# OCCUPATIONAL ADAPTATION IN A STROKE SELF-MANAGEMENT PROGRAM: A MIXED METHODS STUDY

#### A DISSERTATION

# SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN THE GRADUATE SCHOOL OF THE TEXAS WOMAN'S UNIVERSITY

SCHOOL OF OCCUPATIONAL THERAPY

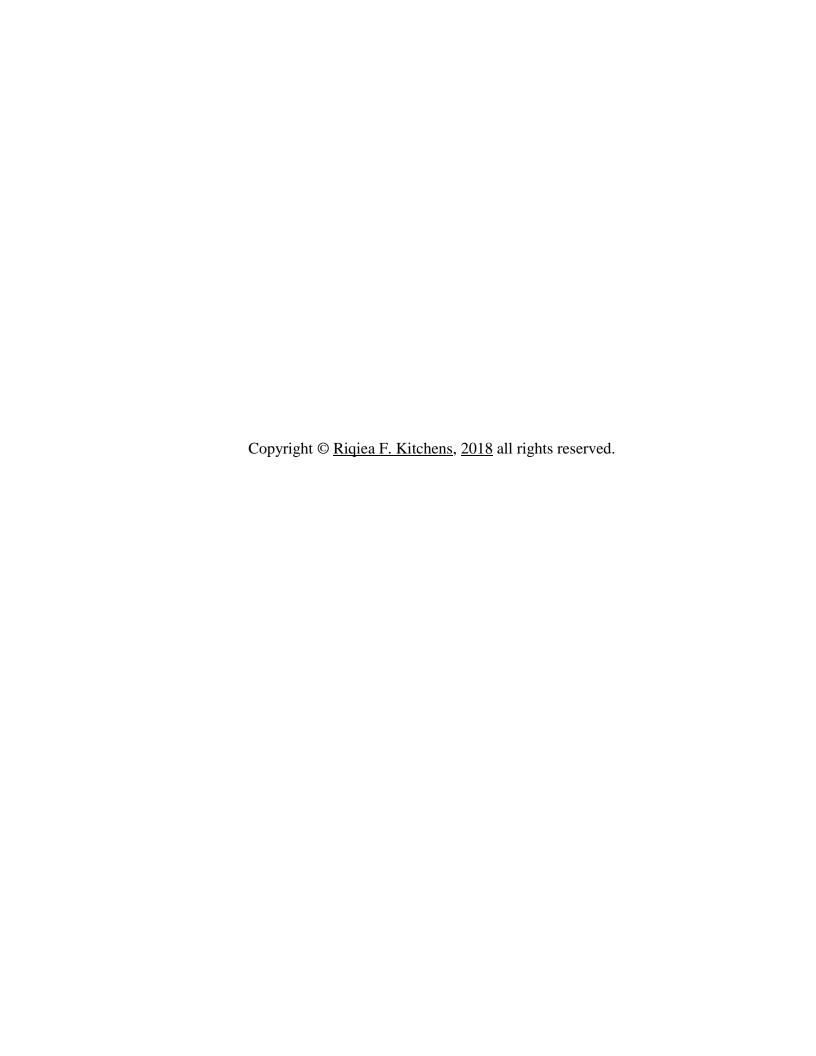
COLLEGE OF HEALTH SCIENCES

BY

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#### **DEDICATION**

This dissertation is dedicated to my family. To my parents Fay and Frank Kitchens and my siblings Jeremy, Brett, and Fione, you all have been my rock during this process. To my Sims and Kitchens families thank you for your unconditional love, support, and prayers during this journey. In the memory of my grandfather C.W. Sims who never had the opportunity to learn to read or write but always believed his grand baby would someday become a doctor. I hope I've made you proud.

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#### **ABSTRACT**

#### RIQIEA F. KITCHENS

#### OCCUPATIONAL ADAPTATION IN STROKE SELF-MANAGEMENT PROGRAM: A MIXED METHODS STUDY

#### DECEMBER 2018

Self-management programs that provide education, practical skills training can promote lifestyle and behavioral change and reduce the risk of recurrent stroke. Occupational Adaptation describes the use of meaningful occupations as a means to achieve adaptation in a desired role or occupation. This research explored the occupational adaptation process and personal experience of stroke survivors who participated in a stroke specific self-management program. Self-efficacy theory, selfmanagement programming, and the theory of occupational adaptation served as the foundational theoretical concepts for this study. A sequential explanatory mixed methods design was used to analyze data gathered from a sample of five participants who were stroke survivors and had participated in a stroke self-management program. The study was conducted in the outpatient clinic of a large urban community owned hospital system. Quantitative data collected included the use of two standardized assessments, the Health-Promoting Lifestyle Profile II (HPLP II) and a stroke specific version of the Perceived Medical Condition Self-Management Scale (PMCSMS). Descriptive statistics were conducted on the quantitative measures. An interview guide was developed to collect the qualitative interview data. The qualitative data were transcribed, coded, and

analyzed for themes. Four key themes were identified: knowledge acquisition promoted a need for change, behavioral change and adjustment in routines, increase proactivity and personal responsibility, and physiological and emotional changes in health. Areas of data convergence included an increase in communication with health care providers and information seeking, increased engagement in productive and leisure activities, increased involved in novel tasks and activities, improved perception of personal health, confidence in caring for themselves, and managing stroke related aspects of health. All five of the participants discussed areas of improvement with self-managing aspects of their stroke-related health, such as an increased monitoring of vitals and adherence to medication regimen, as well as lifestyle modifications that included nutrition and an exercise regimen. The study is the first of its kind to explore the stroke survivors' experience in a stroke self-management program through the lens of occupational adaptation.

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#### CHAPTER I

#### **INTRODUCTION**

#### **Background**

Recurrent stroke occurs in one in four persons who have a stroke (Roger et al., 2012). Persons who have multiple risk factors are at even greater risk of having another stroke (Go et al., 2013). Stroke is one of the leading causes of disability in the United States (Centers for Disease Control [CDC], 2013) and affects 7 million people in the United States (National Stroke Association, 2018) and recurrent strokes increased the rate of mortality and disability (Kurukulasuriya, 2006). The estimated direct and indirect costs associated with stroke including healthcare, medications, and loss of work productivity costs the United States an estimated \$36.5 billion annually (Go et al., 2013).

The Healthy People 2020 initiative suggests the risk of developing and dying from cardiovascular disease, including stroke, can be significantly decreased by addressing lifestyle factors such as healthy diet, physical activity, controlling blood pressure and cholesterol, and smoking cessation. Self-management education is a comprehensive program that aims to improve the overall health of an individual through education, behavior change, and experiential learning. Self-management education addresses the multiple factors that can impact persons living with chronic disease with the goal to improving health and minimizing complications from the illness. Survivors of stroke can also benefit from this type of education.

A person who has had a stroke can experience physical and psychological effects that may result in loss of roles, increased burden of care, and decreased quality of life (QoL). Persons may experience paralysis, and changes in thinking, memory, sensation, speech, and behavior (National Stroke Association, 2018). In a systematic review conducted by Hendricks and colleagues (2002), only 15% of persons with stroke regained full motor function. This suggests that approximately 85% of survivors will continue to experience the effects of stroke in some capacity for the remainder of their life. Self-management education provides skills training for the individual to learn how to live healthy to manage the risk factors related to stroke and the long term changes that may occur following a stroke.

Many factors have been identified as contributors to increased stroke risk. While some factors can be modified, others are not preventable. Those factors include age, gender, race/ethnicity, family history, and prior stroke or TIA (National Stroke Association, 2018). According to the Centers for Disease Control the burden of cardiovascular disease, including stroke, is disproportionately distributed across the population. Preventable risk factors include hypertension (HTN), diabetes (DM), tobacco use, hyperlipidemia (HLD), and obesity. Ethnic and minority populations such as African Americans and Latinos have increased frequency of preventable stroke risk factors (United States Department of Health and Human Services, 2013). According to the United States Department of Health and Human Services, African American adults are 40% more likely to have hypertension and are 18% less likely than non-Hispanic

whites to have their blood pressure under control. African American are also twice as likely to be diagnosed with diabetes when compared to non-Hispanic whites. For Latinos, roughly 31.9% were obese in 2010, compared to 26.1% of whites. While Latinos are less likely to have heart disease compared to non-Hispanic whites, it is thought to be due to their young median age. As the Hispanic population ages, the higher rate of risk factors such as obesity and diabetes can lead to heart disease (United States Department of Health and Human Services, 2013).

Several factors are thought to contribute to the disparity between minority groups and non-Hispanic whites in stroke occurrence risk. Some of these factors are environmental, educational, and socioeconomic; and when several adverse factors are present the population may be considered underserved and vulnerable. Vulnerable and underserved populations include the economically disadvantaged, racial and ethnic minorities, the uninsured, low-income children, the elderly, the homeless, those with human immunodeficiency virus (HIV), those living in rural areas and those with other chronic health conditions including severe mental illness (American Journal of Managed Care, 2006).

Prevention and health promotion have been identified as health priorities of the 2010 Affordable Care Act. The structure and impact of successful prevention and health promotion programs focuses on primary prevention, medically based treatments, and community based services. Once a stroke occurs, measures should be taken to prevent reoccurrence. A self-management program is a method of addressing this issue through

educating survivors on modifiable risk factors to promote a healthy lifestyle. Educating survivors of stroke can contribute to increasing self-management, modifying risk factors, and promoting healthy behaviors.

Self-management education is an intervention that has been implemented with many chronic disease populations including diabetes, arthritis, pain, and stroke. Selfmanagement programs focus on a person's ability to actively manage the day to day tasks needed to live with a chronic condition. Self-management education is comprehensive and addresses the medical, role, and emotional aspects of living with a chronic condition. Evidence supports that self-management programs should be interdisciplinary including nursing, physicians, dieticians, mental health specialists, occupational therapists, and physical therapists. Recent studies have examined the application of self-management interventions in stroke populations. A systematic meta review conducted by Parke et al. (2015) identified 13 systematic reviews on self-management training programs. A total of twenty-eight variables were identified and over 10 different outcome measures were used in the different studies. Results from this meta review suggested that self-management training impacts survivors of stroke in areas of activities of daily living (ADL) and quality of life (QOL). This meta review provided supporting evidence of the effectiveness of self-management programs with a number of chronic conditions. Further, it supported the importance of occupational therapy as a team member when implementing stroke specific self-management programs.

Advances in health care have increased the likelihood for survival after stroke. Health care policy continues to evolve and there has been an increased need to manage the burden of care for chronic conditions. Survivors of stroke may benefit from increased opportunities to learn how to self-manage modifiable risk factors. With an increased knowledge of stroke risk factors and healthful life components, survivors of stroke can make lifestyle changes and adaptations in behavior. Occupational therapy (OT) practitioners contribute to this effort as by delivering interventions that focus on participation in meaningful roles, routines, and habits. The OT therapist also works with the person on problem solving skills to change habits and routines and to educate him or her on alternatives to promote adaption and adoption of healthy behaviors. This adaptation process can be internally driven as the survivor becomes more competent in managing the aspects of their condition. The occupational therapy practitioner is most likely to spend critical the most time with stroke survivors along the continuum of care (Barth et al, 2004) and the components of the self-management paradigm fall within the OT scope of practice.

Occupational Adaption (OA) is a theoretical framework that explores the relationship between the person and the environment (Schkade & Schultz, 1992). This theory hypothesizes that as a person experiences a challenge, an adaptive response is generated to meet the challenge. The response can be effective or ineffective. The theory has been studied and found to be effective in small samples of stroke survivors. It has not been tested in self-management programs, but this theory may provide an

understanding on the individual's process as they participate in a self-management program that may require adaptation of lifestyle and behavior after stroke.

This research seeks to explore the effect of a self-management program in a small sample of stroke survivors and identify factors that support or hinder the adaptive process in making lifestyle changes and behavioral modifications to improve overall health.

#### **Problem Statement**

Self-management education is a comprehensive, multi-pronged, and interdisciplinary approach that has been effective in stroke populations. Previous research has shown that self-management programs can influence many aspects of physical, social, and emotional functioning as well as quality of life and perceived health status. However, the mechanism by which this occurs it not well understood, nor has the experience of the stroke survivor participating in this type of program been explored. This study will closely examine this process of change and how the person, environment, and occupations contribute to constructive adaptation.

#### **Purpose**

The aim of this research is to explore the factors that influence the development of an adaptive response by a stroke survivor to adopt healthy behaviors as well as to measure the perceived ability to manage one's health condition.

This research will examine the influence of a stroke specific self- management program (SSMP) on the occupational adaptation (OA) process in a sample of underserved stroke survivors. This program, titled Healthy H.E.A.R.T.s (Health, Education, and

Recovering Together), is a group program that seeks to explore the process of OA and self-efficacy building in the day to day management of the stroke condition.

#### **Hypotheses/Research Questions**

#### Research hypotheses:

- Participation in a stroke self-management program facilitates the development of adaptive responses that promote adoption of healthy behaviors.
- 2) This program participation increases participation in behaviors that reduce modifiable stroke risk factors and increase self-efficacy managing the stroke condition.

#### **Research Questions and Aims**

#### Quantitative

- 1. What lifestyle behaviors are changed by participation in a stroke self-management program (SSMP) as measured by the Healthy Lifestyle Profile II Assessment?
- 2. How did participation in a SSMP influence a stroke survivor's perceived self-efficacy in self-managing their stroke condition as measured by a stroke specific version of the Perceived Medical Condition Self-Management Scale?

#### **Qualitative Aims**

- 1. Explore the ways participation in a SSMP influences the OA process.
  - a. How does participation in a SSMP influence the OA process?

- b. How does the environmental demand of a SSMP promote or discourage self-management?
- c. How is the desire to improve personal control over self-management affected during participation in a SSMP?
- d. How are efficiency, effectiveness, and satisfaction perceived and affected as a result of participation in a SSMP?

#### **Expected Significance**

OT practitioners are involved in the care of survivors of stroke along the health continuum. Occupational therapists are instrumental in assisting survivors as they adjust and adapt to life after stroke. OA is a frame of reference for occupational therapy that supports the active engagement of the individual and acknowledges the person's desire for mastery as well as addresses the importance of contextual factors that influences an individual's ability to adapt. Self-management is an approach that encourages active involvement of the client in the day to day management of a chronic condition. OA theory and self-management programming have both been successful in stroke survivor samples when studied separately. These two ideas have not been studied together in stroke populations prior to this study. The application of the OA theory within the context of a structured SSMP can influence a person's ability to perform core self-management skills and also influence their perceived performance with self-managing the stroke condition. This research integrated these two concepts to explore the stroke survivor's adaptive process as they learned strategies to management their stroke

condition. The mastery, behaviors, and attitudes that affect modifiable risk factors in person with stroke was also be explored. Additionally, this research provided insight into the lived experience of the stroke survivor in a self-management program. The results of this research have provided further understanding of the process of modifying lifestyle for persons with stroke. This research can inform OT research and practice in better understanding the process of lifestyle change after stroke.

#### CHAPTER II

#### LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Stroke is a complex condition that has long-term effects for the individual affected. Several risk factors have been identified for stroke, including increasing age, gender, family history, hypertension, diabetes, atrial fibrillation, carotid disease, tobacco and alcohol use, nutrition, obesity, physical inactivity, and socioeconomic status (Go et al., 2013; Goldstein et al., 2001). Addressing modifiable risk factors is recommended to prevent recurrent stroke (Flemming & Brown, 2004; Ozark & Silver, 2011; Schmid et al., 2008). Patient education programs aimed at promoting healthy lifestyles and changing behaviors are used to address this concern. This literature review will first outline the risk factors often identified as contributors to stroke risk and second discuss current intervention and the research to support these ideas. Thirdly, this line of research will use the theories of self-efficacy and OA to provide a conceptual foundation. Finally, an explanation of how self-management education will be the medium used in a select sample of stroke survivors to facilitate and better understand the relationship and processes of self-efficacy and OA will follow.

#### **Risk Factors**

Several risk factors have been identified that contribute to stroke. The National Stroke Association and American Heart Association have identified the following non-modifiable risk factors: age, gender, ethnicity, sickle cell disease, family history of stroke, previous history of transient ischemic attack (TIA) or stroke. Modifiable medical

and lifestyle risk factors include the following: hypertension, diabetes mellitus, high total cholesterol, atrial fibrillation, carotid artery, and peripheral artery disease lack of physical activity, cigarette smoking and tobacco use, obesity, and poor nutritional intake.

Socioeconomic factors, drug abuse, excessive alcohol use, and geographic location have also been linked to stroke risk. The most influential risk factors pertaining to this research will be further discussed in detail.

#### Hypertension

Hypertension (HTN) is the leading individual contributor to stroke (American Heart Association, 2014). Hypertension is defined as having a systolic blood pressure ≥ 140 mmHg or diastolic blood pressure ≥ 90 mmHg (Go et al., 2013). Based on 2007 to 2010 data, 33.0% of adults in the United States over 20 years of age have hypertension. This means that approximately 78 million adults deal with hypertension. Age, ethnicity, family history, lower socioeconomic and educational attainment, increased body weight, tobacco use, psychosocial stressors, sleep apnea, and dietary factors have been linked to the development of HTN (Go et al., 2013).

The presence of HTN is similar for men and women; yet African American adults have among the highest prevalence of HTN (44%) in the world. Among people with hypertension in the United States, approximately 82% are aware of their condition and 75% are using antihypertensive medication, but only 53% of those with documented hypertension have their condition controlled to target levels (Go et. al, 2013). Cohort and randomized studies have indicated that with each 10 mm Hg lower systolic blood

pressure, there is an associated decrease in stroke risk of approximately one third in subjects aged 60 to 79 years. The association is continuous down to levels of at least 115/75 mmHg and is consistent across gender, geographic region, stroke subtypes, and for fatal and nonfatal events (Huang, 2007).

#### **Diabetes**

The American Heart Association defines diabetes mellitus (DM) as an untreated fasting blood glucose level greater than 100 mg/dL for children and adults. In 2010, approximately 19.7 million Americans aged 20 and over had been diagnosed with diabetes (Go et al., 2013). This represents 8.3% of the adult United States population. In addition, 8.2 million were estimated to have undiagnosed diabetes and 38.2% fell into a pre-diabetes category. African Americans, Hispanics, and other ethnic minorities carry a disproportionate burden of diabetes mellitus in the United States. The prevalence of diabetes is expected to increase dramatically over time, especially as prevalence of overweight and obesity rises (Go et al., 2013). Additional factors have been identified by the American Diabetes Association to contribute to the development of diabetes. They include: age, gender, ethnicity, obesity, physical inactivity, smoking, and alcohol use. The presence of diabetes has also been linked to an increased risk of stroke recurrence (Kurukulasuriya, 2006). The presence of diabetes in stroke patients has also been associated with increased stroke severity, prolonged hospital stays, increased mortality and overall worse rehabilitation outcomes (Kurukulasuriya, 2006).

#### **Obesity**

Overweight and obesity status represent the second leading cause of preventable death in the United States (Kurukulasuriya, 2006). Obesity is defined as a body mass index (BMI) of more than 30kg/m². The prevalence of obesity has increased in every ethnic group (Kurukulasuriya, 2006). Obesity that is located predominately in the central region of the body is thought to increase stroke risk by triggering a number of maladaptive responses and negatively impacting the cardiovascular, renal and other systems (Kurukulasuriya, 2006). As the prevalence of obesity increases, especially in children, there are increased cases of stroke in younger individuals (i.e., below age 60). BMI in late adolescence is an important predictor of stroke and other heart disease in their adult life. It is also the case that the risk of stroke among overweight and obese children increases with age (American Heart Association, 2014).

Obesity can be correlated to the level of physical activity. In 2012, 29.9% of adults reported engaging in no aerobic leisure-time physical activity (Go et al., 2013). These lifestyle factors contribute to increase of first and recurrent stroke. Over-nutrition in the population worldwide has been considered to contribute to the increase of obesity. Obesity is a risk factor for developing type 2 diabetes, and diabetes is a known risk factor for stroke (Huang, 2007). Persons who experience stroke often resume unhealthy lifestyle and behaviors that increase the risk of subsequent strokes. Educating patients on strategies to modify these behaviors including diet and exercise are encouraged to reduce weight and decrease stroke risk. Researchers suggest that by modifying certain risk factors, the incidence of stroke can be reduced. This is why emphasis of the delivery of

information geared towards self-management should be included in a secondary stroke prevention program (Qureshi, 2001).

#### Nutrition

Average daily caloric intake in the United States is 2,500 calories in adult men and 1,800 calories in adult women (Go et al., 2013). Foods and beverages most positively linked to weight gain included refined grains, starches, and sugars, including potatoes, white bread, white rice, low-fiber breakfast cereals, sweets/desserts, and sugar sweetened beverages, as well as red and processed meats. In contrast, increased consumption of several other foods, including nuts, whole grains, fruits, vegetables, and yogurt, was linked to relative weight loss over time. These findings indicate that attention to dietary quality, not simply counting total calories, is crucial for energy balance. Evidence of these facts can be found in an investigation conducted by Larsson and colleagues (2009). They conducted a correlational study on 76,556 Finnish male smokers concerning their intake of fiber rich foods. Inverse associations were found with vegetable fiber intake, consumption of fruits, vegetable, and cereals and stroke risk. A similar study by Huang (2007) found a correlation between the salt reduction and blood pressure reduction. Lower stroke mortality rate has also been found with higher potassium intake (Huang, 2007). Huang (2007) further reported that epidemiology studies have suggested that increased consumption of green and yellow vegetables, fruits, fiber, and whole grains are protective against ischemic stroke.

In a sample of Japanese subjects, animal products such as eggs, dairy products, and fish have been found to decrease mortality due to cerebral hemorrhage but not cerebral infarction. The research has not been conclusive on whether a low cholesterol level will increase cerebral hemorrhage risk. There is insufficient evidence correlating cerebral hemorrhage risk and dietary fat (Huang, 2007).

#### **Ethnicity**

African Americans and Hispanics are at an increased risk for stroke as these two populations have higher prevalence of risk factors for stroke. When compared to their Caucasian counterparts, African Americans are 1.5 times more likely to have a stroke, 1.5 times more likely to have hypertension, and 2.5 times more likely to have diabetes. In addition, African Americans are 50% more likely to die of a stroke. American Indian and Hispanic populations are two times more likely to have diabetes than Caucasians, another major risk factor for stroke (Byrd, Fletcher, & Menifield 2007).

When studying specific trends in organ- and disease-specific mortality rates among ethnicity in the United States from 1996 to 2005, Lackland et al. (2013) report that despite a 23% decline in age-adjusted stroke death rates, stroke remained the second leading cause of death in African Americans. Among Caucasians, there was a 26% decline in stroke age-adjusted mortality. This resulted in stroke moving from the second to the fourth leading cause of death after ischemic heart disease, lung cancer, and chronic lower respiratory disease (CLRD) among racial and ethnic minorities. Gender differences were also noted in the study conducted by Lackland et al. (2013). In men, stroke age

adjusted death rates fell by 28%, and stroke dropped from the third to the fifth leading cause of death after ischemic heart disease, lung cancer, accidents, and CLRD. Stroke remains the second leading cause of death among women, although stroke age-adjusted death rates declined by 24% (Lackland et al., 2013). The percentage of racial and ethnic minorities in the United States is expected to double by the year 2050 (Cruz-Flores, 2011).

#### **Socioeconomic Status**

Socioeconomic status (SES) level has been identified as a contributor to stroke incidence and stroke mortality. SES takes account of a person's education, occupation, and income, as well as their social and economic standing when compared to a general population. Lower SES levels have been associated with increased stroke risk and mortality (Addo et al., 2012). Addo et al. also reported associations among SES, ethnicity and stroke incidence. A retrospective study conducted by Kapral, Wang, Mamdani, and Tu (2002) examined the relationship between SES level and stroke mortality over a 30-day period. The researchers found that a \$10,000 increase in median neighborhood income was correlated with a 9% reduction in stroke mortality. Patients in lower SES quartile were also less likely to receive rehabilitation services, as SES level has been associated with differences in the access and receipt of healthcare services (Kapral, Wang, Mamdani, Tu, 2002). These differences may influence stroke outcomes. Interestingly, associations between SES level and stroke recurrence have not been established in the literature (Addo et al., 2012). Liao and colleagues (2011) found that

ethnic and minority populations had significantly lower SES levels and were more likely to not have health care coverage due to the cost associated with health care. These studies further suggest that SES levels may limit access to better health care services.

#### **Smoking and Tobacco Use**

Smoking is another modifiable risk factor for stroke. Persons who smoke are twice as likely to have an ischemic stroke and four times as likely to have a hemorrhagic stroke (National Institute of Neurological Disorders and Stroke, 2014). Low levels of exposure to cigarette smoke have been associated with sharp increases in cardiovascular disease risk, including stroke (Go et al., 2013). Significant progress has been made over the past four decades to reduce smoking. Smoking cessation has become a major initiative for the 19th U.S. Surgeon General and the World Health Organization. Despite these efforts, among Americans 18 years of age and older, 20.5% of men and 15.9% of women reported continued to be cigarette smokers in 2012 (Go et al., 2013). Increased life expectancy has been associated with age of smoking cessation. Go et al. (2013) report that smokers who quit at 25 to 34 years of age have an increase life expectancy by an average of 10 years when compared with those who continued to smoke. Persons aged 35 to 44 years increased by 9 years and persons aged 45 to 54 years increased by 6 years.

While it is difficult to address all of the risk factors at once, many of these risk factors are addressed in multi component programs that promote changes in lifestyle and health behavior. Self-management education is one such program.

#### **Self-Efficacy Theory**

Self-efficacy theory was first articulated by Albert Bandura (1977) and has been widely used in research to study human behavior. Self-efficacy serves as the foundational theory for self-management programming. Self-efficacy is defined as a person's belief that they can achieve a desired effect by their own action (Bandura, 1998). Bandura's theory assumes that personal self-efficacy can influence a person's behavior, including coping mechanisms, behavioral change, and duration. A person's perceived self-efficacy influences his or her behavior and selected activities. The stronger the perceived self-efficacy in performing an activity, the more likely a person is to engage in the selected activity. Bandura identified four components to address and enhance perceived self-efficacy: (1) performance accomplishments, (2) vicarious experiences, (3) verbal persuasion, and (4) emotional or physiological state. Performance accomplishments are developed through mastery experiences; such that successful experiences increase self-efficacy. Performance accomplishments can be achieved using participant modeling, performance desensitization, performance exposure, and selfinstructed performance. Vicarious experiences are achieved through watching someone else perform the particular task, as this provides a social comparison and can help to set expectations. Verbal persuasion is used to influence self-efficacy and behavior through the use of suggestion, exhortation, self-instruction, and interpretive treatments. Emotional or physiological arousal is the final component of self-efficacy (see Appendix B).

Once self-efficacy is established, it can be generalized to different settings.

Interestingly, Bandura (1977) suggested that stressful and taxing situations and beliefs can increase emotional arousal and affect self-efficacy and adversely performance. That said, self-efficacy has been found to be an influential component in a number of health-related education programs, including smoking cessation, weight control, and alcohol abuse. Stretcher, DeVillis, Becker, and Rosenstock (1986) conducted a review of these studies and found A summary of these studies was reviewed by Stretcher, DeVillis, Becker, and Rosenstock (1986). In this review, the authors found strong evidence suggesting the self-efficacy enhancement can positively influence modification and maintenance of behavior change.

#### **Self-efficacy in Stroke**

Jones and Riazi (2011) conducted a systematic review to examine use of self-efficacy principles in self-management programs for stroke survivors. Jones and Riazi selected 22 studies for review, and primary outcomes of the study focused on self-efficacy in self-care, balance, falls, and perceived health status. Jones and Riazi (2011) found that self-efficacy was an important concept in measuring stroke outcomes. Various outcome measures were identified in these studies, and further research is necessary to determine the optimal delivery format for these types of interventions in a stroke population.

Jones, Mandy, and Patridge (2009) examined the use of self-efficacy principles in a self-management program. There were ten stroke survivors that participated in the

study, and each participant was provided with interactive workbooks addressing the four components of self-efficacy and completed the intervention over four weeks. The Stroke Self-Efficacy Questionnaire, the General Self-Efficacy Scale, Rivermead ADL Index, Subjective Index of Physical and Social Outcome, and the Hospital Anxiety and Depression Scale were the outcomes of interest. Participants were measured at baseline and post intervention, and results demonstrated improvement for all participants for a majority of the variables measured.

Health management and maintenance is identified as an instrumental activity of daily living and is considered an area of occupation within the domain of OT. As described in the Occupational Therapy Practice Framework, 3rd edition (OTPF III), this area consists of "developing, managing, and maintaining routines for health and wellness promotion, such as physical fitness, nutrition, decreased health risk behaviors, and medication routines" (American Occupational Therapy Association, 2014, p. s19). This domain will serve as the foundation support for OT research within SSMP.

#### **Self-Management**

Self-efficacy theory is the foundation for self-management programming. Self-management education, as defined by Lorig and Holman (2003), is a method of encouraging people to participate in a health promoting behavior and taking an active role in the day-to-day management of their health condition. The goal of self-management programming is for persons to be able to effectively manage and maintain wellness while living with their condition (Lorig & Holman, 2003). Self-management is

a complex process intended to address barriers to self-management that may include the patient and the healthcare professional (Joice, 2012). These barriers may include the attitude of the patient and/or the healthcare professional. Vallis (2009) identified additional barriers that may include motivational, behavioral, emotional, relationshipbased, and environmental. The work conducted by Corbin and Strauss (1988) is considered the predecessor for the current definition of self-management. Selfmanagement programs address three components: (1) medical management of condition, (2) maintaining, changing, or developing new healthful behaviors and life roles, and (3) emotional management of living with a condition (Lorig & Holman, 2003). These three components are addressed by the development of five self-management skills: problem solving, decision making, finding and utilizing resources, developing partnerships with health care providers, and taking action (Lorig & Holman, 2003, see Appendix C). A key component of the self-management program is that it encourages active engagement of the participant in the management of his or her own condition, including addressing psychosocial factors and making lifestyle modifications. These skills are thought to build self-efficacy and thereby influence behavioral change.

#### **Self-Management in Stroke.**

Jones (2006) first proposed the application of self-efficacy and self-management principles in a stroke population. By reviewing the current strategies used in the chronic disease literature, Jones identified areas where similar approaches could be applied in a stroke population. Jones notes that due to the complex nature of stroke, quality of life

and depression are often abnormal in stroke populations as compared to other chronic diseases. Jones (2006) suggests that the principles of self-efficacy can be readily applied and are appropriate for stroke populations. Jones further notes (2006) how the teaching of self-management skills may depend on the impairment and functional limitations of the stroke survivor. While the process of self-management begins acutely after onset of a stroke, learning how to cope with the changes that stroke brings begins after discharge from a health care facility. For this reason, it may be most of appropriate to emphasize self-management training upon discharge. Jones (2006) suggested that interventions which enable adaptation to the chronic condition of a stroke can be useful, and that therapists can play an important role in influencing this process of adjustment and coping to life after stroke and being successful in self-management.

Parke et al. (2015) conducted a systematic meta-review of existing randomized control trials (RCT) to identify the potential effectiveness of self-management interventions within the context of rehabilitation therapy in the stroke population. The authors found that while specific self-management terminology was rarely used in the literature many of the components of self-management skills training were often addressed. There were thirteen RCTs were used in this study and measured various outcomes including personal and extended activities of daily living (ADL), self-efficacy, quality of life (QOL), community integration, health care utilization, compliance as a measure of behavioral change, cognitive function, and mood. Problem-solving, remediation training, goal setting, information provision, support with the use of adaptive

equipment, liaison services and ADL training were identified as interventions used to address these goals in the different studies. The results of this systematic meta-review found mixed reviews to support ADL training in stroke recovery with more benefit identified in the earlier stages of stroke recovery. Stroke liaison services were found to have some benefit on QOL. There were mixed reviews on the benefits of the interventions on community integration. Weak evidence was found to support the influence of caregiver problem solving interventions on community integration. The authors acknowledged that specific self-management training is relatively new within the context of stroke rehabilitation and it is still an underutilized approach. This review suggests that future research opportunities exist to explore and identify specific interventions and outcomes to measure the effectiveness of rehabilitation therapies in self-management training.

Self-management components were applied and evaluated in separate studies conducted by Rimmer et al. (2000) and Bretz et al. (2014). Rimmer et al. (2000) conducted a 12-week health promotion program in a sample of predominantly urban, low-income African-American stroke survivors using a multi-component, interdisciplinary approach. The three areas addressed by this program included exercise, nutrition, and health behavior with an emphasis on coping, risk factor management, role change, and goal setting. The program was delivered in a group format 2-3 times per week for 60-90 minutes each for each class. The effectiveness of the program was assessed using a combination of physical fitness and self-report measures for nutritional

intake and life satisfaction. The results demonstrated a significant decrease in cholesterol, significant improvement on physical fitness measures of strength, flexibility, and cardiovascular endurance, and reported improvements in life satisfaction and decreased depressive symptoms. Participants were also found to maintain their changes over time. This type of program addressed many self-management components and may be replicable in similar settings.

Bretz et al. (2014) set up a transition program for stroke survivors called Steps Against Recurrent Stroke Plus (STARS). Primary outcomes were medication adherence, improving communication between the patient and health care provider, and health status as measured by the Short-Form-12 (SF-12) questionnaire. Potential subjects were recruited following discharge from the hospital setting. Seventy-two participants were provided with educational packets of information that addressed self-advocacy, caregiver well-being, and community integration. Telephone contact was made to assess progress at 4 time points: 30 days, 90 days, 180 days, and 365 days. Results of this study found that participants in the younger age groups (62 years and younger) reported significant role and emotional limitations at the 30 and 365 day time periods when compared to the middle (63-73 years) and older (74 years and above) age groups. There was a significant effect of subjective pain reported to be less over time among all age groups. Adherence to medication regimen was not found to be significant, but subjects reported consistency in adhering to medication regimen over time. This type of study provides insight to potential long-term needs of the stroke survivor. This study may have been more

effective if other self-management components such as active participation of the stroke survivor in determining personal health goals and group interaction were incorporated into the intervention.

In a systematic review conducted by Lennon, McKenna, and Jones (2013), 15 studies were identified that used self-management principles in interventions for persons with stroke. Favorable results were found in six of nine randomized controlled trials, as well as three of the six non-randomized studies. Great variation was identified in content delivery, duration, setting, and outcomes used in the studies. From this review, Lennon et. al (2013) suggested that there are benefits from group-based self-management programming as it relates to measures of disability, confidence in recovery, and quality of life measures. Lennon et. al (2013) further concluded that content, format, and delivery of self-management interventions may vary, and that the most effective approach to these interventions is yet to be determined.

Kendall et al. (2007) examined the influence of Chronic Disease Self-Management Program (CDSMP) on psychosocial recovery. A randomized control trial (RCT) was conducted over an 18-month period in a sample of stroke survivors. An additional week of stroke specific information was added to the original CDSMP format. The Stroke Specific Quality of Life Scale (SSQOL) was used as the primary outcome measure in this investigation. Results of this study found that participants in the intervention group reported improvements in quality of family roles, self-care, work productivity, and functioning while the control group reported declines in these areas.

The participants also demonstrated an ability to maintain a relatively stable adjustment over time.

Cadilhac et al. (2011) conducted a single-blind RCT that compared an eight-week stroke self-management program (SSMP) to the six-week CDSMP versus standard care. Outcomes of interest included participation and completion rates in each program, number of adverse events, positive and active engagement in life, quality of life (QOL), and mood. Following completion of the intervention period, researchers found that participants in the SSMP group demonstrated higher participation and completion rates when compared to the CDSMP and standard care groups. There was not a significant difference in adverse events between the groups. The authors concluded that the SSMP is a feasible program.

Damush et al. (2011) conducted an RCT to compare a SSMP to a placebo in a sample of veteran stroke survivors. Primary outcomes were the stroke-specific QOL (SS-QOL) measure and self-report measures of self-efficacy. Face-to-face group sessions and telephone calls were performed six times biweekly over a three-month period with follow up at six months. The most common behavioral changes reported included increasing physical activity, increased consumption of healthy foods, increased medication adherence and increased used of relaxation strategies. This was supported by demonstrated improvement in SS-QOL scores.

Pearce et al. (2015) conducted a systematic meta-review on qualitative studies on self-management and stroke. Pearce et al. (2015) identified and analyzed seven reviews

that contained data from 130 unique qualitative studies. A synthesis of these studies focused on the lived experience after a stroke and needs after stroke. Results found that needs after stroke changed with the stroke trajectory. In most studies, there was an initial focus on medical and behavioral management. Survivors indicated a need for more emotional and psychological support as their physical progress began to plateau. There was an overarching theme for healthcare professionals to enable survivors of stroke to achieve independence and identify meaningful roles. The authors report saturation in literature on understanding the impact of stroke from a survivor's perspective. However, the authors recommend that future qualitative studies focus on understanding the impact of self-management interventions on stroke survivors.

# **Self-Management in Occupational Therapy.**

Occupational therapists have used principles of self-management with conditions of diabetes (Pyatak, 2011b) and fatigue (Ghahari & Packer, 2011). Pyatak (2011b) conducted a systematic review on self-management interventions in a diabetic population with the goal of identifying a role for OT in the delivery of these interventions. A total of 17 articles were reviewed. Patient education, exercise programming, medication adherence, and health promoting behaviors were identified as appropriate areas for OT interventions. Pyatak (2011b) suggests using interventions addressing sustainable lifestyle changes with an emphasis on improve the physical and psychosocial well-being of the individual.

Ghahari & Packer (2011) used self-efficacy principles as a foundation for a fatigue self-management program. The program consisted of six face-to-face sessions and topics included rest and daily routine, adapting activities, energy conservation strategies, and communication with the primary aim of increasing confidence in ability to engage in specific behaviors. Worksheets and handouts were the primary modes of educational delivery. The study included 105 individuals with multiple sclerosis, Parkinson's disease, or post-polio syndrome. Ghahari and Packer (2011) found that individuals participating in the face to face programming had decreased fatigue levels when compared to the control group. Participants in the online program delivery also reported benefit and this method might increase participant access to education, especially in rural areas.

Packer (2011) highlighted the importance of using an occupation focused approach to self-management programs. OT's primary focus on the work in everyday occupations is separated into two contributions to self-management programs: (1) an intentional and proactive approach to support people to self-manage the emotional and daily consequences of living with a chronic condition, and (2) a focus on diverse and often unseen groups within the self-management literature- programs for people whose condition is not significantly modified by symptom management, medications, or lifestyle factors.

Parke et al. (2015) conducted a systematic meta-review on the use of selfmanagement components therapy rehabilitation for stroke care. Parke et al. (2015) found that comprehensive OT had a beneficial impact on the primary outcomes of ADL (personal and extended) and self-management skills training.

In an editorial, Packer (2011) suggested that occupational therapists to use an occupational lens to approach self-management interventions. Packer (2011) stated that due to the long nature of chronic disease, self-management is an ongoing process. While occupational therapists can address aspects of medical management, they can also contribute their unique skill to the areas of role and emotional management in order to maintain meaningful participation and occupational engagement.

### **Self-Management in Chronic Disease**

Self-management programming has been studied in chronic disease populations including those persons with arthritis, diabetes, and other chronic conditions (Nolte & Osborne, 2013; Richardson et al., 2014). The Chronic Disease Self-Management Program (CDSMP) was developed at Stanford University and is an intervention model for chronic diseases. This program is also referred to as the Stanford program. Regardless of nomenclature, this program uses a group education format that encourages people with chronic conditions to (1) engage in activities that promote health and wellbeing such as adopting healthy behaviors, (2) minimize the negative influence of their illness on their lives, (3) manage the negative emotional impact of their symptoms, and (4) take an active role in their own health by developing partnerships with health professionals. The original format of the course is six weeks for 2-2.5 hours per session and covers the following topics: (1) techniques to deal with problems such as frustration,

fatigue, pain and isolation; (2) appropriate exercise for maintaining and improving strength, flexibility, and endurance; (3) appropriate use of medications; (4) communicating effectively with family, friends, and health professionals; (5) nutrition; (6) decision making; and (7) how to evaluate new treatments.

Nolte and Osborne (2013) conducted a systematic review on outcomes of chronic disease self-management interventions. Nolte and Osbornes (2013) focused on articles that were randomized control trials and utilized self-management interventions that were similar in content and delivery to the Stanford program. There were 18 articles that were selected. Over 70 outcomes were measured across the studies, with the most commonly reported outcomes being pain, disability, depression, self-efficacy, visits to the physician, general health, fatigue, communication with the physician, knowledge, anxiety, and physical functioning. Nolte and Osborne (2013) concluded that due to the variance of outcomes measured, comparison between trials was difficult. This report also suggested that this variance might limit establishing the effectiveness of similar programs.

Richardson et al. (2014) conducted a systematic review on the contributions of physiotherapists and occupational therapists in self-management interventions for chronic diseases. The authors included 57 articles for their review. Richardson et al. (2014) did not identify a guiding theoretical principle in their inclusion criteria, but did find that the following theories were commonly reported in the literature: social cognitive theory, self-efficacy theory, the health belief model, the trans theoretical model of behavior change, social learning theory, social ecological theory, goals system theory, rationale emotive

theory, and the skilled helper model. These theories are all aimed at behavioral change. Richardson et al. (2014) found that self-management interventions were most commonly used with the following conditions: arthritis, chronic pain, cancer, lymphedema, ankylosing spondylitis, fibromyalgia, chronic fatigue, chronic obstructive pulmonary disease, diabetes, and other chronic disease. The primary strategies used to deliver the self-management interventions included goal setting, identifying barriers, goal modification, implementing action plans, self-monitoring, problem solving, and peer support. Physiotherapists and occupational therapists were found to contribute to the development and delivery of these interventions. The outcome measures of the reviewed studies varied, with the majority of the studies using self-report measures. Variables measured included knowledge, function, quality of life, health status, emotional wellbeing, patient and provider satisfaction, health service utilization, pain, sleep, strength, and energy conservation techniques. While this review supports the contributions of the physiotherapist and occupational therapist in self-management programming, the variance in foundational theoretical concept, outcome measurement, and clear role of the therapist in self-management programming may limit the establishment of effectiveness of these professions.

# **Theory of Occupational Adaptation**

The theory of OA describes a holistic, dynamic, and normative process connecting the constructs of occupation and adaptation. This theory was first introduced by Schkade and Schultz (1992) and explores the relationship between a person's desire

for mastery and the occupational environment's demand for mastery. The interaction that occurs between the person and the environment is referred to as a press for mastery. Occupation is viewed as a means that a person uses to facilitate adaptation to changes in a condition. The person's internal desire is used as a catalyst for this process.

As defined by Schkade and Schultz (1992), occupations have meaning, require active participation, and produce a tangible or intangible outcome. Adaptation occurs when there is an alteration in the functional change of the individual in attempt to achieve mastery over the presented occupational challenge. In this theory, the person is seen as the agent of change. OA theory serves as a framework for evaluation and intervention for occupational therapy practice and focuses on developing one's ability to adapt to meet a specific occupational challenge (see Figure 3).

OA is based on six assumptions described by Schultz and Schkade (1992). The first assumption is that competence in an occupation is a lifelong process of adaptation to internal and external demands to perform. The second assumption is that a person demands to perform occur naturally as a part of a person's occupational roles, and the context in which they occur. Third, dysfunction occurs because a person's ability to perform has been challenged to the point at which demands for performance are not met satisfactorily. Fourth on the list is the assumption that a person's adaptive capacity can be overwhelmed by impairment, physical or emotional disabilities, and stressful life events. Fifth, the greater the level of dysfunction, the greater the demand for changes in person's adaptive process. The sixth and final assumption is that success in occupational

performance is a direct result of a person's ability to adapt with sufficient mastery to satisfy self and others. These assumptions state that OA is a lifelong, naturally occurring process and can be influenced by performance demands. The OA process can be overwhelmed by illness, injury, or stress. The onset of stroke is an example of a major period of stress for an individual, one that requires the development of an adaptive response in order to achieve mastery over the environment. Adapting to this change will require an adjustment in perspectives, roles, and methods in order to restore competence and achieve mastery over desired occupations. A person achieves mastery by self-evaluating three factors: efficiency, effectiveness, and satisfaction. These three ideas are combined to define relative mastery. Relative mastery is a patient-centered concept that measures performance from the patient's perspective (Schultz & Schkade, 1992).

Relative mastery is the desired outcome of OA.

### **Occupational Adaptation in Stroke**

OA has also been studied in adult stroke populations. Ross (1994) applied the theory of OA in an acute care setting. Through a case report, the Ross (1994) documented the efforts of an 82-year-old male who desired to return to his role as caregiver for terminally ill wife. The author described how the OA framework was use to evaluate the client's cognitive, sensorimotor, and psychological components within the client's occupational environment. Ross (1994) used this information to use appropriate occupational readiness activities and occupational activities during the OT treatment sessions. The author noted that although the patient's feelings of relative mastery

fluctuated throughout the OA process, the client began to demonstrate integration and increased adaptive capacity through adapting techniques to accomplish certain tasks and generalizing skills to other areas. This case report is another example of OA with the use a client-centered, occupation-based approach to evaluation and treatment.

Gibson and Schkade (1997) studied OA theory in a sample of stroke patients and compared them to a control group. Independence with activities of daily living (ADL) and discharge environment were the primary outcomes. Results found that subjects evaluated and treated using an OA approach had a statistically significant increase in ADL independence and discharge to least restrictive environments.

Dolecheck and Schkade (1999) examined the effects of OA theory in the evaluation and intervention of dynamic standing balance in a small sample (n=6) of stroke patients. Statistically significant changes were found in dynamic standing balance in three of the six patients who were engaged in treatment activities identified as meaningful.

Williams and Murray (2013) used a phenomenological approach to explore the OA process in a sample of five post-stroke subjects. The subjects were interviewed and key themes emerged including feeling that having a stroke was a life-changing experience. The OA process was gradual and subjects identified resilience, motivation, and effort as primary adaptive responses to the challenges they faced. The use of healthy coping strategies were noted to be helpful for the subjects and suggested these strategies be incorporated into occupational therapy interventions.

# Occupational Adaptation and Population Studies.

OA has been applied and studied in samples of elderly adults, orthopedic, and neurologic populations. Spencer et al. (1999) conducted a longitudinal qualitative study on eight subjects to follow their adaptation trajectories as they progressed from a transitional unit into the community. All subjects were given OT protocol based goals, planning, and intervention for deconditioning. The selected eight participants were also provided with adaptation-based goal planning and intervention using the Client-Centered Evaluation and the Community Adaptive Planning Assessment. While outcomes from the OT protocol intervention focused on basic ADLs and occupational performance measures, the adaptation-based interventions focused on client selected daily occupations, activities, and relationships considered meaningful to the participant. Results show that 67% of goals set using the OT protocol were met at discharge. This improved to 91% at community follow up. A similar result was reported for the subjects with the adaptation-based goals, especially when all goals were met in some fashion. Spencer et al. (1999) identified the importance of using a client driven approach and the patient's ability to modify as contributing factors to the observed results.

Jack and Estes (2010) utilized the OA model to facilitate the recovery of a client following hand surgery due to lupus-related arthritis. Jack and Estes (2010) initially evaluated and treated this client using a biomechanical frame of reference; however, they found that the client was not satisfied with the small objective changes that had been made with therapy goals. The Canadian Occupational Performance Measure was used to

shift the intervention plan to an OA approach and establish new objective goals focused on the client's desired roles and performances. Jack and Estes (2010) reported the client had increased motivation and outlook and they were able to document clinically significant functional progress.

Lexell et al. (2011) explored the OA process in persons living with Multiple Sclerosis (MS). Ten participants completed qualitative interviews that sought to understand how changes in the individual's engagement in important occupations, responses to these changes and how these changes have influenced meaningful social relationships. Lexell et al. (2011) reported that the participants often noted how their OA process was an evolving non-linear process. This article sheds light on the psychological aspects of living and adapting to the changes that can occur with a chronic condition.

Lexell et al. (2011) identified the OA approach as beneficial to helping the clients achieve a desired sense of self or desired family life.

### Conclusion

Self-management programming has been established as a feasible intervention in samples of stroke survivors. Each of the SSMPs reviewed have used the CDSMP as a model; however, the delivery and duration of the interventions as well as the outcomes used to measure change have varied in each study. Additionally, the majority of samples of interest were not considered traditionally underserved. The OA approach has also been studied qualitatively in stroke populations and has been found to be a suitable evaluation and intervention approach to improve a client's perceptions of performance.

Self-efficacy, competence, mastery, active engagement, and confidence are constructs valued by both self-efficacy and OA theory. Mastery experiences are important in building self-efficacy. Occupational therapists are equipped to facilitate these processes and influence change. The ability of a person to feel confident in his or her abilities may be influenced by the person's development of an adaptive response in order to better manage their health after stroke. An OA approach applied in a SSMP may facilitate a shift in motivational factors from external to internal and increase a person's active engagement in their care. This line of research can serve as a first step to integrate these two concepts and support the importance of OT in self-management programming as well as better understand the experience of the stroke survivors in this type of program.

The current research project will examine the influence of a SSMP on the OA process in a sample of underserved stroke survivors. This program will seek to explore the process of occupational adaptation and building self-efficacy in the day-to-day management of the stroke condition. This research will explore the individual's OA experience following participation in a SSMP. A stroke specific version of the Perceived Medical Condition Self-Management Scale, an outcome measure that has not been previously used with stroke populations will be introduced to measure self-management, and another tool, the Health Promoting Lifestyle Profile II, was used to measure self-reported healthy lifestyle behaviors. Qualitative interviews will be conducted to further understand the OA process. The specific aim of this study was to explore the factors that influence the development of an adaptive response to adopt healthy behaviors as well as

to measure the stroke survivor's perceived ability to manage his or her health condition following participation in a SSMP.

# CHAPTER III

### **METHODS**

# **Research Design**

A sequential explanatory mixed methods design was used. A mixed methods approach was appropriate for this project because it utilized the strengths of quantitative and qualitative approaches to strengthen the understanding the research problem (Creswell, 2014). The research was conducted in two phases. The first phase addressed the quantitative components of the study and analysis of selected assessment tools. The second phase of this study used qualitative interviews that sought to understand the rationale and perspectives of the participants' experience during the SSMP. The results of the phases were analyzed separately but interpreted together.

# **Hypotheses**

# Research hypotheses:

- Participation in a stroke self-management program facilitates the development of adaptive responses that promote adoption of healthy behaviors.
- 2. This program participation increases participation in behaviors that reduce modifiable stroke risk factors and increase self-efficacy managing the stroke condition.

# **Research Questions and Aims**

# Quantitative

- 1. What lifestyle behaviors are changed by participation in a stroke self-management program as measured by the Health-Promoting Lifestyle Profile II Assessment?
- 2. How did participation in a stroke self-management program influence a stroke survivor's perceived self-efficacy in self-managing their stroke condition as measured by a stroke specific version of the Perceived Medical Condition Self-Management Scale?

# **Qualitative Aims**

- 1. Explore the ways participation in a stroke self-management program influences the occupational adaptation process.
  - a. How does participation in a stroke self-management program influence the occupational adaptation process?
  - b. How does the environmental demand of a stroke specific selfmanagement program promote or discourage self-management?
  - c. How is the desire to improve personal control over self-management affected during participation in a stroke self-management program?
  - d. How are efficiency, effectiveness, and satisfaction perceived and affected as a result of participation in a stroke self-management program?

# **Participant Recruitment and Site**

Both phases of the study took place in an outpatient hospital that is a part of a large community owned hospital system in Houston, TX. This hospital system provides services to a traditionally underserved population that includes three major hospitals and 23 community health centers. The demographic makeup of this population includes Hispanic: 59.6%, African American: 24.9%, Caucasian: 8.3%, Asian/Pacific: 4.8%, Other: 2.1%, American Indian: 0.2% (Harris Health, n.d.). The majority of patients served in this hospital system identify as self-pay (63.6%), 20.7% have Medicaid and children's health insurance program (CHIP), 9% have Medicare, and the remaining 6.2% have commercial insurance or other funding (Harris Health, n.d.).

Participants were selected based on meeting the inclusion criteria, agreement to participate in the SSMP, and consent to participate in the study. Participants were recruited using: referrals from physicians in the acute care stroke center, neurological specialty clinics, and outpatient rehabilitation clinics. The medical charts of all participants in English cohorts of the Healthy Health, Education, and Recovering Together (H.E.A.R.T.s) SSMP between July 2016 and June 2017 were reviewed to determine eligibility to participate in the study. Eligible participants were contacted by telephone by the researcher for recruitment. A total of three attempts were made to contact eligible participants.

### **Inclusion and Exclusion Criteria**

Inclusion criteria included males or females at least 18 years or older, history of ischemic or hemorrhagic stroke, and be at least six months post stroke onset. Participants were able to speak and understand English as the outcomes used for this study are available and have been validated in English. In addition, participants possessed the cognitive ability to participate in a self-management program and follow up interview as determined by the recommendation of the participant's referring provider, previously documented cognitive status, and clinical judgment of the researcher. Participants were within four weeks of discharge from outpatient rehabilitation or had already completed a rehabilitation program.

Participants were excluded if they had moderate to severe aphasia with an inability to complete the interview portion of the study as determined by the clinical judgment of the researcher. These criteria were applied for each phase of this project.

### **Healthy H.E.A.R.T.s Intervention**

The Healthy H.E.A.R.T.s program is an interdisciplinary, cohort style, stroke specific self- management program designed to incorporate the principles and core skills of self-management as defined by Lorig & Holman (2003). This group program contains 10 weeks of educational and application content. Classes are facilitated by a licensed occupational therapist (primary researcher) and a licensed physical therapist. Evaluations were conducted at week 1 and week 12. Each group session lasted for 1.5 hours. The total time commitment for each participant was 12 weeks. This program follows the recommended protocol in the Stanford Chronic Disease Management Program; however,

stroke specific information was integrated into the curriculum to make the program more relevant to the participants. Topics addressed in the class include: stroke risk factors and warning signs, stroke recovery, coping strategies, changing thought patterns, components of a healthy lifestyle, caregiving, guidelines for nutrition, exercise principles and exercise modifications after stroke, goal setting and tracking change, and use of community resources (see Appendix A).

Participants were provided with personal blood pressure monitors during Week 2 to self-monitor blood pressure at home. Participants were also supplied with health logs to track blood pressure, exercise, and weekly short-term goals. Additionally, participants were provided with MyPlates during week 7 to apply nutritional concepts in the home environment. Caregivers were encouraged to attend and participate in the classes to provide moral and social support for the participants.

#### Instrumentation

The Health-Promoting Lifestyle Profile II (HPLPII) is an instrument used to assess self-reported health behaviors and measures six areas: spiritual growth, nutrition, stress management, health responsibility, physical activity, and interpersonal relationships (Walker & Hill-Polerecky, 1996). It is a revised version of the original Healthy Lifestyle Profile (Walker, et al., 1987). The HPLPII contains 52 items and responses are measured on a Likert scale. This tool has an Alpha reliability coefficient = 0.922 and Alpha coefficients for subscales = 0.702 - 0.904 (Walker et al., 1987). This assessment has been widely used in health promotion research in study health behaviors

and older adults (Acton & Malathum, 2000; Callaghan, 2005). This assessment was administered in Week 1 and Week 12 of the program and took approximately 15-20 minutes to complete (see Appendix B).

The Perceived Medical Condition Self-Management Scale (PMCSMS) is an eight-item generic self-management scale that has been validated and found to be reliable in self-management programs when modified and applied in HIV and Diabetic populations (Wallston, Osborn, Wagner, & Kilker, 2011; Wallston, Rothman, & Cherrington, 2007). The PMCSMS was modified to address the stroke condition by replacing the word "condition" with the "stroke." This measure was administered at Week 1 and Week 12 of the program and took approximately 10 minutes to complete (see Appendix C).

The qualitative interview was semi structured and contained 12 open-ended questions focused on understanding the occupational adaptation process and to explore feelings of relative mastery to include: effectiveness, efficiency, and satisfaction. The interview guide was developed to address the qualitative aim and categorized by topic. Interview questions #3 through #9 directly addressed sub-aim A, and interview questions #1, #2, #6, and #8 of the interview guide addressed sub-aim B. Sub-aim C was addressed by interview questions #4, #7, #9, and #10 through #12. Finally, sub-aim D was addressed by interview questions #3 through #9.

Additional questions explored how participants incorporated self-management tools and feelings of perceived confidence with understanding and self-managing their

stroke condition. Follow up questions were asked based on the participant response and the results of the quantitative measures and the flow of the interview in order to derive the most meaningful reflections and responses from the participant. Significant others were permitted to be present and contribute during the interview if they were present during the Healthy H.E.A.R.T.s participation and the participant requested the significant other to be present. Each interview took 25 to 75 minutes to complete. A copy of the interview questions can be found in Appendix D.

### **Procedures/Data Collection**

### **Phase One**

Retrospective data were collected on consenting participants for phase 1 of this study. Participants completed the Healthy H.E.A.R.T.s SSMP. Participants were carefully selected based on meeting the inclusion criteria and consent to participate in the study. For this phase of this study, the stroke specific version of the Perceived Medical Condition Self-Management Scale and the Health-Promoting Lifestyle Profile II that were administered at the beginning (Week 1) and end (Week 12) of the Healthy H.E.A.R.T.s class was collected and analyzed.

### Phase Two

Participants that attended at least 7 of 12 of the Healthy H.E.A.R.T.s SSMP and completed pre-test and post-test measures were asked to participate in the qualitative portion of the study. Once the participant consented to participate in this phase of this study, they were scheduled for the qualitative interview. For this phase of this study, a

1:1 semi-structured interview was conducted. All interviews were audio recorded. The investigator used a notebook to record observations during and after the interview to include the presence of companions, tone of conversation, participant demeanor, and investigator's reflections at the conclusion of the interview.

# **Data Analysis**

### **Phase One**

Means and standard deviations were calculated for all continuous variables for all subjects (n=5) in the sample on the pretest and posttest versions of the Health-Promoting Lifestyle Profile II and the stroke specific version of the Perceived Medical Condition Self-Management Scale. The Wilcoxon signed rank test, a nonparametric test, was used to compare differences in the pretest and posttest pairs of samples for the HPLP II and PMCSMS.

#### Phase Two

The following trustworthiness techniques were used during the qualitative data analysis: thick description, the use of multiple coders, reflective journaling, use of an audit trail, and use of a constant comparative process during the coding, category, and theme development.

Thick description was provided for each case. Demographic information was collected including age, gender, ethnicity, marital status, educational level, time since stroke onset, and living situation. Each qualitative interview was manually transcribed verbatim and coded by the primary researcher and two to three independent coders using

a hybrid coding format (Hedlund de Witt, 2013). A set of pre-set codes were used based on key concepts from the theoretical concepts in the study. Pattern coding, a technique used to identify repetitions in the data was also used. Additional codes were added as they emerged from the interviews. Additionally, the researcher used coding notes to capture thoughts and ideas about the themes that emerged from the interview transcripts. This list of codes from all five participants was compiled and then refined to develop categories. Themes were then identified across the group of participants.

### CHAPTER IV

#### RESULTS

# **Participant Sample**

There were seventeen participants evaluated for the English cohorts of the Healthy H.E.A.R.T.s SSMP and participated in the class between July 2016 and June 2017. There were eight participants excluded from this study due to the following reasons: no posttest assessment completed (*n*=5); did not attend the required number of classes (*n*=2); severe expressive aphasia with inability to communicate thoughts and feelings to participate in qualitative interview (*n*=1). There were nine participants that met the inclusion criteria. Of the eligible participants, two were unable to be contacted, and two other participants expressed interest but were not able to participate due to scheduling conflicts during the data collection period in September 2017. A total of five individuals consented to participate in the study and their assessment data were gathered from their Healthy H.E.A.R.T.s class was retrospectively collected (see Figure 1). All participants were given pseudonyms to protect their identities. The five participants were Kevin, Hannah, Michael, Oscar, and Amy. Each of these participants will be described in further detail in the following section.

# **Description of Participants**

Kevin participated in the 2016 cohort of the Healthy H.E.A.R.T.s class. His primary goal was to learn about his risk factors and how to exercise in his current physical condition. Prior to his stroke, he was gainfully employed and was independent

with all aspects of his health and mobility. After his stroke, he experienced left hemiparesis and has no movement in his left hand. He needed a quad cane to ambulate. His comorbid risk factors include hypertension and type 2 diabetes. He has a history of mood disorder. During the SSMP, Kevin would participate in class by offering advice to other members. He would also have an occasional emotional outburst resulting in him exiting the class session. At the time of the interview, Kevin still used the quad cane to ambulate and presented to the interview with a calm and reflective mood.

Hannah participated in the 2016 Healthy H.E.A.R.T.s cohort. Her stated goal for class participation was to learn how to manage her diabetes. Prior to her most recent stroke, she was not employed. After experiencing three strokes, her short-term memory has been significantly affected and she uses compensatory methods to help her remember important information. Her comorbid risk factors include type 2 diabetes, hypertension, morbid obesity, physical inactivity, previous history of strokes, and being a former smoker. During her participation in the Healthy H.E.A.R.T.s class, she presented with a timid yet receptive demeanor and was able to ambulate without assistance. During the interview, her demeanor was informed and confident. Hannah lives with her roommate who also serves as her primary caregiver. Her roommate is very involved with her care and actively participated in the class and in the interview.

Michael was a participant in the 2016 Healthy H.E.A.R.T.s cohort. His goal was to learn more about what caused his stroke and how to manage his risk factors. Prior to his stroke, he was employed as a cook and was independent with all aspects of his health

and mobility. After his stroke, he has right hemiparesis and performs his daily activities slowly due to the decreased strength and coordination in the extremities. He uses a cane for mobility during the class and during the interview. He is able to use his affected arm and hand for some activities. His comorbid risk factors include hypertension, mixed hyperlipidemia, and he currently smokes approximately five cigarettes per day. Michael was very open about the emotional and physical changes he experienced following his stroke and offered support to his peers in the class. His level of engagement was the same during his 1:1 interview.

Oscar was a participant in the 2016 Healthy H.E.A.R.T.s cohort. His goal was to learn about his risk factors and what actions he could take to prevent another stroke. He also expressed a desire to return to work. Prior to his stroke, he was gainfully employed and independent with all aspects of health, activities of daily living, and mobility. After his stroke, Oscar experienced left hemiparesis and changes in thinking and memory. As a result, he used a cane for mobility during his class attendance. His comorbid risk factors include type 2 diabetes and hypertension. During the SSMP class, he was attentive and was observed to contribute to the class discussion when requested by the facilitators. This demeanor continued during the interview.

Amy participated in the 2017 cohort of the Healthy H.E.A.R.T.s class. Her goal for participating in the class was to learn how to control her high blood pressure and learn how to be healthier so that she could take care of her husband and two toddler-aged children. Prior to her stroke, Amy worked as a caregiver and was independent in all

aspects of her health, activities of daily living, and mobility. After her stroke, she has aphasia and right hemiparesis that has resulted in no movement in her arm or hand. She uses a cane for mobility. Her comorbid risk factors include coronary artery disease and hypertension. Amy's demeanor was cheerful during the class and the interview. She laughed and interacted with the class participants well. She experienced moments of tearfulness in the class and during the interview when discussing how her life had been changed since her stroke. Amy's spouse was present, active, and supportive during the class as well as during the interview.

Demographic data for the five participants are presented in Table 1.

Table 1.

Demographic Information

Participant	Gender	Stroke Onset	Age*	Ethnicity	Education	Marital Status	Living Situation	Annual Income	Insurance Coverage
Kevin	Male	2015	59	Biracial Native American and Spanish	College Degree	Single	Lives alone	\$12,001- \$20,000	Uninsured/ Self Pay
Hannah	Female	2005, 2015 x2	49	Caucasian	College Degree	Divorced	Lives with room mate	≥ \$12,000	Uninsured/ Self Pay
Michael	Male	2016	53	African American	Some College	Widowed	Lives alone	> \$12,000	Uninsured/ Self Pay
Oscar	Male	2016	62	Hispanic	No formal education	Single	Lives alone	> \$12,000	Uninsured/ Self Pay
Amy	Amy	2016	28	African American	Less than 12 <sup>th</sup> grade	Married	Lives with spouse and children	\$20,001- \$30,000	Uninsured/ Self Pay

<sup>\*</sup>Age at the time of the interview

# **Quantitative Results**

To answer the first research question, pretest and posttest versions of the Health-Promoting Lifestyle Profile II were analyzed. The results of the five participants were reported as individuals and as a group and analyzed together. SPSS version 20.0 was used for all data analyses. The mean for all 52 items was calculated for the pretest and posttest. As can be seen in Table 2, the scores for the group on the Health-Promoting Lifestyle Profile II scale increased from the pretest period (M = 2.62) to the posttest period (M = 3.08). These data are presented in Table 2.

# Item by Item Analysis.

Each question on the 52-item Health-Promoting Lifestyle Profile II was analyzed to identify significant differences in the pre- and posttest data at the level of each question of the scale. Results of this analysis for the items that comprise this show statistically significant differences exist with respect to the following questions:

- Question 36 (Find each day interesting and challenging) Wilcoxon signed rank test (z = -2.000, p = 0.046), pretest period (M = 2.60), posttest period (M = 3.40);
- Question 39 (Ask for information from health professionals about how to take good care of myself) Wilcoxon signed rank test (z = -2.070, p = 0.038), pretest period (M = 2.00), posttest period (M = 3.40);

- Question 45 (Attend educational programs on personal health care) Wilcoxon signed rank test (z = -2.000, p = 0.046), pretest period (M = 1.80), posttest period (M = 2.60);
- Question 49 (Settle conflicts with others through discussion and compromise) Wilcoxon signed rank test (z = -2.000, p = 0.046), pretest period (M = 2.20), posttest period (M = 3.00);
- Question 52 (Expose myself to new experiences and challenges) Wilcoxon signed rank test (z = -2.070, p = 0.038), pretest period (M = 2.20), posttest period (M = 3.60).

To answer the second research question, the pretest and posttest versions of the stroke-specific version of the Perceived Medical Condition Scale were analyzed. The five participants were treated as one group and analyzed together. SPSS version 20.0 was used for all data analyses. Questions #1, #2, #6, and #7 of the pretest and posttest versions of the Perceived Stroke Medical Condition Self-Management Scale were reverse coded as per the instructions of the scale. The mean for all eight items was calculated for the pretest and the posttest. As can be seen in Table 2, the scores for the Perceived Stroke Medical Condition Self-Management Scale increased from the pretest period (M = 3.48) to the posttest period (M = 3.80).

Table 2.

Means and Standard Deviations (n=5)

	Pre-Test Mean (SD)	Post-Test Mean (SD)	Change score	
HPLP II				
Participant				
Kevin	2.90	3.01	.11	
Hannah	2.48	3.51	1.03	
Michael	2.90	3.11	.21	
Oscar	2.34	3.55	1.21	
Amy	2.28	2.60	.32	
Group Mean	2.62 (0.23)	3.08 (0.34)	.80	
SS-PMCSMS				
Participant	Pre-Test Score	Post-Test Score	Change Score	
Kevin	30	28	-2	
Hannah	20	24	+4	
Michael	27	32	+5	
Oscar	33	30	-3	
Amy	29	36	+7	
Group Mean	27.8	30	+2.2	

HPLP II: Health-Promoting Lifestyle Profile II

SS-PMCSMS: Stroke Specific version of the Perceived Medical Condition Self-Management Scale

Raw scores are listed. Maximum score is 40. Higher score = increased perception in ability to self-manage stroke condition

# **Qualitative Results**

The second part of this study was to explore the ways participation in a SSMP influences the occupational adaptation process to achieve relative mastery. To address this aim, four subquestions were asked:

- 1. How does participation in a SSMP influence the OA process?
- 2. How does the environmental demand of a SSMP promote or discourage self-management?
- 3. How is the desire to improve personal control over self-management affected during participation in a SSMP?
- 4. How are efficiency, effectiveness, and satisfaction perceived and affected as a result of participation in a SSMP?

The interview guide was developed to answer these questions was categorized by topic. Interview Questions #3 through #9 directly addressed Subquestion 1, and Interview Questions #1, #2, #5, #6, and #8 of the interview guide addressed Subquestion 2.

Subquestion 3 was addressed by interview questions #4, #7, #9, and #10 thorough #12.

Finally, Subquestion 4 was addressed by Interview Questions #3 through #9. A copy of the interview questions can be found in Appendix D.

### **Interview Data Analysis**

Each qualitative interview was manually transcribed verbatim and coded by the primary researcher and three independent coders. A hybrid coding format was used (Hedlund de Witt, 2013). Hybrid coding is the use of two or more coding methods that

are integrated into the data analysis to strengthen the trustworthiness of the analysis. The primary researcher used four techniques as part of the hybrid coding strategy. First, preset codes were identified based on key concepts from the theoretical concepts in the study. A line-by-line analysis of the transcript was then performed, and pattern coding, a technique used to identify repetitions in the data, was applied to the data. Additional codes were added as they emerged from additional readings of the interviews.

Additionally, the researcher used reflective journaling to capture thoughts and ideas about the themes that emerged from the interview transcripts. Once done, an independent coder used a line-by-line coding technique, and two additional coders used a descriptive coding technique. The list of codes developed from all coders for all five participants was compiled, compared with one another for similarities, and then refined to develop 12 separate coding categories. A total of four themes were identified from these twelve coding categories for the data collected from all five participants. An audit trail was developed for the interviews of Kevin, Hannah, Michael, Oscar, and Amy.

#### **Themes**

The OA theory assumes that every human being has a desire for mastery. Based on the interview data, it can be said all participants had expressed the desire to make a change and to learn more about their health to entering the Healthy H.E.A.R.T.s class. In addition, four major themes were developed from analysis of all five cases (see Table 3). The four themes revolved around knowledge acquisition, behavioral change, personal responsibility, and evaluating outcomes.

Theme 1: Knowledge acquisition promoted a need for change, generating an adaptive response. All five participants reported that they did not know much about stroke and how it affected them following their stroke prior to participating in the SSMP.

All of these participants acknowledged an increased awareness and understanding of their health and personal risk factors for stroke. Each participant discussed how their awareness of their health and knowledge of stroke changed as a result of participating the Healthy H.E.A.R.T.s class. For example, Hannah stated, "I wasn't really sure what I needed to be doing" (Line 22). She also reported, "There was a lot of stuff I learned in that class that I'd never known before" (line 169-170).

Oscar talked about having a desire to get better following his stroke and prior to taking the class but was not sure how to do it when reporting "I just wanted to get better...but I don't know how to do it" (Lines 106-107). Kevin had a similar attitude and reported, "After I took the Healthy H.E.A.R.T.s program, I started paying more attention to what I was doing when I was eating" (Lines 148-149). Along these same lines, Michael stated, "I pay more attention now to the things I do now than I did before my stroke" (Michael, lines 589-590).

The participants discussed how this new knowledge helped to utilize core selfmanagement skills and as their confidence ability to self-manage their stroke condition, they being to share their new knowledge with others.

Subtheme A: Communication with healthcare providers. As the participants began to acquire the necessary knowledge and skills to manage aspect of their health after

stroke, Kevin, Hannah, Michael, and Oscar reported increased confidence when communicating with their health care providers. When asked by the interviewer about their interaction with their health care providers, these four participants specifically discussed their experiences with their health care professionals. They reported that they regularly attend their doctor's appointments and therapy appointments, that they were able to ask questions of the health care professionals, and that they were able to understand the information provided.

Subtheme B: Sharing learned information. As the participants began to master elements of their self-management program, they began to share their knowledge with family and friends. Hannah and Michael talked about how they shared the information they learned with family members and friends as a way to encourage them. Michael talked specifically about how he shared information with a family member, and as a result, the family member made lifestyle changes.

"I also helped my brother. He was four hundred and seventy something pounds and he was asking me how did I lose my weight and I said, I asked him, I did just like you, I said, what your portion look like on your plate?" (Michael, line 444-447).

Hannah's roommate reported making lifestyle changes as she learned along with the participant during the classes. She stated that she "did not realize that so much contributed to someone having a stroke and could be repetitive. So it's helped me. I've quit smoking since the program" (Hannah, lines 500-504).

Theme 2: Behavioral change and adjustment in routines – internal desire for change. All five participants reported a desire to make changes in at least one aspect of their health as a result of the information learned in the class. The following subthemes support this point. Three subthemes leading to behavioral change based on a desire for change were monitoring vitals and medication adherence, diet and nutrition changes, and coping and stress management.

Subtheme A: Monitoring vitals and medication adherence. Participants reported increased monitoring of blood pressure, blood glucose (if diabetic), and energy expenditure during exercise as a regular part of their routine following SSMP participation. Michael reported taking his blood pressure twice day, "once in the morning, once at night" (Line 411).

Adhering to medication regimen was reported as a challenge for Kevin and Amy prior to participating in the SSMP. Both reported increased adherence to medication regimen following class participation. Kevin discussed this change as he described the struggle prior to class participation: "I was kinda dragging my feet you know? Cause I was getting tired of taking them. And now I'm not tired of taking 'em. I know it's gonna make me feel better" (Lines 70-71, 73-74). Amy, who has hypertension, discussed her challenges with adhering to medication routine reporting that prior to the stroke; she was not taking her medicine at all. Her spouse noted that "after the stroke, before Healthy H.E.A.R.T.s it was um, she was taking the medicine, but not…every day… because… it was making me sick" (Lines 64-66; 71). She further reported that after changing her

medication, she no longer has side effects as she now adheres to medication regimen and is able to set up and organize all of her own medications and takes them as prescribed. She did not perform these actions prior to SSMP participation. Kevin discussed how he changed his nightly regimen when reporting "at night time when I go to bed I make sure I take all medication. I always make sure I eat a snack before I go to bed." When asked why, the participant elaborated stating, "It helps my, my blood sugar from... skyrocketing" (Lines 75-77; 79).

Subtheme B: "You really have no idea if you're not measuring it." Nutrition was another topic that all participants spoke about when discussing changing their health since the program. A good example of this point is found in the comment of one of the participants: "I've learned a lot about my eating habits from Healthy H.E.A.R.T.s."

(Oscar, line 17). Oscar discussed how he tried to eat foods from all five food groups to eat balanced meals to help manage his eating and health.

Removing unhealthy foods and increasing consumption of healthier foods were also strategies used by two of the participants. Amy reported cutting out fried foods and candies from their diet and eating more vegetables when stating, "we eat a lot of vegetables. Like, a lot of frozen vegetables" (Line 215). Michael supported this statement during his interview who noted that "I quit drinking caffeinated coffee... I don't even drink soda that much no more" (Lines 440-441) and reported instead that he drinks a lot of water and juices and "I been eating a lot of fruit" (Lines 443-444).

Food substitutions and monitoring portion sizes were strategies that were discussed by two of the participants as a way to make a healthy lifestyle change. Kevin, who has diabetes, discussed how he managed his portion sizes when reporting that "instead of eating like 2 or 3 hamburgers...I just eat 1 hamburger and that's it" (Lines 46-47, 50). Hannah, who also has diabetes, reported that she closely monitors her food by measuring her portions:

"serving sizes, which before sometimes you look on the back of a bottle and you see the fat or the sugar content, and that's all I would only look at and then eat all of it or drink all of it and not realize it was more than one serving ... you really have no idea if you're not measuring it" (Hannah, lines 29-32; 46-47).

Hannah shared that despite her efforts to change her eating patterns and adhere to her medication as well as exercise regimen, she experienced another stroke after participating in the class. She reported that it was "frustrating cause, even when I felt like I'm doing good... then I still have strokes" (Lines 250-251, 253). Hannah reported experiencing another stroke since participating in the SSMP. She stated that even though she experienced this setback, she continued to use the tools she acquired from the SSMP to help her maintain her health.

Subtheme C: Managing stress and staying away from negativity. Another area that participants discussed was their response to the social and psychological stressors present in their respective environments and how that had changed following their participation in the Healthy H.E.A.R.T.s SSMP. Stress was mentioned as a factor by

three participants. Kevin discussed how he became aware that stress was affecting him and described how he adapted his response to stress. He reported, "when I'm not calm and something bothers me, my blood pressure goes up" (Lines 229-230). He went on to say that when he begins to feel stressed he "sat down and watched TV and relaxed...or go walking (Lines 237, 238). Michael discussed the effects that stress had on him and how his coping mechanisms had changed. He reported "I don't get angry anymore, I don't let nobody stress me out. Cause stress what causes, I think, stress and alcohol cause me to have my stroke" (Lines 398-400).

Theme 3: Increased proactivity and personal responsibility – occupational response. All participants reported taking a more active role in their health in at least one area that contributed to their stroke risk. As the participants learned how to properly self-manage their stroke condition they reported responding to occupational challenges in new ways including: maintaining a regular exercise regimen, utilizing social support to promote health, and finding or resuming productive occupations.

Subtheme A: "Without exercise, you just fall back into your same routine." All participants discussed a change in exercise routine, whether beginning an exercise routine or adjusting the exercise routine. Oscar stated, "Sometimes I don't have enough energy to exercise, but, I try to do everyday when I get, before I go to sleep and in the mornings when I, before getting out" (Lines 85-87). In discussing the effects of exercise on health, Hannah reported, "with the exercise I was surprised that your blood pressure actually goes down" (Lines 189-190). Hannah also began to incorporate more exercise into her

daily routine. Kevin discussed how exercise had become a part of his regular routine. He began using a local community center that provided exercise equipment and different activities, and he talked about his regular use of the pool, weight machines, and walking for exercise. He talked further about how exercise had helped him to maintain his health when noting, "exercise is everything. Without exercising, you just fall back into your same routine" (Kevin, lines 313, 315-315).

Amy, however, discussed her lack of motivation to maintain a regular exercise regimen even though she knew it would help her reach her health goals. She stated, "I don't exercise, cause I don't know why I, I don't exercise" (Lines 278-279).

Subtheme B: Effects of physical, social, and cultural environment on adaptation. The presence or absence of social support and its impact on the participants' health after stroke was also discussed. Hannah and Amy both had caregivers present and, with consent of the participants, both caregivers were actively involved in the interviews. Aspects of socialization were discussed as either being stressful or used as a coping mechanism to manage their health and adjust to life after stroke. Kevin reported that one method he uses to manage his stress is to "stay away from negative people" (Line 255). Michael discussed how his sister helped to encourage him and keep him on track with monitoring himself. He also discussed how he changed his social environment to keep his stress level low. He describes, "if I'm around you and I don't like the way I'm feeling around you and it's...I stay away from stress. I stay away from drama" (Lines 584-586).

Subtheme C: Productive occupation and leisure interests. Several participants discussed how the discovery or resumption of preferred occupations and/or leisure interests helped to maintain the management of their health in positive ways. Michael discussed how he has discovered new hobbies such as gardening, cooking, and sketching as means to stay productive. He also talked about how his role as a grandfather and caring for his granddaughter has given him motivation. He stated, "My plants and my grand baby that's therapy for me" (Line 704). Amy discussed her satisfaction with the ability to perform the necessary occupations in her role as a mother to young children reporting, "I take care of them. I bathe them and clothe them and feed them" (Lines 317-318).

Theme 4: Evaluating response outcomes: Physiological and emotional changes in health. All of the participants discussed how their behavioral and lifestyle changes had affected their physiological and emotional health, including changes in risk factor values and increased confidence with managing aspects of their stroke condition. More specifically, several participants reported that as they became more effective and efficient in self-managing aspects of their health, they began to notice changes in their health and vital signs including decreased blood pressure, decreased blood sugar and weight loss. Amy stated that prior to participating in the class, "my blood pressures would be like 200 or, and the bottom will be like 100 or something and the class help me learn about controlling my blood pressure" (Participant 105, lines 202- 204). She went on to say that at the time of her interview her blood pressure readings were "117 and the

bottom number like 87 or 82" (Lines 473-474). When Amy was asked how she viewed her health since being in the Healthy H.E.A.R.T.s class, she responded by noting that it was "a priority" (Line 477).

Hannah discussed how her insulin dosages had decreased due to her having better control of her diabetes following her participation in the class. She reported, "it's made my blood sugar come down they've lowered my insulin down some" (Lines 52-53). She went on to say, "I feel more confident in making food choices, and portion control, definitely" (Line 157-158). Her caregiver, who was present and contributed to the interview at the participant's consent, further elaborated on the behavioral changes she had observed in Hannah when stating that the she was:

"settling into what and who you had become, I think. And then after the program you thought, well, I can make a difference, I can change some things... made you realize that, you know, you can control some of this you know" (Lines 396-398, 404-405).

#### Hannah affirmed this statement.

Michael discussed the emotional impact that the stroke had on him and how his perspective of his health has changed following his participation in the Healthy H.E.A.R.T.s class. He reports, "having this stroke this stroke, it really, psychologically and physically it, it tore me down a lot... before the Healthy H.E.A.R.T.s program I was kind of like, almost kind of at the point of giving up." (Lines 61-62, 64-66). Michael went on to state, "I made up my mind that I'm not gone let this beat me and I'm not gone let

this beat me up" (Lines 264-265). He reports feeling more patient and having more control over his health choices and his environment.

Kevin described the changes he made to his diet, his exercise, and taking his medications as prescribed. As a result, he reported that he lost weight from 225 pounds to 171 pounds and that his A1C test used measure his diabetes control had returned to normal. When asked about his satisfaction with his health and his ability to implement and maintain healthy lifestyle changes following his participation in the Healthy H.E.A.R.T.s class he reported, "I'm real happy with myself now" (Line 349).

Once the quantitative and qualitative data were analyzed, the results were brought together for interpretation. The goal of this interpretation was to determine where areas of convergence and divergence exist within both the qualitative and quantitative data. This was done by comparing the results of the HPLP II and SSMP findings to the themes reported within the interviews. Data that was found to not overlap between the qualitative and quantitative data was also identified as an exercise in data divergence.

Interestingly, there were five questions on the HPLP II that were found to be statistically significant in the pre and posttest data. The five questions were:

- 36. Find each day interesting and challenging.
- 39. Ask for information from health professionals about how to take good care of myself.
  - 45. Attend educational programs on personal health care.
  - 49. Settle conflicts with others through discussion and compromise.

### 52. Expose myself to new experiences and challenges.

This statistically significant result in the quantitative analysis dovetailed with the participants' reports of increased comfort with communicating with health care professionals, regularly attending their health care visits, and understanding their health post stroke. Question #45 regarding attendance in educational programs on health care in the quantitative data was also discussed by all five participants during their interviews, as each had participated in the Healthy H.E.A.R.T.s stroke self-management program.

Question #49 in the quantitative data asked participants about their self-reported ability to settle conflicts through discussion and compromise. This finding paralleled what was found in the qualitative data theme of stress management and staying away from negativity in the qualitative analysis. Questions #36 and #52 in the quantitative data both fell into the spiritual growth subscale of the HPLP II assessment and were similar to the theme that several of the participants' reported in terms of increased interest and engagement in productive occupations, discovery of new leisure interests, and improved outlook on their health.

While there were several areas of overlap between the quantitative and qualitative data, some areas that did not overlap. For example, the scores from the stroke-specific Perceived Medical Condition Self-Management Scale, an assessment used look at the participants' self-reported confidence in self-managing aspects related to their stroke, increased with some participants, but declined with other participants. However, all five participants discussed the change in confidence, effectiveness, efficiency, satisfaction,

and ability to manage aspects of their health during the interviews. Participants identified medication adherence, monitoring vitals, changes in diet and exercise, and coping mechanisms as relevant during the interviews. The participants' interview data do not align with the findings in the quantitative data.

Overall, the results found in the quantitative data largely align with the participants' experiences as described in the qualitative interviews. Each of the five participants reported changes in their personal perspectives of their health, understanding of their health, and took an increased active role in self-managing at least one aspect of their health. A summary of the results can be found in Figure 2.

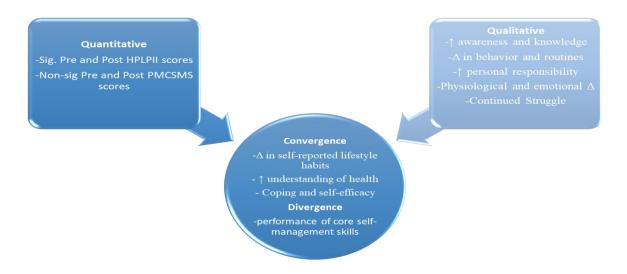


Figure 1. Integration of quantitative and qualitative results.

Table 3.

Overall Qualitative Themes

Themes	Illustration
Theme 1	"There was a lot of stuff I learned in that class
Knowledge acquisition promote a need for change, generating an adaptive response.	that I'd never known before."
Theme 2	"It's become part of our routine."
Behavioral change and adjustment in routines- intrinsic motivation	
Theme 3  Increased proactivity and personal responsibility- occupational response	"I feel like I have more control in um, my choices that I pick, and how they affect my body."
Theme 4 Evaluating response outcomes: experiencing physiological and emotional changes in health	"my blood pressures would be like 200 or, and the bottom will be like 100 or something and the class help me learn about controlling my blood pressure"

### CHAPTER V

### DISCUSSION AND CONCLUSION

### Introduction

This study examined the impact of a 12-week stroke self-management program on the occupational adaptation process in persons that have experienced stroke. Self-management is the active participation in the health promoting behaviors to in the day-to-day management of a health condition. The components of self-management are built on the concepts of self-efficacy theory. Occupational adaptation, a normative process is experienced when a person is presented with an occupational challenge. The person uses an adaptive process that is reflected in a change in perception and behaviors in order to master the challenge.

Five participants took part in this research study. The results of this study support the constructs of self-management including the development and application of the five self-management tools to address the medical, emotional, and role management aspects of the participant's stroke related health. The participant's occupational adaptation process was evident as they adapted their behaviors and perceptions to meet the occupational challenges they encountered in the environment. Each participant experienced a level of adaptation necessary to master at least one aspect of his or her stroke related health. The level of occupational adaptation experienced by the participants varied. While some participants were able to master one area of their stroke related

health, other participants were successful with managing more than one aspect. The influential factors for these results will be discussed below.

### **Discussion**

Each participant exhibited changes that reflect the themes and major theoretical concepts. Kevin began this study as a survivor with multiple comorbidities and difficulty identifying successful strategies to manage aspects of this stroke related health. As a result of this process, Kevin increased in self-reported engagement in healthy lifestyle behaviors as noted by his score on the HPLP-II. His self-reported perception of this ability to self-manage his stroke condition decreased as noted in his score on the SS-PMCSMS. However, Kevin discussed how he used self-management tools to improve his health including communicating with his health professionals, utilization of community resources, and using specific coping strategies to manage his emotional health. Kevin adapted several behaviors including a reported changed in his diet and nutrition through portion control and adapted his daily routine to incorporate regular exercise to improve his health after stroke. Through his experience, Kevin expressed improved satisfaction, effectiveness, and efficiency with his ability to manage his stroke related health following his participation in the SMMP.

Hannah entered the Healthy H.E.A.R.T.s SSMP with a reported desire to learn how to manage her diabetes, which was a primary risk factor for her recurrent strokes. Hannah scores improved on both measures, the HPLP II and SS-PMCSMS. Hannah's ability to utilize self-management techniques to increase monitoring of her food portions

was communicated in her interview. Her adaptive process was supported by the presence of a caregiver who helped her maintain an exercise regimen. As a result of Hannah's participation in the SSMP, she experienced improved satisfaction and self-efficacy in her ability to manage aspects of her stroke related health and this was demonstrated by a reported decrease in her diabetes medications. While she was successful in many aspects of self-management, she reportedly experienced another stroke that resulted in a setback.

Michael entered the SSMP with expressed difficulty with managing his hypertension and managing his emotions. Michael's scores on both the HPLP II and SS-PMCSMS improved. His self-reported improvements demonstrate improved medical management by monitoring his vitals and emotional management by utilizing of health coping strategies. He accomplished this by identifying productive leisure interests, and assuming a new role in his family as grandfather that provided a source of motivation for him to continue his healthy habits. Michael adapted his responses to social and environmental stressors by limiting his interaction with people who increased stress and changing living environments to limit external influences. Michael's adaptation through his participation in the SSMP further demonstrates the benefit of this type of program.

Oscar's score on the HPLP II indicate improved participation in self-reported healthy behaviors however, he had a decrease in his SS-PMCSMS score. He demonstrated adaptation in his lifestyle behaviors through changing his diet to include balanced meals. He reported increased awareness of his stroke risk factors and self-monitoring of his blood glucose. Oscar reported a decrease in his perceived ability to

self-manage his stroke related health and demonstrated some difficulty adapting other areas of his behavior. This difficulty might be due to lack of social support and environmental demand to return to gainful employment.

Amy improved on both the HPLP II and SS-PMCSMS measures. The presence of consistent social support was an influence in her successful adaptation. Amy adapted her daily routines to improve the medical management of her condition through increased medication adherence and role management by adapting her behaviors to perform of role as a mother. Amy struggled with adapting her behaviors to perform exercise regularly. Amy indicated increased satisfaction and self-efficacy in her ability to manage aspects of her stroke related health and perform her desired occupations.

The participants as a group improved their ability to self-manage and adapt considerably. The influences of self-efficacy, self-management, and occupational adaptation will be further discussed in relation to the results.

### **Influence of Self-Efficacy**

Several of the participants discussed identified components of self-efficacy that were changes as a result of their participation in the SSMP. The group format of the SSMP helped to facilitate self-efficacy behaviors. Peer support, learning from others' successes and challenges in similar conditions through vicarious experience as well as verbal persuasion given from the therapists were all discussed as influential factors to increasing the participant's self-efficacy. These themes of external motivation and

vicarious experiences are similar to findings identified a study of neurologically disabled adults by Dixon, Thorton, and Young (2007).

Increased self-efficacy was also demonstrated through the participants' acknowledgement of engaging in new experiences and challenges. This finding is correlated in the qualitative and quantitative data and supports Bandura's (1977) assertion that as person has mastery experiences they are more likely to engage in new experiences. Participants with spouses or caregivers also talked about the importance of social support to promote self-efficacy.

Social persuasion, another component of self-efficacy was demonstrated as participants became more confident with their ability to understand the information being provided in the class and began to take more responsibility for their health. Michael, began to share this health information with family and friends to encourage them to make changes in their health, demonstrated this. This finding is important because it suggests that the impact of a program such as the stroke specific SSMP can be impactful beyond the participants.

Lastly, the subtheme, "changes in physiological and emotional health"; spoke to the fourth component of self-efficacy, emotional or physiological state. During the interviews, participants reported less apprehension and feelings of depression. They also reported improved use of healthy coping strategies, an increase in energy, near normal or normal vital signs, and an increased confidence understanding and appropriately handling tasks required in caring for themselves to maintain their health following stroke.

## **Occupational Adaptation Process**

All participants in at least one area achieved the OA goal of engagement in preferred life roles. Each participant was able to develop an appropriate adaptational response to meet the demand from the occupational environment. The participants initially reported incongruence between the demand for mastery of these skills by the occupational environments, primarily work, and self-care aspects, yet were not successful in adequately rising to level to meet the press (i.e., interaction with the environment) and meeting the occupational challenge. The occupational challenges experienced and described by Kevin and Amy in their respective interviews reflect this press. The occupational challenges necessitated that the participants make changes in their perspective, level of engagement, or daily routine to meet the environmental demand to move toward mastering aspects of their stroke self-management. Michael, Oscar, and Hannah's stories demonstrate how this adaptation occurred.

Stroke Self-Management Programming and the Occupational Adaptation

Process. Many of the participants reported that participation in the Healthy H.E.A.R.T.s

class gave them tools to begin to make the adaptation. Knowledge acquisition was a vital
component to facilitate the adaptation process. These tools ranged from the knowledge
of stroke and identifying their personal risk factors as well as sharing information about
their experiences with their peers. As the participants became more aware, they begin to
apply the knowledge that they learned and could share what strategies were successful
and what strategies were not successful. Other tools were the provision of personal blood

pressure monitors and MyPlates that allowed participants to regularly monitor their vitals and nutritional intake to make dietary changes. Michael and Hannah reported how using the MyPlate during meal times helped to provide a visual cue of the amount of food and types of food they were consuming, and as a result, improved portion control and awareness to select foods that helped them to have a balance diet. These tools helped the participants adapt their current responses to the environmental demands, which, prior to participation in the SSMP, was reportedly maladaptive and inconsistent. This issuance of these type of tools to remove potential hindrances to self-management within stroke specific programs has not been previously reported and may facilitate the participants' ability to adapt successfully.

Environmental Demand and Occupational Adaptation. The environmental demand placed on each participant was variable. Schkade and McClung (2001) identified the components of the occupational environment as including work, play/leisure, and self-care. In the participants, at least one or more of these areas had been disrupted by the experience of stroke. Each of the stroke survivors had been affected in one or more of the three identified person systems, described in the OA framework to include the following areas: sensorimotor, cognitive, or psychosocial. These changes affected the participants' ability to develop an adaptive response, and as a result, changed the way that each of them interacted with their environment. For example, Kevin, a participant who experienced hemiparesis (i.e., a change in the sensorimotor person system) developed a way to adapt his exercise regimen to participate in the recommend amount of exercise.

Michael, who reported being heavily affected in the psychosocial person system, had to adapt his responses to others in his social environment to help manage his stress.

Role expectations were important to many of the participants. Kevin, Michael, Oscar, and Amy were employed prior to experiencing their stroke and were not able to work following the stroke. Three of these participants were male, single, and the sole income earners in the home. A return to work was listed as a motivating factor for these participants and served and the driving desire to adapt. Kevin desired to return to work, but due to significant left hemiparesis following his stroke he was not able to use his left arm or hand. He expressed difficulty meeting the environmental demand. While he was not able to return to his previous work role, he changed his environment and found a local community center with an adapted exercise program and social activities that he frequented. Oscar reported success with adaptation in his sleep, exercise, and diet regimen to improve his health. At the time of the qualitative interview, he had resumed employment with regular hours. Michael, at the time of the interview, had performed occasional work as a cook, his previous occupation, but had adapted his work responsibilities to meet his current capacity. At the time of his interview, he reported 90% satisfaction with his current level of ability and engagement in his desired occupation. One of the female participants, Amy, expressed a desire to adapt her occupations in order to resume role responsibilities as a mother to young children. The results of the qualitative show that the desired area of change and adaptation was different for each participant based on the demands of the environment and role expectations. These

findings are in alignment with findings from Gibson and Schkade (1997) study that found that when role expectations were considered during the intervention process, functional independence was improved when an OA approach was used.

Desire and the Occupational Adaptation Process. All of the participants reported an increase in desire to make changes. Hannah and Michael discussed how they had almost given up or had become complacent with living with the changes after their stroke prior to participating in the SSMP. Words such as "empowered" and "control" were used to describe the change in personal control and responsibility following SSMP participation. Several of the participants described feeling more control over their decisions and choices regarding their environment, response to stressors, and diet. This may be due to the tools provided in the SSMP that the participants identified as successful.

Program. All of the participants initially reported low mastery of certain aspects of their health. During the qualitative interview, it was the case that diet, an exercise regimen, and coping were often reported as areas where maladaptive responses were present.

These reports were supported by the increase in the posttest scores on the HPLP II assessment. The results correlate with the findings in a study conducted by Dolecheck and Schkade (1999) that reported that engagement in personally meaningful occupations was improved when an OA approach was used.

The presence of the occupational therapist in the SSMP intervention helped to shape the adaptive response generation process concept that is identified by the Schkade and McClung (2001). This may be due to the provision of education and opportunities for group process, problem solving, and learning about their stroke, personal risk factors, and healthy lifestyle factors. The structure of SSMP was such that the participants had a guided process to adapting to new habits and lifestyles and strategies to promote adaptation.

## **Influence of Self-Management**

Kevin, Hannah, Michael, Oscar, and Amy reported that they did not know much about stroke and how it affected them following their stroke prior to participating in the stroke-specific self-management program. This admission is aligned with the findings that recognition of stroke symptoms is low (Greenlund et al., 2003). Education on stroke signs, symptoms, and effects, as well as the individual participant's personal stroke risk assessment, was included in the SSMP. This information laid the foundation for skills acquisition for self-management and the ability to address the occupational challenges presented to them. Several participants discussed how the awareness of their health and knowledge of stroke changed as a result of participating and completing the Healthy H.E.A.R.T.s class.

The five core self-management skills of problem solving, decision-making, finding and utilizing resources, forming partnerships with healthcare providers, and action planning were all discussed by the participants during the qualitative interviews

and were identified as themes or subthemes in the data. Indeed, each of the participants appeared to connect to at least one of the aspects of self-management (medical, emotional, or role management) in different ways. In some participants, the ability to understand the effects of their stroke and their role in the stroke and monitoring vitals or adhering to a set medication regimen made a significant difference in their ability to monitor and understand the readings on their vital signs. As a result, they experienced more control of their risk factors including diabetes and blood pressure. For Michael, his ability to learn how to manage the emotional effects of the stroke and tools for coping was beneficial to managing stress and the participant reported increased success with taking control of his social environment to support healthy recovery and coping. Stress management and coping skills were also found to be significantly changed in both the quantitative data and the qualitative data. Another example was Amy who found significance in her ability to engage in her role as a mother. She regained confidence in her ability to manage those roles and she discussed how she prepares healthier meals for her family.

Action planning was a skill that was utilized differently by each participant. Each of the participants set short term and long term health goals during the class, but the goals were individualized and tailored to the participant's health related interests and capabilities. Kevin and Amy were focused on starting, or adhering to, a medication regimen, while Michael, Hannah, and Oscar were focused on monitoring their vital signs at regular intervals and understanding their personal stroke risk factors. Kevin, Hannah,

Michael, and Oscar changed their dietary habits using portion control or reading food labels. Kevin, Hannah, and Michael took action steps to begin or modify exercise routines. The different aspects of self-management were emphasized by each of the participants and discussed during the qualitative interviews. These findings in a stroke population are similar to results reported in an occupation based self-management program by O'Toole, Connolly, and Smith (2013).

From the researcher's perspective, it was intriguing and exciting to observe how, while seated in the same group class and receiving the same information; each participant gravitated toward and personally connected to a different component of self-management.

#### Limitations

### **Small Sample Size**

This study included five participants. Ideally, this study would have gathered data from at least 10 participants. However, time constraints on the data collection period and strict inclusion criteria limited the sample size. Additionally, the geographic region where this study was conducted experienced a major natural disaster during the data collection time frame, and several eligible participants were unable to be located after the event. This may have impacted recruitment into the study. While the sample is small, the sample was diverse in terms of age, education, gender, and ethnic background and provided rich data that was used to inform this study. To strengthen similar studies in the future, a larger sample size is recommended.

## **Demographic Sample**

This study used a small sample of English-speaking stroke survivors to examine the OA process in SSMP. The primary research is an English speaker and the assessment tools used in the study are available in English. Non-English speakers were excluded from this study for these reasons. As the US population becomes increasingly diverse, it would be interesting to examine if a similar study carried out with a larger and ethnically and culturally diverse population would yield similar results. Future research can explore how the OA process is similar or different from the results of this study.

Additionally, data on the type of stroke, time since stroke onset, and lab values can be collected in future participants. This type of information may provide some insight to what types of stroke presentations may be more successful in SSMPs and the how SSMP participants affects other stroke risk factors such as cholesterol.

#### Instrumentation

The stroke specific version of the PMCSMS was used for the first time during this study. While there is psychometric information available for its utility in other populations, the PMCSMS has not been studied or validated in a stroke population. Some of the participants reported difficulty understanding the aim of the questions that required a simplified explanation by the researcher or assistance by a family member to reread the questions and complete the assessment. While the assessment did not yield any significant results this study, its utility cannot be truly determined with such a small sample size. No formal cognitive testing was performed on the participants in the study.

This may have affected some of the participants' performance on the questionnaire's and in the interview. The addition of a cognitive screen is recommended in future studies.

There is not currently a standardized assessment to measure change in self-management for survivors of stroke; however, the development of such an assessment is needed and would be a valuable contribution to future research.

### **Theoretical Terminology**

In an effort to clearly link the qualitative interview questions to the theoretical concepts, the questions developed on the semi-structured interview guide used terminology from the theory of occupational adaptation, self-efficacy theory, and self-management. Questions using the OA terminology were difficult for several of the participants to understand, and several of them asked for clarification or rephrasing of the questions. Previous studies using the OA describe the use of OA to guide OT interventions, and the terminology is used at the clinician level. The current terminology may not be easily communicated to patients or laypersons, and future research may be warranted to adapt the terminology to be useful, easily transferrable, and understood between skilled and unskilled persons. This recommendation is echoed in a scoping literature review conducted by Grajo, Boisselle, and DaLomba (2018).

### Researcher as Facilitator

The researcher for this project also served as the facilitator for the Health H.E.A.R.T.s SSMP, and for several of the participants, was the primary OT for their outpatient rehabilitation prior to entering the SSMP. During the researcher's extended

period of time with these participants, she was able to establish a therapeutic relationship with all the participants and their families and caregivers. This served as a benefit to the study as she had earned the participants' trust and, as a result, the participants were willing to share their personal struggles and successes adapting to life after experiencing a stroke. This also provided an opportunity for the researcher to observe the participants' growth from the early stages of their recovery following stroke, observe, and support their transition into the Healthy H.E.A.R.T.s SSMP as they learned how to manage and cope with life after stroke. However, this extended period of exposure may present a bias to overestimate or underestimate the progress of the participants. The use of independent coders during the qualitative analysis, as well as standardized tools to measure change in the quantitative phase helped to reduce researcher bias.

## **Implications for Occupational Therapy**

OT practitioners are involved in the care and support of survivors of stroke along the health continuum. Occupational therapists are instrumental in assisting survivors as they adjust and adapt to life after stroke. OA describes a naturally occurring and normative process that OTs use as a frame of reference to guide evaluation and intervention planning that supports the active engagement of the individual in meaningful activity. Self-management programs facilitate the active involvement of the clients affected by long term conditions learn skills to effectively manage the day to day responsibilities of living with a chronic condition. OA theory and self-management programming, when researched separately, have both been successful in samples of

stroke survivors. The role of OT in self-management programs has been reported and supported by Parke et al. (2015). The implications of the research show that there is a role for occupational therapy to facilitate the acquisition of adapted and modified techniques to improve client participation, confidence, and the adoption of healthy habits and adjustment in daily routines to preserve health and potentially reduce risk of recurrent stroke. This can be achieved through increased roles in self-management programs and the application of OA concepts. As the number of stroke survivors continue to grow, there is an increasing interest in preserving function, secondary stroke prevention, increased personal responsibility, and maintaining quality of life. OT's focus on purposeful and meaningful engagement in occupation is uniquely suited to address this growing need.

### **Recommendations**

The development and implementation of self-management programs continue to spur interest and research in chronic condition populations. Self-management programs use a comprehensive, interdisciplinary approach and can be beneficial in medically unserved populations where access to resources are limited and health literacy is low. This type of program has been successful in a hospital-based outpatient clinic setting. However, this type of program may also be successful in community centers to increase outreach to the target population. To date, there has not been a standardized, universally recognized method to measure the effectiveness of self-management programs within a stroke population. Previous research has used assessments that measure products of self-

management such as participation and retention (Cadilhac et al., 2011), risk factor management (Song & Nam, 2015), or self-efficacy (Lee et al., 2017). The development of a standardized tool to measure self-management in stroke populations can promote uniformity in assessment and improve communication amongst researchers.

While there have been many studies and resources to promote primary prevention and stroke awareness efforts, it is also important to provide resources and study the most optimal types of programs to help stroke survivors as they learn to live with stroke and to give them the necessary tools to be successful in self-management. These types of programs can support a stroke survivor's OA process to be more effective and efficient and it may also reduce the likelihood of recurrent stroke.

### **Summary and Conclusion**

Stroke remains one of the leading causes of disability, and one in four survivors experience a recurrent stroke. Efforts to decrease secondary stroke risk and increase the adoption of healthy lifestyle changes are being used to help decrease this risk. Self-management programs use a comprehensive approach to provide tools to clients to address the medical, emotional, and role components of managing the day-to-day responsibilities of living with a chronic condition are gaining popularity as a feasible approach in populations of stroke survivors.

This study explored the process of occupational adaptation of stroke survivors who participated in a stroke specific SSMP. This study is the first of its kind to view the impact of SSMPs through an OA lens. The use of guided and supportive learning

experiences, focus on personal risk factors, individualized goals, and the provision of information and tools to support adaptation helped to support that participants change and increase personal responsibility. As a result, the participants in the study experienced mastery in areas of their lifestyle habits and improved their confidence in managing their stroke related health. The role of the occupational therapist helped to facilitate this process and served as a partner in the participants' change. The results of this study hold promise for an expanded and integral role for occupational therapists in stroke self-management programs and can support a survivor's occupational adaptation process to be more effective, efficient, and satisfied as they earn to adapt and adjust in the lifetime management of living with the effects of stroke.

## CHAPTER VI

# FIGURES AND TABLES

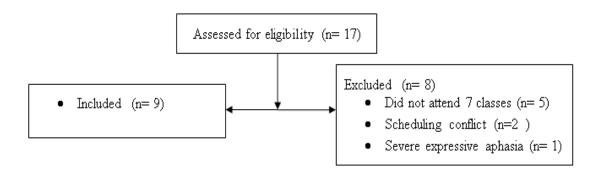
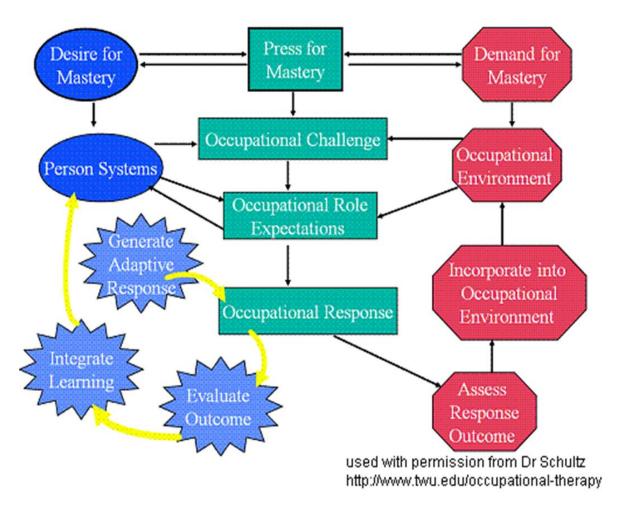


Figure 2. Participant recruitment flow chart



*Figure 3.* Occupational Adaptation Model-Normative process (Schultz and Schkade, 1992).

## EFFICACY EXPECTATIONS

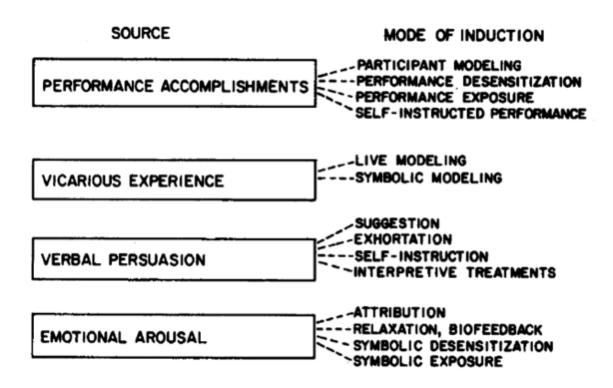


Figure 4. Bandura's modes of self-efficacay (1977)

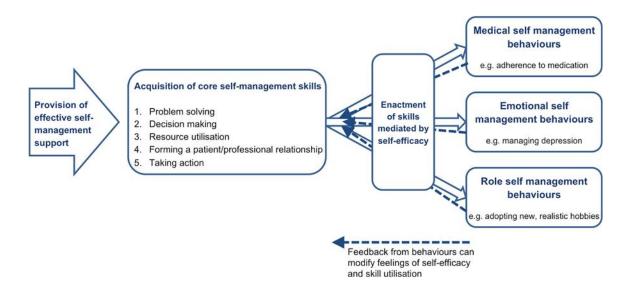


Figure 5. Integration of self-management skills. Adopted from Parke, et. al (2015)

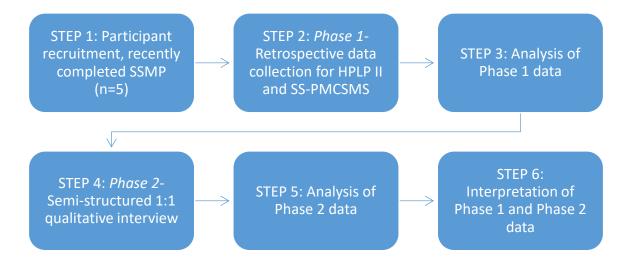


Figure 6. Methods diagram.

### APPENDIX A

### Healthy H.E.A.R.T.s Class Outline

### **MODULE 1- Building Awareness**

#### Week 1

- 1. Assessments completed PT/OT evaluation-completed Individually
- 2. Days, times, content, and patient folder provided

### Week 2

- 1. What is a healthy lifestyle?
- 2. Personal Stroke Risk Factors
- 3. Signs and symptoms of stroke
- 4. Monitoring blood Pressure
- 5. Provide BP monitors
- 6. Issue Health Log

### Week 3

- 1. Introduction to short term goal setting
- 2. Effects of stroke
- 3. Healthy Coping strategies and Changing thought patterns

#### Week 4

- 1. Coping and Caregiving
- 2. S.M.A.R.T. Goal Setting

#### MODULE 2- Building Knowledge and Making Changes

### Week 5

- 1. Activity Pyramid
- 2. Increase daily activity
- 3. Monitoring exertion

#### Week 6

- 1. Exercise types
- 2. FITT principles

#### Week 7

- 1. Food groups
- 2. Issue MyPlate

#### Week 8

- 1. Reading food labels
- 2. Calories, Salt, Sugar, and Fat

## MODULE 3- Building Carryover and Accountability

### Week 9

1. Comprehensive review of all materials

## Week 10

- Establish long term health goals
   Group led exercise

### Week 11

- 1. Exercise Modifications
- 2. Recipe Exchange

## Week 12

- 1. Discharge assessment
- 2. Class wrap-up
- 3. Review participant's scores individually

### APPENDIX B

# Lifestyle Profile II

### LIFESTYLE PROFILE II

DIRECTIONS: This questionnaire contains statements about your *present* way of life or personal habits. Please respond to each item as accurately as possible, and try not to skip any item. Indicate the frequency with which you engage in each behavior by circling:

 ${\bf N}$  for never,  ${\bf S}$  for sometimes,  ${\bf O}$  for often, or  ${\bf R}$  for routinely

1. Discuss my problems and concerns with people close to me.	NSOR
2. Choose a diet low in fat, saturated fat, and cholesterol.	NSOR
3. Report any unusual signs or symptoms to a physician or other health professional.	NSOR
4. Follow a planned exercise program.	NSOR
5. Get enough sleep.	NSOR
6. Feel I am growing and changing in positive ways.	NSOR
7. Praise other people easily for their achievements.	NSOR
8. Limit use of sugars and food containing sugar (sweets).	NSOR
9. Read or watch TV programs about improving health.	NSOR
10. Exercise vigorously for 20 or more minutes at least three times a week (such as	NSOR
brisk walking, bicycling, aerobic dancing, using a stair climber).	
11. Take some time for relaxation each day.	NSOR
12. Believe that my life has purpose.	NSOR
13. Maintain meaningful and fulfilling relationships with others.	NSOR
14. Eat 6-11 servings of bread, cereal, rice and pasta each day.	NSOR
15. Question health professionals in order to understand their instructions.	NSOR
16. Take part in light to moderate physical activity (such as sustained walking	NSOR
30-40 minutes 5 or more times a week).	
17. Accept those things in my life which I can not change.	NSOR
18. Look forward to the future.	NSOR
19. Spend time with close friends.	NSOR
20. Eat 2-4 servings of fruit each day.	NSOR
21. Get a second opinion when I question my health care provider's advice.	NSOR
22. Take part in leisure-time (recreational) physical activities (such as swimming,	NSOR
dancing, bicycling).	
23. Concentrate on pleasant thoughts at bedtime.	NSOR
24. Feel content and at peace with myself.	NSOR
25. Find it easy to show concern, love and warmth to others.	NSOR
26. Eat 3-5 servings of vegetables each day.	NSOR
27. Discuss my health concerns with health professionals.	NSOR
28. Do stretching exercises at least 3 times per week.	NSOR
29. Use specific methods to control my stress.	NSOR
30. Work toward long-term goals in my life.	NSOR
31. Touch and am touched by people I care about.	NSOR
32. Eat 2-3 servings of milk, yogurt or cheese each day.	NSOR
- · · · · · · · · · · · · · · · · · · ·	

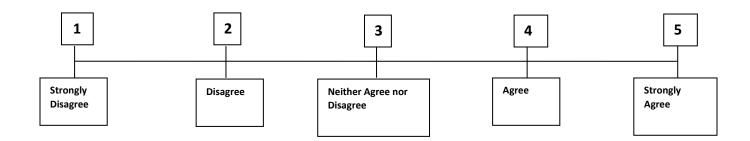
33. Inspect my body at least monthly for physical changes/danger signs.	NSOR
34. Get exercise during usual daily activities (such as walking during lunch, using	NSOR
stairs instead of elevators, parking car away from destination and walking).	
35. Balance time between work and play.	NSOR
36. Find each day interesting and challenging.	NSOR
37. Find ways to meet my needs for intimacy.	NSOR
38. Eat only 2-3 servings from the meat, poultry, fish, dried beans, eggs, and	NSOR
nuts group each day.	
39. Ask for information from health professionals about how to take good care	NSOR
of myself.	
40. Check my pulse rate when exercising.	NSOR
41. Practice relaxation or meditation for 15-20 minutes daily.	NSOR
42. Am aware of what is important to me in life.	NSOR
43. Get support from a network of caring people.	NSOR
44. Read labels to identify nutrients, fats, and sodium content in packaged food.	NSOR
45. Attend educational programs on personal health care.	NSOR
46. Reach my target heart rate when exercising.	NSOR
47. Pace myself to prevent tiredness.	NSOR
48. Feel connected with some force greater than myself.	NSOR
49. Settle conflicts with others through discussion and compromise.	NSOR
50. Eat breakfast.	NSOR
51. Seek guidance or counseling when necessary.	NSOR
52. Expose myself to new experiences and challenges.	NSOR

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### APPENDIX C

## The Perceived Medical Condition Stroke Self-Management Scale

- 1. It is difficult for me to find effective solutions for problems with managing my stroke condition. *(r)*
- 2. I find my efforts to change things I don't like about my stroke condition are ineffective. *(r)*
- 3. I handle myself well with respect to my stroke condition.
- 4. I succeed in the projects I undertake to manage my stroke condition.
- 5. I am able to manage things related to my stroke condition as well as most other people.
- 6. Typically, my plans for managing my stroke condition don't work out well. (r)
- 7. No matter how hard I try, managing my stroke condition doesn't turn out the way I would like. (r)
- 8. I'm generally able to accomplish my goals with respect to my stroke condition.



### APPENDIX D

#### **Qualitative Interview Questions**

Analysis: tape recorded and transcribe verbatim for analysis

### **Key Point/Definitions:**

Efficient: performing or functioning in the best possible manner with the least waste of time and effort; having and using requisite knowledge, skill, and industry; competent; capable

Satisfaction: fulfillment of one's wishes, expectations, or needs, or the pleasure derived from this

Self-efficacy: as one's belief in one's ability to succeed in specific situations or accomplish a task

**Prompt:** You recently completed the Healthy H.E.A.R.T.s program. These questions will seek to understand how your participation in this program has affected your ability to manage your condition and adapt to changes in your health after your stroke.

### Self-Management

- 1. Describe what actions you took to manage your health after your stroke before participating in the Healthy H.E.A.R.T.s program.
- 2. Describe what actions you take to manage your health after your stroke after participating in the Healthy H.E.A.R.T.s program.

### **OA Process**

- 3. Did you feel efficient with your ability to handle changes in your health prior to participating in the Healthy H.E.A.R.T.s program?
- 4. Before you entered the Healthy H.E.A.R.T.s program can you tell me what areas of your health your felt dissatisfied with?
- 5. Do you feel that you were effective with managing your health before participating in the Healthy H.E.A.R.T.s program? What strategies did you have? Please explain.
- 6. Do you feel efficient with your ability to handle changes in your health prior to participating in the Healthy H.E.A.R.T.s program?
- 7. Is there any area of your life or health that you feel more or less confident in since participating in the Healthy H.E.A.R.T.s program?

- 8. Do you feel that you are effective with managing your health after participating in the Healthy H.E.A.R.T.s program? Please explain. What strategies do you have? Please explain.
- 9. How satisfied are you with your ability care for yourself and manage the things related to your stroke since participating in the Healthy H.E.A.R.T.s program?

## Personal Care and Daily Activities

10. Are there any areas of your day to day activities that have changed as a result of your participation in the Healthy H.E.A.R.T.s program?

## Self-Efficacy

- 11. How did your participation in Healthy H.E.A.R.T.s affect the way you viewed your health after your stroke?
- 12. How do you feel your life will be changed now after participating in the Healthy H.E.A.R.T.s program?

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