Anderson & Whitfield, 2012; Becker, 1997; Charmaz, 1995). With stroke, these changes can all occur in an instant. Some researchers have reported primarily negative changes to social identity after stroke (Anderson & Whitfield, 2012; Becker, 1997; Haslam, et al., 2008). In contrast, findings from this dissertation demonstrate that the women in this sample generally held a positive point of view regarding self-identity. Some felt that they had gained a new perspective on life and were even a better person than before, including the ability to embrace a new normal. All accepted the label of survivor, some reluctantly. But others enthusiastically saw this label as a new “badge” of strength. Factors in maintaining social identity after stroke found in the literature include biographical disruption (Becker, 1993, 1997; Bury, 1982) and resilience (Sarre, et al., 2014) which were both supported by the findings of this research.

In terms of theoretical perspectives, continuity theory represents the idealized view of aging as a linear process, including an expectation that self will remain consistent across the lifespan (Becker, 1997). In the event of a life altering condition, such as stroke, the life course is disrupted, according to the theory. This disruption generates an uncertainty about the future, and there is an innate desire to re-create order. According to this theory, in order to restore a sense of identity, one must be able to reconcile changes in oneself, be able to set appropriate new goals, and envision how life will continue into the future (Becker, 1993, 1997; Bury, 1982;

Satink, 2014). Based on their own perspectives, the women in this study were generally successful in being able to envision moving forward, and clearly most had done so. Seven of the women emphatically declared that they were a different person, yet they were able to embrace this change, and declare a new normal. Joan and Rosemary are examples from the sample of being so strong in sense of self identity in that they were assertive in letting others know that they were now changed women. They both wanted to be sure that others did not overlook their new identities. In addition, several believed that their changes in self-identity were for the better, such as Evelyn's shift away her role as a driven executive to settling down in her marriage. In cases where there was loss of function or lifestyle changes, women in this sample found ways of accepting these changes and/ or working around them. Abby is an example of someone who had to move several times, face financial challenges, and live with the challenges of aphasia. Yet, she was engaged in social activities, made new friends, and did some volunteer work while attempting her goals of finding paid work.

Resilience is another important concept in the continuance of self-identity, and is related to the concept of continuity, as described above. Resilience, which has also been referred to as the disability paradox, is the ability to have a good or even better than expected life despite living with some condition or ongoing loss (Bujick, et al, 2014; Clarke & Black, 2005; Sarre, et al., 2014). It can also be described as being able to adjust to these circumstances and can be applied to life after stroke. Sarre and associates. (2014) conducted a systematic review of 40 qualitative studies on resilience after stroke. In their review, they found that the nature of stroke

recovery was not temporally bounded, and that changes occurred over time. This meant that adjustment was not a single event, and that adjustment to disability and recovery were interwoven over time. Sarre and colleagues identified 3 factors that were important in resilience. All three of the factors were consistent with the findings in this dissertation and are further described below.

1) Personal characteristics: This included, determination, a positive outlook, hope, and inner strength. Several of the women in this study used words such as “determined,” “strong,” and “feisty” to describe themselves and their experiences. Abby described herself as “optimistic,” and Maryann and Rosemary talked about their positive attitudes.

2) Individual adjustment practices: This referred to practical and mental strategies that the survivors employed in order to adapt. Examples from the data in this sample include Evelyn getting a job in a department store so she could continue to improve her speech by talking to customers; and Abby taking a zentangle class to improve the function of her hand in order to get back to following her longstanding interest in creating art.

3) Relationships: This referred to family and friends, as well as support groups. There was acknowledgement that some social relationships might be weakened or not helpful in providing support. Florence, Delores, and Abby all cherished the relationships with their daughters and benefitted from their support. Not all women in the sample received adequate support from family and friends. Although Rosemary had many siblings, they were of no support to her, and were rather critical of her ongoing debilities after her stroke.

### 5.2.3. Aim 3: Normal life

*To establish how women define normal life before and after stroke*

Life after stroke presented challenges that ranged from minor to major.

Physical and functional ability, lifestyle, and relationships were all subject to change. There was disruption in life as known before stroke, which required adjustment and acceptance. Much of the literature on stroke experiences and recovery focuses on disability and loss of normalcy. Several studies reported that stroke survivors saw themselves as abnormal right after stroke (Hartigan, O'Connell, McCarthy, & Mahoney, 2011; Satink, et al., 2014). This self-assessment of abnormality continued over time for some or eventually shifted to acceptance as a new normal (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004; Hartigan, O'Connell, McCarthy, & Mahoney, 2011; Satink, et al., 2014; Schreck, 2013; Theadom, Rutherford, Kent, & McPherson, 2018)

Not surprisingly, Hartigan, O'Connell, McCarthy, & Mahoney (2011) found that new stroke survivors (4-7 days after stroke) did not see themselves as normal and wanted to return to the same status as before stroke. Participants in the current study were not asked if there was a turning point as to when they used the term "normal." Evelyn, however, did mention that for her there was a change over time.

*I was normal, then I was abnormal or below normal, and I came back to normal. - Evelyn*

A semantic synthesis of multinational qualitative studies on impact of stroke found that survivors initially had hope of returning to pre-stroke normal status, but some eventually realized it was not possible (Satink, et al., 2014). These researchers

found that survivors struggled with discontinuity of body, self and roles. In their research, “I am half a person” was a subtheme which reflected the frustration and disappointment of no longer being whole even years beyond the initial onset. Satink and colleagues (2014) noted that survivors were in flux between the old, new, and future selves, and “normal” was seen as their pre-stroke status. Daphne and Lydia’s narratives reflected the struggle of reconciling normal in comparison to past, present and future self. Daphne referred to “normal life right now” as she described daily life which required her husband’s assistance in the shower. Her goal was to be independent.

*So that's my normal life right now, but to me that's not normal. Hopefully it won't be normal later on that I can take my own shower, get my own food, get myself up. – Daphne*

Lydia explained that her definition of “normal” was, “*not what it used to be, because, then I'd go crazy.*” Lydia and the other women in this study redefined “normal” to label the circumstances of their daily lives.

The narratives revealed that all participants in this study professed that they were normal, despite any changes that may have occurred since the stroke. Certainly, many of those changes were not initially welcomed. But achieving a “new normal,” concurrent with their sometimes-ongoing functional and physical recovery, ultimately seemed quite positive to many of the participants. For some, this new normal was seen as temporary, as they hoped for continued recovery, ending in another new normal. For others, a new normal appeared to signal an acceptance of and adjustment to a permanent change that could be economic, physical, social, or in another domain.

Several researchers have identified a new normal as a phenomenon in stroke recovery (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004; Schreck, 2013; Theadom, Rutherford, Kent, & McPherson, 2018) and this was consistent with the findings of this dissertation. In a recent longitudinal qualitative study in New Zealand by Theadom et al. (2018), 54 stroke survivors and 27 significant others participated in interviews at 6, 12, 24, and 36 months after stroke (52.7% of survivors were women). They found that establishing a new normal was an evolving process, and that survivors had to reconcile and adapt to old versus new abilities and adjust expectations accordingly. Theadom and colleagues found that, at 6 months, expectations were often unrealistic, but that survivors had typically adjusted by the one-year mark. The sample in this dissertation was smaller and only two women were less than a year post stroke. It is interesting to note that Daphne, who voiced the most frustration with reconciling past and present “normal” status, was only eight months post stroke. Joan, at four months post stroke, did not express the same level of frustration, but in comparison to Daphne, she was fully independent and had minimal deficits. The majority of the sample in this dissertation were well beyond the one-year mark and were not hesitant in professing a “new normal.” Lydia, at seven years post stroke, does stand out, however, as she also expressed the bitter reality of her new normal. It is important to note that Daphne, who had relatively more physical limitations, and Lydia, who had more social limitations, may have struggled more because they were less satisfied with their new normal.



#### 5.2.4. Other factors related to recovery

Overall, the narratives in this study reflected relatively positive attitudes toward recovery and adjustment to life after stroke. The results of findings in qualitative studies can not be generalized, because the samples have specific characteristics and are typically smaller than quantitative studies. However, there is benefit in identifying what does or does not align with current literature. In conjunction with discussions of recovery, there were other dimensions reflected in this sample and the narrative data that are important to note.

*Age and aging.* A study by Faircloth, Boylstein, Rittman, Young, & Gubrium (2004) included primarily male veteran stroke survivors (57 men and 1 woman; mean age 66.18). These researchers found that, for their participants, stroke was seen as a normal component of aging and part of the biographical flow rather than being a disruption. Faircloth and colleagues concluded that survivors in their study accepted and even expected stroke as they aged. This point of view was not expressed by the participants in this dissertation. The women in this study were not expecting stroke to happen. However, the oldest participants in this study noted aging as a contributing factor in some of her physical limitations. Lydia (78) noted that her mobility deficits were due to both stroke and aging. Joan (78) questioned whether her efforts to recall words was from stroke or aging. Delores (70) also commented on her memory problems.

*“And I think that's a sign of getting old too. I mean, aging.” Maryann (78) stated: I think that getting tired at night is because of the stroke. Maybe it's because I've gotten older?” - Delores*

Other women in the study (ages 60 to 69) did not refer to aging in relationship to recovery. Abby (69) reluctantly used the word “elderly” to describe herself but did not refer to age in terms of her recovery. She, in fact, was upset that she was in senior housing and felt that she did not belong there, because she was different (i.e. able to walk and to be more active) compared to the other residents.

*Time since stroke.* The amount of time since stroke had occurred varied widely among the study participants, from four months to fifteen years. There appeared to be no difference in recall of the events that transpired at the time of stroke based on the number of years since the stroke event. Lydia did not have much detail of her stroke because she passed out when it occurred. However, Rosemary and Evelyn, at 10 and 15 years respectively, recalled many details from that day, as did the others. It is also important to point out that adjustment to stroke and acceptance of a new normal was not bound by time in this sample. Joan at four months used the term “new normal” to describe her status, whereas Daphne, at eight months struggled a bit more in accepting that label.

*Social Support and social ties.* Prior research had identified having a supportive social network as an important positive factor in stroke recovery. Positive well-being, hope, empowerment, sense of belonging and connectedness have all been identified as benefits of social support after stroke (Brunborg, & Ytrehus, 2014; Ch’ng, French, & Mclean, 2008; Cross & Schneider, 2010; Erikson, Park, & Tham, 2010; Sarre et al., 2014). In addition, family and friends provide physical assistance, emotional support, and advocacy for stroke survivors (Anderson & Whitfield, 2013; Ch’ng, French, & Mclean, 2008; Erikson, Park, & Tham, 2010). All of the women in

this study had good support in their daily lives. When asked if they felt they received adequate support from family and friends, all replied, “yes.” Seven women lived with family members who provided physical and/ or emotional support. Two women lived alone but described strong support from friends (Joan) and family (Abby). Although Georgia lived with her mother, she described herself as the primary caregiver and noted a great deal of conflict and dissatisfaction with that arrangement. In her case, her friends were her source of social and emotional support. In addition to family and friends, six of the women had attended stroke support groups. Of those who attended, Rosemary and Florence identified the support groups as a significant factor in their lives and made new friendships that extended beyond the group meetings.

Researchers have shown that participation in stroke support groups is beneficial in normalizing the stroke experience through interaction with others in similar circumstances (Anderson & Whitfield, 2013; Ch’ng, French, Mclean, 2008).

*Spirituality and religiosity.* Researchers have found that, for some stroke survivors, spirituality and religiosity are associated with less emotional stress, less anxiety and depression, and increased hope (Cross & Schneider, 2010; Giaquinto, Spiridigliozzi, & Caracciolo, 2007; Johnstone, Franklin, Yoon, Burris, & Shigaki, 2008). The narratives of six of the women in this study (Florence, Daphne, Delores, Rosemary, Maryann, and Lydia) reflected some degree of spiritual belief or religious practice (i.e., mentioning prayer, faith, God, higher power, healing, blessing, Church attendance and involvement in church activities), and those factors played an important role in the lives of four of the ten women in this study. Overall, spirituality

and religiosity is perceived by many participants as a factor in their overall positive outlooks.

*Other factors.* Narratives were also examined for differences related to race and ethnicity, socioeconomic status, and education level. There were no meaningful differences or patterns related to these factors in this sample

### 5.3. Limitations

There are some limitations to this study. The sample size is small but not inconsistent with other qualitative studies based on a phenomenological approach (Patton, 2002). The sample also has a specific profile. Most of the women in the study have college degrees and live in a large metropolitan area. Consequently, their experiences may not be reflective of the experiences of women with dissimilar backgrounds. In addition, the study only includes women who were willing and able to operate the camera, excluding anyone with more pronounced motor or vision deficits. Furthermore, although these participants were not asked to provide information on their socioeconomic status, the researcher was able to observe neighborhood quality and homeowner status. One participant lived in a low income apartment building, and all other participants were homeowners or lived in family owned homes. Consequently, there was limited representation of participants on the lower end of the socioeconomic scale. Another limitation was the researcher's limited experience in conducting qualitative interviews and analysis using a phenomenological approach.

#### 5.4. Strengths

The study offers several strengths. This study adds to the literature and fills a gap on stroke recovery for older women. In fact, there is only one other qualitative study on women stroke survivors in the United States (Hilton, 2002), and only a few from other countries. The sample was racially diverse with 50% minority representation. The use of qualitative methods was also a strength, as it was seen here as an effective means of obtaining in-depth data on the lived experiences of participants. In addition, the study included the use of an innovative technique, auto-photography, with stroke survivors.

#### 5.5. Implications and Recommendations

##### 5.5.1. Implications and recommendations for stroke rehabilitation

The narratives of older female stroke survivors in this study revealed some conflicts in their perceptions and experiences relative to healthcare professionals. The participants in this dissertation study expressed frustration at the conflict between their expectations for support in their recovery versus what was offered in terms of health and rehabilitation services to meet those needs. Across this sample, there was also a belief that hard work and determination were necessary to make progress in recovery. Survivors felt empowered and motivated in doing what was necessary to make progress, including taking the initiative to find or fund needed services. They also believed that they were capable of being active agents in setting and achieving goals for their lives and for recoveries.

These views represent a gap in perceptions, communication, and expectations between the stroke survivor and relevant professionals. The stroke survivor may not receive the services that are deemed essential by the stroke survivor based on their personal needs and may leave the rehabilitation setting feeling dissatisfied and disappointed. In addition, they may continue to live with unmet needs due to rules limiting services. Since the rehabilitation specialists are trained in the medical model, they may be unaware of the gap that exists for many stroke survivors between their goals and expectations and those of the rehabilitation professional. Therefore, healthcare professionals would benefit from additional training to heighten their awareness in order to provide a more individualized [and less standardized] approach to recovery. Changes could be incorporated in two ways:

- 1) Educating rehabilitation providers through existing training programs (i.e. university settings and professional development offerings), Educators could introduce a modified version of the personal recovery framework to inform treatment approach and to provide greater consideration for stroke survivors' individualized needs.
- 2) Within the existing clinical interaction, rehabilitation professionals could be more intentional in identifying expectations and goals in collaboration with the stroke survivor. In addition, since providing discharge information is standard procedure, as part of this process, care providers could recommend practical resources and solutions to continue to work on personal goals outside of the rehabilitation setting. Thereby reinforcing the

concept that recovery is a continuous process, even when formal treatment has ended.

#### 5.5.2. Implications and recommendations for policy

Rising healthcare costs have been a national concern for many years, with national health expenditures at \$3.3 trillion in 2016, and projected to rise to \$5.7 trillion by 2026, according to the National Health Expenditures report from the Centers for Medicare and Medicaid (CMS.org). In addition, adequate coverage for medical needs is a challenge for many individuals and families (Emanuel, Glickman, & Johnson, 2017). Imposing standardized limits on specific rehabilitation and medical services provided to stroke survivors is one way to address the challenge of exorbitant cost. However, these limits can place added stress on survivors, which was indicated in the findings of this study. Another example of a limitation that aging adult stroke survivors may have faced, up until 2018, is the Medicare therapy cap (CMS.gov). There has been a longstanding issue with a Medicare therapy cap that placed an annual dollar limit (most recently \$2010 per year in 2017) on combined outpatient services of speech therapy and physical therapy, regardless of diagnosis or services needed (Bunis, 2018). This meant that, if a patient needed both speech and physical therapies, the amount allowed for each was half of that total dollar figure, or that there had to be some decision made as to which modalities to prioritize. So in some instances, a stroke survivor and rehabilitation team might have to prioritize whether it was more important to treat walking or talking or to offer more limited services for each. It is possible that participants in this study could have been negatively affected by this cap. Fortunately, the Medicare cap was removed as of

January 2018 (Bunis, 2018). However, similar limitations in service and coverage occur for other health insurers, and many stroke survivors are still facing these challenges.

Policy makers should listen to the concerns of stroke survivors and be open to suggestion for solutions to meet their needs. For example, there could be considerations to cover group therapeutic programs in the community that may be beneficial, but less costly, and are typically not covered.

#### 5.5.3. Recommendations for future research

Recent studies have indicated that women have worse physiological and psychosocial stroke recovery outcomes than men (Di Carlo, et al., 2003; Fukuda, Kanda, Kamide, Akutsu, & Sakai, 2009; Gargano & Reeves, 2007; Persky, Turtzo & McCullough, 2010). However, the women in this study were independent in the community and generally functioning well. In order to gain a broader perspective on recovery outcomes for women, future research can expand in terms of study participants, but also in how outcomes are measured. A qualitative study with women who have more pre-existing (socioeconomic, educational) or stroke-related challenges would be beneficial. Interviewing participants who live in a senior living community with different levels of care might provide an opportunity to study individuals with higher levels of disability. Another gap in knowledge is how women with socioeconomic challenges experience recovery, so a study that included women in this group would be beneficial. There still remains some ambiguity in the literature on recovery, and particularly consideration of a non-medical recovery model for stroke, so this would also be another area of potential research. The women stroke



survivors in this study as a group reflected positive self-identity, however, studies in this area are limited in the United States, and with only one other known qualitative study regarding lived experience for this group. Additional qualitative studies regarding self for women recovering from stroke would be of interest. Finally, in regard to measuring recovery outcomes, researchers should re-examine outcomes that are being used in comparing men and women. These measures have been primarily based on the medical model, but future studies should include outcome measures that are client centered and reflective of stroke survivors' personal goals.

### 5.6. Conclusions

This study utilized qualitative methods and a phenomenological approach to examine the recovery experiences of women stroke survivors who were 60 and older.

Although stroke was a sudden, unexpected and disruptive life altering event, the women in this study were able to continue on, despite changes and challenges, into recovery. Overall, the sample identified changes in self-identity, including the way they saw themselves and the way that others saw them. Many were also able to experience hope, empowerment, and to resume social activities in the larger community. The women in this study were generally able to reconcile this new and altered identity and body through resilience, adaptation, and acceptance of a new normal. They saw themselves as survivors, and not victims of stroke. Their experiences of recovery were unique, and many were able to quantify their perceptions regarding their current level of recovery in some way.

The narrative data revealed that the concept of recovery is complex and was, for this sample, an individualized phenomenon. Unfortunately, there is often a

mismatch in how stroke survivors conceptualize recovery in comparison to the professionals and the healthcare system that are responsible for provision of services. Consequently, a non-medical model of recovery was identified as more in alignment with the recovery experiences of the women in this study.

## Appendices

Appendix A	Cognitive Screening
Appendix B	Pre-Screening Inclusion Questionnaire for Eligibility
Appendix C	Interview Guides


## Appendix A: Cognitive Screening

# VAMC SLUMS EXAMINATION

Questions about this assessment tool? E-mail [aging@slu.edu](mailto:aging@slu.edu)

Name \_\_\_\_\_ Age \_\_\_\_\_

Is the patient alert? \_\_\_\_\_ Level of education \_\_\_\_\_

____/1 ____/1 ____/1 ____/3 ____/3 ____/5 ____/2 ____/4 ____/2 ____/8	<ol style="list-style-type: none"> <li>1 1. What day of the week is it?</li> <li>1 2. What is the year?</li> <li>1 3. What state are we in?</li> <li>4. Please remember these five objects. I will ask you what they are later.            Apple      Pen      Tie      House      Car</li> <li>5. You have \$100 and you go to the store and buy a dozen apples for \$3 and a tricycle for \$20.            1 How much did you spend?            2 How much do you have left?</li> <li>6. Please name as many animals as you can in one minute.            0 0-4 animals      1 5-9 animals      2 10-14 animals      3 15+ animals</li> <li>7. What were the five objects I asked you to remember? 1 point for each one correct.</li> <li>8. I am going to give you a series of numbers and I would like you to give them to me backwards. For example, if I say 42, you would say 24.            0 87      1 648      1 8537</li> <li>9. This is a clock face. Please put in the hour markers and the time at ten minutes to eleven o'clock.            2 Hour markers okay            2 Time correct</li> <li>10. Please place an X in the triangle. </li> <li>1 Which of the above figures is largest?</li> <li>11. I am going to tell you a story. Please listen carefully because afterwards, I'm going to ask you some questions about it.            Jill was a very successful stockbroker. She made a lot of money on the stock market. She then met Jack, a devastatingly handsome man. She married him and had three children. They lived in Chicago. She then stopped work and stayed at home to bring up her children. When they were teenagers, she went back to work. She and Jack lived happily ever after.</li> <li>2 What was the female's name?      2 What work did she do?            2 When did she go back to work?      2 What state did she live in?</li> </ol>
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\_\_\_\_ TOTAL SCORE

SCORING			
HIGH SCHOOL EDUCATION		LESS THAN HIGH SCHOOL EDUCATION	
27-30	.....	NORMAL	..... 25-30
21-26	.....	MILD NEUROCOGNITIVE DISORDER	..... 20-24
1-20	.....	DEMENTIA	..... 1-19

\_\_\_\_ CLINICIAN'S SIGNATURE

\_\_\_\_ DATE

\_\_\_\_ TIME

SH Tariq, N Tumosa, JT Chibnall, HM Perry III, and JE Morley. The Saint Louis University Mental Status (SLUMS) Examination for detecting mild cognitive impairment and dementia is more sensitive than the Mini-Mental Status Examination (MMSE) - A pilot study. *Am J Geriatr Psych* 14:900-10, 2006.

## Appendix B: Pre-Screening: Inclusion Questionnaire for Eligibility

This questionnaire will be used in the initial conversation with potential participants to determine if inclusion criteria are met. This will typically be conducted on the phone, but may occur in person.

Inclusion Questionnaire for Eligibility		
Date:		
Name:		
What is your age?	60 or older	
When is your birthday (to confirm)		
When did you have a stroke?	> 6 months	
How old were you when you had a stroke?	55+	
I will provide a camera to use for the study. Do you think you will have any trouble using it?	Able to use camera	
I will conduct 2 interviews with you. They may last about 1 to 1 ½ hr. Will you have the time to meet?	Available time	

## Appendix C Interview Guides

### **Session 1: Interview Guide**

#### **A. Background and demographic questions**

- First name ONLY
- Year and month of birth ONLY
- Please tell me about your family.
- Do you live alone?
- What is the highest grade of school you completed?
- Tell me about employment in your life.

*PROBE (as needed): Do you or did you work? What kinds of work have you done?*

- How would you rate your health right now? Would you say that your health is excellent, good, fair or poor?
  - Do you have any medical problems that might interfere with participation in this study?

#### **B. Life before stroke**

- Tell me the story of your life: Whatever occurs to you about it.... Perhaps you can start with where you were born and where you grew up.....

*PROBE (as needed): What activities were you involved in? Who did you interact with (family/ friends?)*
- Thinking about your life, do you divide it into times before the stroke and since the stroke?
  - Are there any other ways you divide your life?
- Before the stroke, how would you rate your life?

- Were you very happy, pretty happy or not so happy?
- Can you please describe that for me?
- How would you rate your health just before the stroke? Would you say that your health was excellent, good, fair or poor?
  - Could you describe any health related worries or limitations you had then?

### **C. The stroke event**

- Can you please tell me the story of your stroke?
 

*\*\*NOTE: Allow participant to talk in as much detail as she would like. The questions that follow will be used to guide the discussion, if the participant does not cover a particular element of the experience.*

*PROBE (as needed) Include hospitalization experience?  
Rehabilitation experience? Was rehabilitation helpful?*

- ☐ Did you have limitations right after the stroke? (if yes)  
What were they?
  - *PROBE: What was that like for you?*
- ☐ Did you have any changes in emotions? Any depression?
  - *PROBE: What was that like for you?*
- ☐ Are there things that you feel are still not working right with your body or mind?
- ☐ Which of the changes you described after the stroke have improved since then?
- ☐ Tell me about your family's response to your stroke.

- *PROBE: (responses/ reactions immediately after the stroke and now)*

☐ Tell me how your friends responded to your stroke.

- *PROBE: (responses/ reactions immediately after the stroke and now)*

- **Thinking about your life, what things about it have changed since the stroke?**

*PROBE: (activities, social interactions, work, attending church, home chores, driving, transportation.)*

#### **D. Recovery and “normal”**

- Would you describe your improvements from your stroke as a process of recovery, or would you have some other way to describe it?
- For you, is there a difference between recovery and “getting better” after the stroke?
- How do you think about yourself today in terms of recovery?
- **Has your recovery had different phases or chapters? \*\*If yes:** please describe them  
**\*\*if no: Please describe what your recovery (or the period of change since your stroke) has been like.**

**\*\*NOTE: Allow participant to talk in as much detail as she would like. The questions that follow will be used to guide the discussion, if the participant does not cover a particular element of the experience.**



- ☐ Has the speed of recovery been slower or faster at different times?
- ☐ How much do you feel you have recovered?
- ☐ What have the doctors said about your recovery?
- ☐ Has there been anything unexpected about changes or improvements after the stroke?
- ☐ Has this process been emotional for you? Tell me more about that.
- Do you think you received enough social and emotional support from family and friends initially? What about now?
  - Were there times when you needed more help and support early on? What about now?
- What does “normal” mean in your life now?
 

*PROBE: Are things normal or are they not quite normal? Why do you say that?*
- Where do you think you are now in terms of getting back to “normal?” Please explain in detail.
- Sometimes people who have gone through a serious health crisis are described as survivors. Do you think of yourself as a survivor? Please explain.

## **Session 2 Interview Guide**

### **A. Sharing photographs**

Tell me about your photographs. Describe what is in each picture and explain why you took it and its meaning for you.

[Ask follow-up questions as needed]

### **B. Recovery and Normal**

- In the first session, I asked you questions about recovery. Is there anything else that has occurred to you about recovery and how it relates to your life today?
- In the first session, I also asked you about the word “normal.” Is there anything else that has occurred to you about “normal” and how it relates to your life today?
- Do you feel you are the same person as you were before your stroke? Explain.
- Is there anything else that you want to share about your stroke experience?

### **C. Auto-photography feedback**

- How was working the camera? (allow narrative)  
On a scale of 1 to 5, where 1 is very difficult and 5 is very easy, how would you rate the ease of taking photographs?
- How easy or difficult was it to decide which pictures to take? (allow narrative)  
On a scale of 1 to 5, where 1 is very difficult and 5 is very

easy, how would you rate the ease figuring out which pictures to take?

- How comfortable did you feel about taking photographs?  
(allow narrative)

On a scale of 1 to 5, where 1 is very uncomfortable and 5 is very comfortable, how would you rate your comfort level with taking the photographs?

- How helpful were the photographs in telling your story? (allow narrative)

On a scale of 1 to 5, where 1 is not helpful at all, and 5 is very helpful, how would you rate the helpfulness of using photographs?

- How did you feel about using this technique, auto-photography? (allow narrative)

On a scale of 1 to 5, where 1 is hated doing it and 5 is really enjoyed doing it, how would you rate using this method?

- Explain why you think auto-photography **is or is not** an effective tool in doing research on women who have had a stroke.

Thank you so much for your participation!

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