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MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

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SCHOOL OF PUBLIC HEALTH

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by

Barbara Kimmel, MS, MSc., DrPH

DEDICATION

To my husband Marek, son Jan, daughter Katarzyna,
my parents Felicja and Zdzislaw Stankiewicz
and my mother in-law Janina Kimmel

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in Partial Fulfillment

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Summary

Background and Aims: Self-management (SM) skills help stroke survivors achieve behavior risk factors control. Goal setting and attainment are fundamental for SM. The most salient elements of SM effectiveness and measurements are just beginning to be understood. Investigation of measurement of goal attainment of SM risk factors has been the major aim of the study. My dissertation explores research questions concerning the goal attainment measure using data collected at the Veterans hospital.

Methods and Results: Introductory Chapters 1 and 2, include the background on stroke prevention through self-management interventions and a preliminary literature review of goal attainment in the context of self-management and relevant patients' experience.

Paper 1 (Chapter 3) is a systematic review of systematic reviews of outcome measures for goal attainment in secondary stroke prevention. Goal attainment has not been systematically reviewed for post-stroke patients. To address this shortcoming, I completed the review using Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. I focused on use of the goal attainment measures in research and clinical contexts, but I found no measures of goal attainment in the SM context. In addition, consensus on the SM process and its quantitation is just beginning to emerge. This might be due to the lack of clear concept definitions and their operationalization. Future research is needed to develop reliable and valid measures of goal attainment in SM.

Paper 2 (Chapter 4) is a phenomenological study of stroke survivors' lived experiences after discharge. Since little is known about survivors' experiences with adopting SM behaviors, I determined that papers systematically obtaining and analyzing data about increase of patients' activities associated with goal attainment were absent from the literature. I carried out a phenomenological qualitative study with eight Veterans to describe lived experiences of Veterans within one year of discharge and with 2 risk factors. The outcome is that SM coping behaviors and goal setting aided recovery process and improved quality of life, and hence that SM interventions hold promise in assisting stroke survivors to regain physical and emotional well-being.

Paper 3 (Chapter 5) described the design and results of a pilot test and psychometric analysis of the goal attainment measure for management of secondary stroke risk factors. I performed pilot testing of the Goal Attainment Measure-Stroke (GAM-S) scale and tested it

for usability, content validity, and internal consistency. Ten registered nurse dyads and 44 patients were recruited from Veterans Administration Medical Center. Nurses telephoned patients 2 weeks after discharge and evaluated goal attainment with GAM-S. Content validity was evaluated based on experts' rating. Patients and providers rated GAM-S with respect to ease of use, understandability, credibility and motivational appeal. Participants: $N = 44$, 95% male, 36-81 yrs, mean age 67, providers, $N = 20$, and experts, $N = 7$. Forty-two patients (95%) completed GAM-S. Most experts (71%) specified that each scale item was essential, indicating content validity. GAM-S providers' usability was high: mean score 3.7/4.0 (SD 0.24). Cronbach's α was 0.962 indicating strong internal consistency. In conclusion, the GAM-S may improve patients' self-efficacy, coping, and quality of life following stroke. GAM-S is easy to use and can be completed in a timely manner by patients and providers. It facilitates a patient-shared decision process in terms of complicated risk factor control following a stroke. The test may be improved by using more gradation in the questionnaire. Overall, the findings suggest future efficacy of GAM-S to determine its impact on patient goal setting behavior.

TABLE OF CONTENTS

List of Appendices.....	i
CHAPTER 1	1
INTRODUCTION, BACKGROUND, AIMS AND SIGNIFICANCE	
1.1 INTRODUCTION AND STATEMENT OF THE PROBLEM.....	1
1.2 BACKGROUND.....	5
1.2.1 Burden of stroke	
1.2.2 Stroke risk factors and prevention to reduce stroke and disability	
1.2.3 Self-management approach as gold standard to stroke risk management	
1.2.4 Self-management interventions in stroke risk factors control	
1.2.5 Goal setting, action planning and goal attainment measure in the self-management framework	
1.3 SPECIFIC AIMS AND RESEARCH QUESTIONS.....	9
1.3.1 Paper # 1.....	10
1.3.2 Paper # 2.....	11
1.3.3 Paper # 3.....	12
1.4 RATIONALE FOR THE STUDIES.....	13
1.5 PUBLIC HEALTH SIGNIFICANCE.....	16
1.6 DEFINITIONS OF TERMS.....	17
CHAPTER 2.....	21
LITERATURE REVIEW.....	
2.1 Goal setting as an outcome measure (goal attainment) in the context of self-management.....	21
2.2 Patients' experience with action planning and goal attainment in the context of self-management.....	28
CHAPTER 3.....	33
Paper # 1: Outcome Measures for Goal Attainment in Secondary Stroke Prevention: A Systematic Review of Systematic Reviews	
Abstract.....	33
Introduction and Background	
Purpose, Aims and Research Questions	
Methods	
Evidence Synthesis	
Results	

Discussion	
Strengths and Limitations	
Conclusions	
Future Research	
References.....	55
Appendices.....	60
CHAPTER 4.....	74
Paper # 2: Veteran Stroke Survivors’ Lived Experiences After Being Discharged Home: A Phenomenological Study	
Abstract.....	74
Introduction	
Purpose and Aims	
Design and Methods	
Study Procedures	
Data Collection and Analysis	
Findings	
Discussion	
Strength and Limitations	
Implications for Clinical Practice	
Conclusions	
Future Research	
References.....	101
Results Tables.....	105
CHAPTER 5	
Paper # 3 The Goal Attainment Measure (GAM-S) for Secondary Stroke Risk Factors Management: Pilot Test and Psychometric Analysis	
Abstract.....	112
Introduction and Background	
GAM-S Prototype Description	
Purpose and Aims	
Methods	
GAM-s Validity Testing	
GAM-S Reliability Testing	
Data Collection and Measures	
Data Analysis	
Results	
Discussion	
Limitations	
Conclusions	
Implications for Clinical Practice	
Acknowledgment	

References.....	145
Results Tables.....	150
Dissertation Conclusions.....	159
Directions for Future Research.....	162
Appendices.....	164
REFERENCES.....	193

APPENDICES

Appendix A: GAM-S Presentation for the VA Providers.....	164
Appendix B: Procedures summary handout provided for nurses during the In-Service presentations.....	169
Appendix C: Action Plan Form.....	171
Appendix D: Action Plan Attainment Measure for Stroke (GAM-S).....	172
Appendix E :GAM-S Usability Questionnaire for Patients.....	174
Appendix F: GAM-S Usability Questionnaire for Providers.....	176
Appendix G: Study Brochure.....	178
Appendix H: IRB Study Approval Letters.....	179
Appendix I: Consent Forms (Patients and Providers).....	180
Appendix J: Interview Discussion Guide.....	192

CHAPTER 1

INTRODUCTION, BACKGROUND, AIMS AND SIGNIFICANCE

1.1 INTRODUCTION AND STATEMENT OF THE PROBLEM

Chronic conditions constitute a serious public health concern in the United States (US), with most people experiencing two or more chronic conditions in their lifetime (Centers for Disease Control {CDC}; US Department of Health and Human Services; World Health Organization and Rotheram-Borus et al., 2012). Specifically, more than 125 million Americans have at least one chronic condition; and 60 million suffer with multiple conditions. It is projected that by the year 2020, one quarter of the American population will be living with more than one chronic illness, creating a cost burden in the trillions of dollars (Institute for Health and Aging, 1996).

While stroke is an acute vascular event, it is associated with multiple common chronic illnesses that compound risk for stroke (i.e., hypertension, diabetes and hyperlipidemia) (Song & Nam, 2015; Teal et al., 2012). Moreover, lifestyle choices such as smoking, physical inactivity and high-fat, high-sugar diets also increase risk for stroke and other cardiovascular diseases (CVD; Boger et al., 2015). Despite recent advances in stroke prevention and management, and the decline of incidence stroke rates in high-income countries with increased life expectancy, lifetime risk in low-income countries still remains high (Pearce et al., 2015).

According to the American Stroke Association (ASA) and the CDC, nearly 800,000 Americans suffer a stroke each year, one every 40 seconds; and stroke costs the United States \$38 billion a year. In the United States stroke has decreased from the third to the fifth leading

cause of death (American Heart Association [AHA]/ASA). However, it is estimated that, by 2020, stroke will still be a leading cause of death and disability worldwide, adversely affecting individuals' health and well-being.

Recovery from stroke as well as management of stroke risk factors to prevent another stroke has been recognized as a multidimensional and complex health behavior change process that includes management of clinical, psychological and social factors (Boger et al., 2015). Patient self- management (SM) has been identified as an important strategy to effectively address the burden of chronic diseases and to help manage patients' chronic illness more effectively (Boger et al., 2015). SM has been successfully applied to reduce stroke risk factors and to aid patients in the post-stroke recovery time with improvement to quality of life (Anderson, 2011; Boger et al., 2015; Lorig & Holman, 2003; Sallar 2010). The SM approach includes specific skills that can be adopted by patients to better control their chronic conditions. Healthcare provider support is essential to help patients develop SM skills. This involves healthcare providers working collaboratively with their patients to provide knowledge about chronic conditions and to teach their patients the skills necessary to keep their condition under control and make lifestyle adjustments to enhance quality of life (DeSilva, 2011; Foster et al., 2007; Lennon, McKenna & Jones, 2013).

The creative challenge of health related-behavior change for SM of stroke risk factors is to develop goal setting theory-based methods and to translate these methods to successful intervention programs aimed to improve SM stroke risk factors. The literature shows that health behavior change and health-related behavior goal (HRBG) setting are widely recognized as an integral part of SM, including stroke risk factors control, such as of

hypertension, diabetes, smoking, obesity and stress. Goals are internal motivation factors for human behavior. Collaborative goal setting with clinicians and patients is used to enhance patients' motivation, adherence, and autonomy and improve their satisfaction with intervention programs. It has been studied extensively as a primary skill needed for effective patient SM (Bodenheimer & Handley, 2009; Glasgow et al., 2005 and Naik et al., 2011). In addition, patients' active involvement in goal setting tends to result in a positive association between the goal-setting process and treatment outcomes (Hurn, Kneebone & Cropley, 2006). In this context, goal setting is defined as the process of establishing priorities and setting criteria for learning and performing a new behavior or for modifying behavior. Goal attainment is needed to assess and improve task performance and team work, and to evaluate progress.

Varied approaches are described in the literature concerning how patients establish HRBG and attain goals. Three major behavioral change theories that relate to the concept of HRBG setting within the context of chronic SM are Social Cognitive Theory, Goal Setting Theory, and Health Action Process Approach Theory (Bandura, 1986; Latham & Locke, 1991; Locke, 1996; Swartz, 2008). Together, they provide a stepwise process that includes establishing and monitoring goals for attaining and responding to the monitoring feedback. At the core of this cognitive process is "self-regulation," involving identification of a self-care need and initiation of a decision to change a specific behavior. This step is followed by planning and implementation of the behavior change and, ultimately, evaluation of a desirable outcome. Self-regulation and SM behaviors are important for making healthy decisions concerning chronic disease management and require individuals to have the

necessary cognitive skills for adaptive behavior, self-regulation, planning and organization. Cognitive abilities are part of the goal setting and goal attainment process. Setting, attaining and measuring HRBG constitute an important part of the successful SM process. Measuring goal attainment has been considered an important outcome measure in research concerned with post-stroke rehabilitation. Although extensive research has been done regarding the strong theoretical background of goal setting, the assessment and measures of goal attainment have not been studied, despite serious disease burden and its public health impact. According Hurn, Kneebone & Cropley, 2006, goal setting as an outcome measure in the post-stroke population has been scarce, except to measure goal attainment outcomes of older people and in the physical rehabilitation setting. It should be also noted that with the exception of the goal attainment functional recovery measure in post stroke rehabilitation, goal attainment measures as a self-directed behavior change have not been fully explored empirically. Functional recovery goal attainment is different than attainment of the self-directed goal because these measures are usually directed to assess specific scores. For example, Goal Attainment Scaling (GAS) has been used frequently to assess goal attainment in diabetes and rehabilitation research (Hurn, Kneebone & Cropley, 2006; Naik et al., 2011).

Furthermore, there is a lack of valid and reliable measures for goal attainment, specifically in the patient population that has experienced stroke. Therefore, a study to measure health behavior goal attainment (Goal Attainment Measure for Stroke – [GAM-S]) in SM for patients who have experienced stroke is proposed. Development and initial testing of the GAM-S will fill the gap concerning lack of availability of a measure for patient and

provider collaborative assessment of health behavior goal attainment during clinical encounters among a cohort of patients who have experienced stroke.

1.2 BACKGROUND

1.2.1 Burden of stroke

Stroke is the number one cause of disability and poor quality of life, number two cause of dementia and number five cause of death in developing countries (CDC). It is a major cause of epilepsy, falls and depression, representing a substantial and economic societal burden (Mukherjee & Patil, 2011). In 2007, the AHA estimated the cost of stroke in the United States to be around \$40 billion. Estimates of total stroke cost between 2005-2050, in U.S. dollars is projected to be \$1.52 trillion for non-Hispanic whites, \$313 billion for Hispanics, and \$379 billion for Blacks. Lost financial earnings are expected to be the highest cost contributor in each race/ethnic group (AHA). Although rates in stroke incidence decreased by 42% in high-income countries, they have doubled in low-to-middle income countries (Feigin et al. 2009).

People who survive stroke experience major challenges associated with adjusting to a new phase of life, managing expectations for recovery and efforts to reclaim independence, with survivors rating their quality of life as poor (Sprigg et al., 2012). Many post-stroke patients experience depression and anxiety related to slow physical and emotional recovery and being a burden to their family (Lincoln et al., 2013). A large body of evidence shows that addressing the health, social and environmental issues associated with life after stroke may improve life for post-stroke patients.

1.2.2 Stroke risk factors and prevention to reduce stroke and disability risk

Stroke risk factors are conditions or behaviors that have the potential to increase the possibility of stroke. Stroke risk factors can be characterized as non-modifiable and modifiable. The non-modifiable risk factors are age, gender, race and heredity. The modifiable risk factors are characterized as medical conditions and certain behaviors. Medical conditions include hypertension, atrial fibrillation, hyperlipidemia, diabetes mellitus, carotid stenosis, prior transient ischemic attack (TIA) or stroke. In terms of behavioral risk factors, tobacco smoking, alcohol abuse, physical inactivity and poor diet constitute behaviors that may contribute to stroke. According to Lawes, Vander Hoorn and Rodgers (2008), hypertension, atrial fibrillation, diabetes, physical inactivity and smoking account for over 60% of all first- ever strokes.

Preventing stroke (primary or secondary) should be recommended to all individuals beginning at an early stage of life by controlling nutrition and obesity. In adolescence, accumulated risk for stroke may be increased by tobacco smoking, excessive alcohol use, lack of physical activity, poor diet and obesity. In the adult, established risk factors such as hypertension, diabetes and other diseases can further increase risk for stroke. Therefore, every effort should be made to reduce modifiable stroke risk factors.

1.2.3 Self –management approach as a “gold standard” for stroke risk management

Stroke risk management has been a serious challenge for healthcare professionals. It continues to be a major concern in the healthcare field, resulting in problems for patients and causing great expense for healthcare systems (Rotheram-Borus et al., 2012). According to Lorig (1996), primary prevention of stroke, in addition to treatment with medication,

emphasizes lifestyle behavior change in areas such as nutrition, exercise and smoking. In recent years, public health professionals have focused on the secondary and tertiary disease prevention of stroke. These efforts allow patients to prevent them from having another stroke and to return to their maximal function. Therefore, stroke risk factors management is essential to decrease both primary and secondary events. Over the last several decades, management of multiple stroke risk factors using the patient-centered approach has been emerging, as researchers and healthcare professionals discovered that care depends on more than just disease-specific care processes (Jones, 2006; Jones & Riazi, 2011). In addition, disease-specific outcomes may not fully correlate with treatment effects in patients with multiple chronic conditions, such as post-stroke patients with uncontrolled blood pressure and elevated blood sugar level. Therefore, to help patients return to their full functional status, efforts have to be made to develop and refine healthcare models, which are not only patient centered, but must be built within the framework of individual patients' health behavior goal settings (Wagner, 2001). This approach puts patients first and in the center of the decision-making process. Engaging patients in goal setting, action planning, problem solving, decision making, resource utilization, and self-tailoring associated with modifiable risk factors for stroke has been at the core of risk factor SM. In many cases it has been shown to lead to successful outcomes (Battersby et al., 2009). Furthermore, persons with strong SM skills have been found to be more successful at attaining and sustaining lifestyle behavior changes (Lorig & Holman, 2003).

1.2.4 Self-management interventions in stroke risk factors control

SM interventions are designed to help people manage their health problems more effectively. It has been reported that individuals involved in SM interventions can improve their self-efficacy, coping mechanisms and quality of life following stroke. According to Lorig and Holman (2003), SM interventions reduce hospitalizations, emergency department use, and overall managed care costs. Qualitative studies also report that SM interventions have been important for stroke survivors as a means of providing psychosocial support (Catalano et al., 2003; Hirsche et al., 2011). However, a recent systematic review showed that conceptual relationships between the instruments to evaluate SM outcomes remain not fully understood. This is particularly important in regards to the psychometric properties of these measures. Despite the recognized value of valid and reliable outcome measures, research shows that the quality of these measures, especially in stroke and across all SM outcomes has been poor (Boger et al., 2013). Lack of outcome measures that specifically measure goal setting and goal attainment may create serious limitations in outcome evaluation of SM programs.

1.2.5 Goal setting, action planning goal attainment measures in the SM framework

Goal setting is a primary skill needed for effective patient SM (Bodenheimer & Hadley, 2009; Glasgow et al., 2005; Naik, Palmer & Petersen, 2011) and is widely recognized as an integral part of healthcare delivery in the context of SM. However, the effects of goal setting and strategies to enhance attainment of health outcomes have shown that the best evidence appears to favor positive effects for psychosocial (i.e., health-related quality of life, emotional status, and self-efficacy; Levack et al., 2015) and physiologic

outcomes (i.e., controlled blood pressure or diabetes; Loring, 2006; MacGregor et al., 2005). Over the last several decades multiple studies have been published about prevention programs focused on patient-centered care and aimed to improve chronic diseases (Bartholomew & Naik, 2007; Bodenheimer et al., 2002; Bodenheimer & Hendley, 2009; Brown, Shegog et al., 2006; Ruben & Tinetti, 2012).

Comprehensive identification, understanding and measurement of patient-specific treatment goals, processes, and evaluation of outcomes play a central role in health prevention programs. While SM appears to offer significant improvements in patient outcomes, widespread agreement of elements that constitute a SM process and how it can be measured are just beginning to be understood (Riegel et al., 2000). Furthermore, studies have shown that conceptualization and operation of SM as a discrete concept create much difficulty in the scientific community. Moreover, research is inconclusive regarding what specific elements of SM interventions should be included in stroke SM (Hirsch et al., 2006; Lennon, McKenna & Jones, 2013; Nour et al., 2006). More research is needed to understand current thinking related to the SM process and its valid and reliable measure of the process of goal setting and goal attainment. This understanding could aid clinicians in designing effective SM programs aimed to improve patients' clinical outcomes, as well as in conducting proper program evaluations (Boger, Demain & Latter, 2015).

1.3 SPECIFIC AIMS

The overall purpose of this dissertation is to develop and validate an instrument to measure goal attainment in the domain of stroke and with an outpatient patient population. Designing and testing the Goal Attainment Measure for Stroke (GAM-S) will not only fill the

gap concerning lack of reliable measures for goal attainment but may also provide a measure to better understand the impact of goal attainment on patient self-management of stroke risk factors in the clinical and research contexts. To meet the dissertation objectives, three major studies are proposed, with the following specific aims and research questions.

1.3.1 PAPER #1:

Outcome Measures for Goal Attainment in Secondary Stroke Prevention: A Systematic Review of Systematic Reviews

The purpose of this study was to identify existing measures of goal attainment for SM of stroke risk factors in clinical and research contexts and to identify their different strengths and weaknesses. The secondary objective was to identify current evidence for the impact of goal attainment in effective SM of chronic diseases related to stroke risk. In addressing the study aims, a systematic review was carried out to evaluate peer-reviewed systematic review studies (from year 2006 on) that included measures for goal setting and goal attainment specific for chronic conditions related to stroke risk, such as hypertension, diabetes and obesity.

This paper is the first systematic review of systematic reviews conducted on goal attainment measures for stroke risk factors and the impact of goal attainment in effective SM of chronic diseases related to stroke risk. Based on a brief literature review on the topic, we discovered a growing number of systematic reviews concerning the research topic under consideration. According to French et al. (2017), systematic reviews of systematic reviews have been increasingly carried out for comparison and synthesis of recent work on goal

attainment measures and current evidence for the impact of goal attainment in effective SM of chronic diseases, with emphasis on stroke.

The research questions underlying this review were:

1. What measures have been developed to assess goal attainment for chronic disease SM in clinical and research contexts and what are the different strengths and weaknesses of current goal attainment measures?
2. What is the current evidence for the impact of goal attainment in effective SM of stroke risk factors?

1.3.2 PAPER #2:

Stroke Survivors Lived Experience After Being Discharged Home: A Phenomenological Study

The purpose of this research was to describe stroke patients' lived self-management experience following hospital discharge after stroke.

Specific aims:

- a) Describe challenges faced by patients related to goal setting by using the action plan process for SM of stroke risk factors.
- b) Define the strategies used by patients to apply the action plan process to attain their goals for SM of stroke risk factors.
- c) Discuss the perceptions identified by patients related to self-assessment of goal attainment, using the action plan process for SM of stroke risk factors.

Research questions:

- a) What challenges do patients describe related to goal-setting using the action plan process for self-management of stroke risk factors?
- b) What strategies do patients define related to the action plan process to attain their goals for self-management of stroke risk factors?
- c) What perceptions do patients identify for self-assessment of goal attainment using the action plan process for self-management of stroke risk factors?

1.3.3 PAPER #3:

The Goal Attainment Measure (GAM-S) For Secondary Stroke Risk Factors Management: Pilot Test And Psychometric Properties

The purpose of this study was to pilot the Goal Attainment Measure – Stroke (GAM-S) scale with stroke patients and primary care providers and test the scale for usability, content validity and internal consistency.

Specific aims:

- a) Conduct a usability study with patients, using the GAM-S.
- b) Conduct a usability study with healthcare providers using the GAM-S.
- c) Examine the content validity and reliability of the GAM-S.

Research questions:

I. How do patients (N=16) rate the GAM-S on ease of use, understandability, credibility, motivational appeal, and perceived impact in assessing goal attainment?

Specifically, what is the patients' perception of the GAM-S:

- a) On ease of use and understandability to assess their goal attainment?

- b) On credibility to assess their goal attainment?
- c) On effectiveness to motivate patients to achieve their goals?
- d) On capability to impact goal attainment?

II. How do healthcare providers (N=10) rate the GAM-S on ease of use, understandability, credibility, motivational appeal, and perceived impact in assessing goal attainment?

Specifically, what is the providers' perception of the GAM-S:

- a) On ease of use and understandability to collaboratively assess patients' goal attainment?
- b) On credibility to assess collaborative patients' goals attainment?
- c) On effectiveness to motivate providers to collaboratively work with patients to achieve patients' goals?
- d) On capability to impact patients' goal attainment?

III. What are the preliminary psychometric properties of the GAM-S?

- a) What is the content validity of the GAM-S among a sample of N=7 clinical experts?
- b) What is the reliability of the GAM-S among a sample of N=44 patients using the GAM-S?

1.4 RATIONALE FOR THE STUDIES

Over the past several decades, goal-oriented patient care has been promoted as an alternative health outcomes paradigm, focusing on patients' individual goals. Goals in secondary stroke prevention have been focused on different dimensions, such as symptoms,

physical function status and social functions (Ruben & Tinetti, 2012). There are numerous advantages of goal setting, outcomes assessment and measuring goal attainment in the context of stroke management. Work in the area of management of risk factors associated with stroke shows that there exists a positive association between setting goals in adherence to healthy diet, exercise, healthy weight, alcohol reduction and smoking cessation, and positive patient outcomes (Myers, 2002; Wilde & Garvin, 2007; van Achterberg, 2010). Individual patients' desires and positive results achieved based on common goals and goal-oriented care has been reported as characteristic of good medicine beneficial for the patient. Although researchers have been using goal attainment to measure the effect of interventions or treatment, the literature shows that goal setting as an outcome measure has not been well examined. In particular, goal setting as an outcome measure was not systematically reviewed for post-stroke patients. For this reason, goal setting as an outcome measure seems to be an important inquiry to systematically assess the current understanding of goal setting and patient beliefs about goal attainment and to test the goal-attainment measure.

The rationale for the first study (Aim 1) was the need to conduct a systematic review focusing on current knowledge regarding goal setting as an outcome measure not only in rehabilitation (Hurn, 2006) but also in self-management for effective secondary stroke prevention. Since the work by Hurn was published in 2006, we have not found any studies that review both goal setting and goal attainment employed as outcome measures for patients with chronic illnesses with the emphasis on stroke. The first study proposed under this investigation fills the gap in the current understanding of definitions, measurement and application of goal attainment in the context of SM of chronic diseases. On the basis of the

findings from this study, we described recent goal-attainment measures and their differential strengths and weaknesses. The review also provides a valuable and unique contribution to the goal-attainment measure application in SM programs.

The second study (Aim 2) qualitatively examined the phenomenon of patients' post stroke experience while self-managing their stroke risk factors. The theoretical study framework is based on the concept of phenomenology (Husserl, 1962). On the basis of the current literature review, published papers that systematically obtained and analyzed data related to the increase of patients' everyday activities associated with goal attainment were lacking. In this study, stroke survivors described their lived experience after being discharged home. Patients acted as "co-researchers" and provided descriptions of their own experience. The rationale for the study was to capture in a holistic way the meaning of an experience without splitting it into parts, which would lead to the loss of context and the meaning that the person is trying to experience. Upon the second study completion, we obtained a deeper understanding of patients' challenges, strategies and perceptions while working with clinicians to attain their personal goals.

Informed by the findings from the second study, we conducted the third study (Aim 3) and first performed usability testing on parameters such as ease of use and usefulness for goal attainment and other factors important to establish usability of the GAM-S prototype. Because patients and providers work together to develop a plan of action, we obtained patients' and providers' input and tested initial content validity and reliability of the GAM-S. To our knowledge, no studies have been conducted to develop valid and reliable measures of goal attainment for patients using goal setting and the action planning process. This study

provides preliminary knowledge as to how to measure goal attainment in patients who experienced stroke and are engaged in the self-management of stroke risk factors.

1.5 PUBLIC HEALTH SIGNIFICANCE

This proposed project may significantly contribute to better understanding of definitions, measurement and application of goal attainment in the context of SM of stroke risk factor prevention for patients in the outpatient setting. It may also help clinicians develop more effective intervention programs focused on setting up health behavior goals and accurate measures of goal attainment. Public health consequences of ineffective intervention programs and lack of proper measures may adversely affect advances in stroke prevention management, including economic consequences for the population as a whole. For this reason, development and pretesting of the goal attainment measure for patients with stroke was the guiding principle in the proposed project. The literature does not demonstrate the existence of a reliable measure for goal-attainment measures. Also, the use of the existing measure is unclear (Ruben & Tinetti, 2012), especially in various intervention programs, of which a goal-attainment measure is a crucial part. Therefore, there is a need for developing a goal-attainment measure and for testing its psychometric properties, particularly in the specific domain of patients with stroke in the primary care setting.

The proposed study addressed the aforementioned gap, with development and pretesting of a measure of health behavior goal attainment in post-stroke patients who developed secondary stroke prevention action plans. This research provides valuable preliminary knowledge to guide future research in the area of reliable goal-attainment

measures. The presented framework can then be expanded as a model for developing goal-attainment measures for other chronic illnesses in the general population.

1.5 DEFINITION OF TERMS

Chronic condition- any condition that requires ongoing clinical management and monitoring to effectively control symptoms and slow specific disease progression and that persists for a long time (lasting three months or more)

Ischemic stroke- (most common) arises from blood vessel narrowing and platelet adhesion as with coronary artery disease (CAD), leading to blood clot formation and brain injury

Hemorrhagic stroke - results from the rupture of a blood vessel or aneurysm.

Transient ischemic attack (TIA) - results when an artery in the brain gets clogged or closed off and then reopens on its own. This can happen if a blood clot forms and then moves away or dissolves.

Primary stroke prevention – prevention of a stroke in an individual with no prior history of stroke

Secondary stroke prevention- stroke risk factors control for individuals who survived stroke

Risk factor- a condition or behavior that has the potential to increase the possibility of stroke

Stroke risk factors:

- Controllable- hypertension, diabetes, high cholesterol, smoking, physical inactivity, obesity, poor diet
- Uncontrollable- age, gender, race, family history, personal history

SM skills- set of proactive behaviors to manage the work of dealing with chronic illness, continuing daily activities and managing the changing emotions brought about by chronic illnesses, as well as reactive actions related to a circumstantial change to achieve the goal

SM interventions- interventions that rest on the foundation of five core actions: 1- activate motivation to change; 2- apply domain-specific information from education and self-monitoring and develop skills; 3- communicate with health care professionals; 4- acquire environmental resources and 5- build social support

Healthy behaviors to behavior change- methods that seek to change and increase self-efficacy

Self-regulation—one's ability for self-regulate. It outlines the process and components involved when one decides what to think, feel, say, and do (making a “good” choice when one actually have a strong desire to do the opposite)

Self-efficacy – one's ability to have confidence that one can make positive decisions about health

Goal setting- the process of establishing priorities and setting criteria for learning and performing a new behavior or for modifying behavior

Action planning- set of “behavior-specific” steps that will help one to realistically accomplish actions within a specific period of time (what, how much, when, how often)

Goal attainment- set of behaviors leading to attainment of certain life goals, using action planning

Coping skills—the reactions and behaviors one adopts to manage psychological and instrumental challenges

Problem solving, planning, and monitoring strategies targeted around goal attainment-
making midcourse changes to the action plan

Purposive sampling – it represents a group of different non-probability sampling techniques. Also known as judgmental, selective or subjective sampling, purposive sampling depends on the judgment of the researcher who selects the units such people, cases, events or pieces of data that are to be studied.

Health-related behavior change theories and models

1. Schwarzer's Health Action Process Approach (2008)
2. Health Believe Model (Rosenstock, 1974)
3. Protection Motivation Theory (Rogers, 1975)
4. The Transtheoretical Model (Prochaska & Di Clemente, 1986)
5. Self-Determination Theory (Deci & Ryan, 2001)
6. Theory of Reasoned Action (Fishbein & Azjen, 1975)
7. Theory of Planned Behavior (Azjen, 1985)
8. Goal Setting Theory (Latham & Locke, 1991; Locke, 1996)
9. Self – Regulation Theory (Carver & Scheier, 1985)
10. Social Cognitive Theory (Bandura, 1997)
11. *Transactional Model of Stress and Coping (TMSC)*—a model that is used in public health research that delineates different types of coping and visually explains the transaction between stress and coping (Glanz et al., 2002)

12. *Precaution Adoption Process Model (PAPM)*—a stage theory in which each stage represents a different behavior, belief or experience; different types of information are relevant as one progresses from one stage to the next (Glanz. et al., 2002)
13. SMART —five golden rules of successful goal setting (specific, measurable, attainable, realistic, and timely)
14. *Phenomenological theory* - a qualitative research methodology using a bottom-up approach whereby data collection proceeds theory generation (Glaser & Strauss, 1967)
15. Theory of Goal Attainment (Imogene M. King)

CHAPTER 2

REVIEW OF THE LITERATURE

We performed a brief literature review of the major studies published in peer- review journals that address goal setting, action planning and goal attainment measures in the context of SM. As stated in the dissertation aims, systematic review of these subjects will be specifically addressed in Aim 1 of the dissertation. Therefore, in this chapter, a structured review of major studies published in the medical and psychological databases for the past two decades is presented, and general Web searches were performed to establish support for the proposed dissertation studies.

2.1 GOAL SETTING AS AN OUTCOME MEASURE (GOAL ATTAINMENT) IN THE SM CONTEXT

According to Clark et al., 1980, SM is defined as a set of behaviors that minimizes the frequency and severity of disease symptoms/and or progression, minimize dysfunction caused by the disease and promotes optimum participation in normal activities. Goal setting is one of the behaviors and the primary skill needed for effective patients SM (Bodenheimer & Handley, 2009; Naik, Palmer & Petersen, 2011; Wade, 2009). For the past several decades, goal setting has been widely recognized as an integral part of healthcare delivery in the United States (Glasgow et al., 2005; Stevens et al., 2013). Unlike the patients' education or skills training, SM programs that include the goal-setting concept enable patients to take charge of their own health conditions and enact lifestyle adjustment to improve their outcomes (Tinetti, Naik & Dodson, 2016). Research on goal setting was first carried out by Locke (1975) and applied by business organizations. It was used as a technique for

increasing employee motivation and performance (Latham & Locke, 1975). In 1985, Carry introduced mutual goal setting in families and postulated that it is an individual person's responsibility to take care of his/her own life. People usually "do not like to be told what to do," especially concerning their health care. Therefore, setting goals should be a mutual effort centered on the patient as his/her own "primary care taker" and the healthcare provider as the "advisor" who supports him/her in this role (Bodenheimer et al., 2002; Lorig & Holman, 2003). Further development and application of goal setting have been carried out by Lorig and Handley. Handley suggested a revised concept of "goal setting" and named it the "action plan," defined as the "agreement between clinician and patients that the patient will make a specific behavior change" (Handley et al., 2006). This resulted in a new operationalization of the goal-setting concept and led to development and application of numerous SM programs designed to assist people to manage their chronic diseases, such as rheumatoid arthritis, diabetes and asthma (Lorig et al., 2001).

Lorig and Holman (2003) describe five core SM skills: problem solving, decision-making, resource utilization, collaboration, and goal setting and action planning. SM programs utilizing the specific action planning concept and goal achievements have been extensively studied, especially as part of behavior change intervention programs. It has been shown that patients with strong SM skills (with an emphasis on strong self-efficacy) are more successful at attaining and sustaining healthy lifestyle behavior changes (Jones & Riazi, 2011; Jones, Riazi & Norris, 2013).

Many systematic reviews have already provided overviews of the evidence in this area. However, these reviews often lack a clear focus as to theory-based components and

may be inconclusive concerning what instruments should be used to measure outcomes and what their psychometric properties are (Hirsche et al., 2006; Nour et al., 2006; Lennon, McKenna & Jones, 2013). Therefore, a more precise synthesis of the existing literature still remains a challenge for the research community. Similarly, it is challenging for healthcare providers and policy makers to translate the research outcomes into clinical practice. For example Lennon, McKenna and Jones (2013) conducted a systematic review of SM intervention programs of people post-stroke to examine the most appropriate content and the best approach for delivery of SM interventions. Fifteen studies have been included in the review, and statistically significant findings were reported in favor of the SM group concerning disability, confidence in recovery and quality of life and the 36-item Short Form Survey. Although goal setting and problem solving were included in the SM intervention components, none of the studies included goal setting as an outcome measure. The review of Lennon, McKenna and Jones (2013) also revealed poor descriptions of the intervention components in the studies included, and absence of power calculations when determining sample sizes. This review supported previous findings concerning the importance of SM interventions for post-stroke patients. However, authors recognized that tailored interventions with well-defined content, timing, and mode of delivery; targeted outcomes, and measures should still be explored for this particular population.

Hurn, Kneebone and Cropley (2006) conducted a systematic review of goal setting as an outcome measure. The review specifically emphasized the reliability, validity and sensitivity of the scaling used in the reviewed studies. Participant populations included patients undergoing rehabilitation after stroke, as defined by the World Health Organization.

The major finding of the study is that there is strong evidence of the reliability, validity and sensitivity of goal-attainment scaling. Empirical support was found for the validity of goal setting, but research demonstrating its reliability and sensitivity is limited. Even though this review followed strict systematic review guidelines and covered the 36 years since the goal-setting theory was proposed, the authors concluded that further work needed to be carried out with goal setting to establish its reliability and sensitivity as a measurement instrument. Also, the findings cannot be directly applied to the instruments measuring goal attainment as an outcome measure in the context of controlling behavioral risk factors for stroke, as this specific review was limited to goal setting and goal attainment scaling approaches in particular physical and neurological rehabilitation settings.

Family support using SM goal-oriented models constitutes another aspect that may help to improve behavioral outcomes for post- stroke patients. Several models using caregiver goal-oriented support in arthritis and rheumatologic disease have been reviewed by Rosland and Piette (2015). This study showed improvements in communication and patients' self-efficacy and also resulted in improved patients' outcomes. However, it is not clear what instruments have been used in the programs to assess the change in the targeted family role or behavior. Specifically, number of family goals set or met, whether the goals have been revised, or building on achieved goals has not been clearly described or measured.

A further literature search revealed studies examining the evidence of effects and experience of goal setting in stroke rehabilitation. Sugavanam et al. (2013) performed a systematic review of studies that included goal setting in the design, reporting stroke-specific data, and evaluating the effects or experiences. Seventeen studies were included, of which

seven evaluated effects, while ten explored experiences of goal setting. Due to weak-to-moderate methodological strengths and different designs, pooling of methods of goal setting and outcome measures data was challenging. The authors report that goal setting appeared to improve recovery, performance and goal achievement, and to positively influence patients' perceptions of self-care ability and engagement in rehabilitation. However, to what degree patients were involved in the goal-setting process was not made clear, since patients could not define their role in the process. In addition, patients and professionals differed in how they set goals, types of goals set, and how they perceived goal attainment. In conclusion, the authors suggested more rigorous research to strengthen the evidence base. In another study, Rosewilliam, Roskell and Pandyan (2011) performed a systematic review to map out the nature, extent and effects of the application of goal setting in stroke rehabilitation practice. This study revealed that the effects of following patient-centered goal-setting practice have been studied mostly using weak methodologies and that the studies show a benefit limited to psychological outcomes. Therefore, the authors suggest that more research is needed to investigate the effect of patient-centered goal-setting on patient outcomes.

The literature further expounds much on the measurement of goal setting in an environment increasingly focused on patient – centered care (Scobbie, 2009; Scobbie, 2011; Scobbie et al., 2013), largely targeting instruments that support and monitor the goal- setting process (Stevens et al., 2013). Several studies conducted by Scobbie contributed to goal setting in rehabilitation research by developing and testing a theory-based goal setting practice framework (Scobbie, 2011). They identified four components of a goal-setting and action-planning practice framework: goal negotiation, goal identification, planning, and

appraisal and feedback. The variables hypothesized to effect change in patient outcomes were self-efficacy and action plan attainment. Scobbie (2011) followed-up with a practical application of his framework, which guided the goal-setting practice and was implemented in the community rehabilitation program for 6 months in 23 stroke patients (Scobbie, 2013). Although this study supported inclusion of goal setting and action planning and feedback, it did not offer new knowledge as to how the feedback was operationalized and measured. The author also noted that collaborative partnerships between health professionals and patients were apparent throughout the process. However, the regulatory function of goal nonattainment and the importance of creating flexible partnerships with patients have been highlighted, suggesting that further evaluation of this framework is required across diverse community rehabilitation settings. We found one systematic review that evaluated whether the goal planning in clinical rehabilitation was effective. The review by Levack (2006) searched for randomized controlled trials of the therapeutic effectiveness of goal planning in the rehabilitation of adults with acquired disability. Nineteen studies were included in the review, but six studies investigated the immediate effects of goal planning on patient behavior. Limited evidence was identified showing that goal planning may influence a patient's adherence to treatment regimens; and strong evidence was provided that prescribed, specific, challenging goals can improve immediate patient performance in specific clinical contexts. However, evidence regarding how these effects translated to improved outcomes following rehabilitation programs was inconsistent. Furthermore, methodological limitations of the specific measure employed, and the program's sustainability and generalizability were noted.

Finally, we found two studies that addressed measurement of goal setting and goal attainment in the SM domain. Stevens et al. (2013) published a systematic review of the use of patient-specific measurement instruments in the process of goal-setting. A total of 25 patient-specific instruments were identified, and 11 were included, which can be used for goal negotiation, goal-setting and evaluation. Goal Attainment Scaling was time consuming and difficult for patients with cognitive problems but facilitated goal setting in a client-centered approach. The most important finding from this study is that, out of 11 instruments identified, there was no single good instrument that could be recommended specifically for a goal-attainment measure in clinical practice.

Another study that systematically examined the psychometric properties of outcome measures used in stroke SM interventions was published by Boger, Demain and Latter (2013). Two major objectives guided this study. The first objective was to inform researchers and clinicians about the properties of the measures in use; the second objective was to make recommendations for the future development of SM measurement in stroke. Thirteen studies of stroke SM originating from six countries were identified, with no studies measuring SM as a discrete concept. Six studies (46%) included untested measures. Eleven studies (85%) included at least one measure without reported reliability and validity in stroke populations. The major finding of the study is that outcome measures that are related, indirect or proxy indicators of SM have questionable reliability and validity. Therefore, it is difficult to evaluate the effectiveness of stroke SM. The authors suggested that “further enquiry into how the concept of SM in stroke operates would help to clarify the nature and range of specific

SM activities to target and aid the selection of existing appropriate measures or the development of new measures” (p. 1425).

In summary, the review demonstrates an absence of outcome measures that specifically measure goal attainment in SM of stroke in the clinical setting. It also reveals that most of the studies with goal setting in stroke have been conducted in the clinical rehabilitation context rather than in the SM context. Studies in rehabilitation, although large in volume, are still lacking a good methodological framework and are inconclusive in many areas of research that have been examined. Two studies with goal setting in the SM context are also lacking clear directions as to which measures to use to accurately quantitate stroke SM. The review confirms that, while SM appears to offer significant improvements in patient outcomes, a consensus in the SM process and its quantitation is just beginning to emerge (Riegel et al., 2000). Researchers should continue to develop psychometrically sound measures of stroke SM to promote effective evaluation of interventions in stroke.

2.2 PATIENTS’ EXPERIENCE WITH ACTION PLANNING AND GOAL ATTAINMENT IN THE CONTEXT OF SM

An additional literature review was conducted to examine patients’ experience with a goal-attainment measure. In particular, we searched for qualitative studies using the phenomenological approach of patients’ lived experience. As previously mentioned, successful SM of chronic illnesses, particularly for the post-stroke patient, is a complex set of behaviors based on the mastery of different skills. How people implement and maintain a behavioral regiment based on those skills is not a simple matter. Mastering skills such as successful goal setting and goal attainment has been addressed in three studies (Boger,

Demain and Latter, 2015; Jones 2006). Review of the literature concerning the use of a goal-attainment measure in patients' daily lives resulted in limited examples of studies with a problematic theoretical framework, methodology and generalizability. Some studies addressed patients' experiences after their hospital discharge and in the context of rehabilitation immediately after the acute event. We also found studies that examined patients' lived experience during the prolonged rehabilitation period, addressing issues such as stress, adaptation, coping and disability, and poor quality of life.

For example Burton, (2000) conducted a study to understand how stroke survivors coped with challenges after stroke and what was their experience of recovery. The authors conducted 73 interviews with patients with the follow-up time of 12 months after the stroke. This study revealed that recovery from stroke involved restructuring and adaptation of physical, social and emotional aspects of an individual's life. The main study recommendation was that social services should concentrate on the long-term needs of stroke patients and their families in their home environment.

An interpretative phenomenological study of the experiences of stroke patients and their caregivers was conducted by Negi (2014). While most studies concentrate on the clinical outcomes among patients with a stroke diagnosis, this study assessed the experiences of stroke patients and their caregivers. Semi-structured interviews with 10 stroke patients and their caregivers were conducted over the course of one year. Data were analyzed using an interpretative phenomenological approach and identified three major themes: reality adjustment by adapting to the new normality, the grown self and limited support for caregivers. This finding suggests that recovery is difficult but did not address any goal

measures. McKevitt et al., (2004) conducted a systematic review of qualitative studies that addressed a wide range of issues related to the impact of stroke on individuals and caregivers, and to the organization and delivery of services. Ninety-five articles were included in the review, which emphasized the “human” experience of stroke, identification of needs as perceived by patients and their families, differences in priorities between patients and professionals, and barriers to best-quality care. The final review of 12 studies suggested that problems still exist with high-quality stroke care delivery that could be solved by improving collaboration between nonclinical and clinical scientists and healthcare providers. This review also revealed that theoretical frameworks, methods and research strategies to formulate research questions of interest could improve study findings and more effectively translate to patient care. We have not, however, found any comments as to how healthcare delivery programs might better utilize the goal setting and goal attainment concepts and measures to improve intervention programs.

Another study examined patients’ perception of quality of life after surviving the first episode of stroke (García-Moriche et al., 2009). On the basis of the outcome of semi-structured interviews of 20 participants, the authors concluded that the patient perception of the stroke is not that of a disease but rather of a momentary event in health. Furthermore, patients’ perception of quality of life has been found to be subjective. Patients noted that they had to adjust to a new identity, as well as to a new social context. Although this study offered sound findings, it did not refer to any intervention programs in which SM goal-setting concepts have been used.

Finally, we found a review of four studies that used a phenomenological approach to examine young adults' experience with stroke (Lawrence, 2010). The review, based on the perspective of young adults (18-45), offers a distinct view of the effect of stroke, which might be "invisible" but can significantly influence the ability to return to work and to enjoy family and social life. The author concluded that successful recovery from stroke for young adults may be associated with improvement in communication between patients, healthcare providers and family members. We have not found any mention of the SM component, either as a description of the method or in program implementation.

This review offers evidence of the patients' physical and emotional experience after surviving a stroke. Knowing the patient's stroke experiences may enable healthcare providers and caregivers to view stroke survivors from a broader and more humanistic perspective. However, we have not found any published papers that systematically obtained and analyzed data to increase knowledge of patients' everyday activities associated with goal setting and goal attainment. Therefore, as a result of conducting the activities described in AIM 2 of our study, patients will be able to describe in their own words the shared lived experience and their perceptions of the GAM-S measures.

In summary, the diversity of the findings from both literature reviews highlights that there exist many more factors that should be considered to understand current thinking related to the SM content, process, method of delivery, patient lived experience and valid and reliable measure of the process of goal setting and goal attainment for stroke patients. This understanding could assist clinicians in designing effective SM programs aimed to improve patients' clinical outcomes, as well as in conducting proper program evaluations in this area

of research (Boger, Demain & Latter, 2013 ; Lennon, McKenna & Jones, 2013; Wade, 2009).

CHAPTER 3

PAPER #1

Outcome Measures for Goal Attainment in Secondary Stroke Prevention:

A Systematic Review of Systematic Reviews

Abstract

Background

Multiple self-management (SM) interventions have been developed to support stroke survivors in achieving behavior changes to control their stroke risk factors. Goal setting and attainment are fundamental SM skills essential for effective behavior change and secondary stroke prevention. Through the application of valid and reliable measures the most salient elements of effective chronic disease self-management are just beginning to be understood.

Purpose

The purpose of this study was to identify existing measures of goal attainment applied in the context of SM of chronic conditions in clinical and research contexts and to identify their differential strengths and weaknesses. A secondary objective was to identify current evidence for the impact of goal attainment in effective SM of chronic diseases related to stroke risk.

Methods

To identify measures of goal attainment for SM of stroke risk factors, in both clinical and research contexts, we applied the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines to complete a systematic review of systematic reviews. We sought to describe differential strengths and weaknesses, and effectiveness of goal attainment measures for patient SM of stroke risk factors. Source databases used were Medline (Ovid), PubMed (National Library of Medicine), Embase (Ovid), and PsycINFO (Ovid). A priori eligibility criteria required

that studies included outcome measures for goal attainment for stroke patients, be published in English, and be published between 2006 through 2017, which was the period following the last major review of this topic.

Results

Of 1363 citations found, 808 unique titles and abstracts were screened; 52 articles were included in the full review, and 9 were included in the final analysis. No measures of goal attainment for SM of stroke risk factors were identified in the review. The only published measures of goal attainment related to stroke were in the context of stroke rehabilitation: The Goal Attainment Scaling (GAS) and the Canadian Occupational Performance Measure (COPM). While the GAS demonstrated measurement of improvement in goal attainment for physical function and included published feasibility parameters (time to administer, instructions, training and availability), no psychometric properties were reported. The impact of goal attainment on effective SM of stroke risks factors could not be determined since no valid and reliable measures were identified within this context.

Conclusions:

To our best knowledge, this is the first systematic review of systematic reviews conducted to identify and evaluate goal attainment measures used for SM of stroke risk factors. This review demonstrates an absence of outcome measures that specifically measure goal attainment for SM of stroke risk factors in both the research and clinical setting. Future research is needed to inform the development of reliable and valid measures of goal attainment in stroke SM.

Outcome Measures for Goal Attainment in Secondary Stroke Prevention: A Systematic Review of Systematic Reviews

Introduction and Background

Chronic disease continues to be a major challenge in health care, resulting in difficulties for patients and causing great expense for healthcare systems (Rotheram-Borus et al., 2012). According to Lorig (1996), primary prevention of chronic diseases emphasizes lifestyle behavior change in areas such as nutrition, exercise and smoking, in addition to treatment with medication. In recent years, public health professionals have also focused on secondary and tertiary disease prevention in chronic diseases. These efforts when aimed at stroke include engaging stroke survivors in development of self-management skills to reduce risk of subsequent stroke and to enable return to optimal functional status (Lennon, McKenna & Jones, 2013). Therefore, development of self-management skills for effective behavior change has great potential to decrease both primary and secondary stroke events when targeting chronic conditions that are also stroke risk factors, like hypertension and diabetes.

Over the last several decades, multiple patient-centered interventions to support stroke survivors in self-management of stroke risk factors have emerged. This approach puts patients first and in the center of the decision-making process for management of their stroke risk factors. For example, healthcare professionals and stroke patients work together to develop a treatment plan for uncontrolled blood pressure or elevated blood sugar levels. Patients are supported in the use of self-management skills like goal setting, action planning, problem solving, decision making, resource utilization, and self-tailoring of their modifiable stroke risk factors. This approach defines risk factor self-management (SM) and has been shown to lead to successful outcomes including improvements in blood pressure control, healthy eating habits and increased

physical activity (Battersby et al., 2009). Furthermore, persons with strong SM skills have been found to be more successful at attaining and sustaining lifestyle behavior changes (Lorig & Holman, 2003).

According to Clark et al., 1980, SM is defined as a set of behaviors that minimize the frequency and severity of disease symptoms and or progression, minimize dysfunction caused by the disease, and promote optimum participation in normal activities. Goal setting is one of the behaviors and is the primary skill needed for effective patient SM (Bodenheimer & Handley, 2009; Naik, Palmer & Petersen, 2011; Wade, 2009). For the past several decades, goal setting has been widely recognized as an integral part of healthcare delivery in the United States (Glasgow et al., 2005; Stevens et al., 2013). Unlike patient education or skills training, SM programs that include the goal setting activities enable patients to take charge of their health conditions and adjust their lifestyle to improve their outcomes (Tinetti, Naik & Dodson, 2016; and Locke, 1975).

Further development and application of the goal setting process in the context of SM programs have been carried out by Lorig and Handley. Handley suggested application of the action plan as described in numerous behavior change models (Schwarzer & Luszczynska, 2008; de Vries, Mesters, van de Steeg, & Honing, 2005 Goehner, & Seelig, 2011; Hagger & Chatzisarantis, 2013). When applied to goal setting the action plan specifies the what, how much, when and how often aspects of goals that are directed toward a specific behavior change. Handley further defined the action plan as a contractual agreement between the clinician and the patient toward a specific behavior change (Handley et al., 2006). This approach makes it possible to operationalize goal setting and is applied in numerous SM programs to assist people in

managing their chronic diseases, such as rheumatoid arthritis, diabetes and asthma (Lorig et al., 2001; Schwarzer & Luszczynska, 2008; Lorig et al., 2013).

Lorig and Holman (2003) described five core SM skills: problem solving, decision-making, resource utilization, collaboration, goal setting and action planning. SM programs using the action planning concept and goal attainment have been extensively studied, especially as part of behavior change intervention programs. These studies show that patients with strong SM skills (particularly goal setting and/or action planning) and strong self-efficacy are more successful at attaining and sustaining healthy lifestyle behavior changes (Jones & Riazi, 2011; Jones, Riazi & Norris, 2013; Hagger & Luszczynska, 2013). More specifically, action plan completion measures were associated with improvement in activity limitations, aerobic exercise and self-efficacy (Lorig et al., 2013).

Goal setting and goal attainment are important components in SM programs and multiple theories describe a mediating effect between goal setting/attainment and behavior change. Therefore, to understand the nature of the effects of goal setting/attainment on behavior change valid and reliable measurement of these components is essential. Many systematic reviews describe the importance of goal setting and goal attainment for behavior change: but few reviews describe available instruments that specifically measure goal setting/attainment. Moreover, in cases where measurement is described, the theoretical basis and psychometric properties of the instrument are often not provided (Hirsche et al., 2006; Nour et al., 2006; Lennon, McKenna et al., 2013; Stevens et al., 2013). Goal attainment and/or successful completion of an action plan are included in multiple systematic reviews (Hurn, Kneebone & Cropley 2006, Lennon et al., 2013, Stevens et al. 2013, Heron et al 2016).

At the time of this writing, Hurn and colleagues provided the only systematic review to identify valid and reliable measures for goal setting/attainment as applied to populations undergoing rehabilitation after stroke. The review followed rigorous systematic review guidelines and covered the 36 years (1970-2006) following the establishment of goal-setting theory. The authors found several reliable and valid goal-attainment scales and empirical support for valid measurement of goal attainment. However, studies demonstrating reliability and sensitivity were limited. One study reported evidence of test-retest reliability for goal attainment within populations undergoing physical and neurological rehabilitation. No studies were found that reported test - retest reliability within the goal attainment scaling literature. The authors concluded that further work was needed to establish the reliability and sensitivity of measures of goal attainment. Further, the generalizability of these findings is limited to the instruments measuring goal attainment in physical and neurological rehabilitation settings and cannot be applied in the context of stroke risk factor self-management. Moreover, the clarity on measures to accurately quantitate SM of stroke risk factors is lacking. We were unable to identify any published systematic reviews of systematic reviews that describe contemporary definitions and measurement of goal attainment in the context of stroke risk factor self-management.

Purpose, Aim, and Research Questions

The purpose of this study was to identify existing measures of goal attainment applied in the context of SM of chronic conditions in clinical and research contexts and to identify their differential strengths and weaknesses. The secondary objective was to identify current evidence for the impact of goal attainment in effective SM of chronic diseases related to stroke risk. In addressing the study aims, a systematic review was carried out to evaluate peer-reviewed systematic review studies (from year 2006 on following the last review by Hurn et al., 2006) that

included measures for goal setting and goal attainment specific for SM of chronic conditions, with further examination specifically related to stroke risk factors, such as hypertension, diabetes etc.. To our knowledge, this paper is the first systematic review of systematic reviews conducted on goal attainment measures for stroke risk factors and the impact of goal attainment in effective SM of chronic diseases related to stroke risk.

The research questions underlying this review were developed to first identify existing measures for goal attainment in chronic disease SM and their use in clinical and research context. Subsequent questions narrowed the review to include goal attainment measures for SM of chronic diseases that increase stroke risk and the impact of goal attainment in effective SM of stroke risk factors:

1. What measures have been developed to assess goal attainment for chronic disease SM in clinical and research contexts and what are the differential strengths and weaknesses of current goal attainment measures?
2. What is the current evidence for the impact of goal attainment in effective SM of stroke risk factors?

Methods

Study Design

We adhered to previously published methods for conducting a systematic review of reviews (Smith et al., 2011) and used the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines in which the review structure, framework and methods were established (Moher et al., 2009). A health science librarian assisted in establishing the search criteria, eligibility criteria, and a study sample to satisfy PRISMA guidelines (Moher et al., 2010). We used a validated appraisal tool, the Assessment of Multiple Systematic Reviews

(AMSTAR) for systematic reviews to determine whether the potentially eligible reviews met minimum quality requirements (Smith et al., 2011). The AMSTAR tool identifies 11 items that may affect quality. A score of 0-4 indicates low quality, 5-8 indicates moderate quality, and 9-11 indicates high quality.

Search Criteria

Medline (Ovid), PubMed (National Library of Medicine), Embase (Ovid), and PsycINFO (Ovid) were searched following the protocol described by Hurn, Kneebone and Cropley (2006) (Appendix 1). A health sciences librarian experienced in developing search strategies for systematic reviews assisted with the searches. The last search was performed in September 2017. Key words included: adults; chronic diseases (with emphasis on chronic diseases related to stroke risk such as diabetes, hypertension, smoking, stress, and obesity); disease SM; goal setting and goal attainment (including individually set goals or goals set in collaboration with family members, healthcare providers or caregivers) (Appendix 2, Tables 1a, b, and c). Key words related to theories of health behavior change were not included as search concepts, but were included in the full review of selected publications and are included in Table 1.

We used a combination of MeSH terms and titles, abstracts, and keywords to develop the initial Medline search and then adapted our strategies to search other databases. Specific strategies and date searched for each database are included in Appendix 2 (Tables 1, 1a, 1b and 1c). Additionally, reference lists within relevant articles were examined for suitability.

Inclusion and Exclusion Criteria

Inclusion criteria for selected systematic review publications were based on the following criteria: met PRISMA criteria for systematic review, adult (>18 years) study participants with one or more chronic diseases, receiving a self-management support intervention of behavioral

risk factor control, with goal setting and/or goal attainment as an outcome measure. Systematic reviews were not limited to a specific geographic location. Reviews included both quantitative and qualitative full-text studies published in English in a peer-reviewed journal from 2006 through 2016. Exclusion of a review article was based on the following criteria: not a systematic review per PRISM criteria, full text of the article was not available in English, the article was an audit without patient data and the article reported no outcome measures related to goal setting and/or goal attainment.

Review Procedure

The review procedures were carried out independently by two investigators using the PRISMA guidelines. The review procedure was organized using RefWorks (ProQuest) to store all citations found during the search process and to check for duplicates. Search strategies and results were tracked iteratively using a series of Excel workbooks specifically designed for systematic reviews (Appendix 5) (VonVille, 2015). A PRISMA study flow diagram was included to track each citation found. See Appendix 3 (Figure 1).

To ensure the agreement for eligibility criteria between the investigators, a random sample of 75 titles and abstracts were independently reviewed prior to screening citations found during the search process (Higgins & Green, 2011). The level of precision (agreement between investigators) was assessed and reported as a kappa statistic (Viera and Garret, 2005). Kappa is intended to give a quantitative measure of the magnitude of agreement between reviewers. Kappa values represent the following: 0.21– 0.40 fair agreement, 0.41–0.60 moderate agreement, 0.61–0.80, substantial agreement and 0.81–0.99 almost perfect agreement (Viera & Garret, 2005). The initial kappa achieved was 0.60, indicating fair to moderate agreement ($\kappa < 0.60$). To increase agreement between investigators, additional clarification of review criteria was

discussed followed by a second review of 75 randomly selected articles and a Kappa of 0.68 was reached (CI: 0.507-0.856), indicating substantial agreement. The investigators then proceeded to independently screen all titles and abstracts, blinded to authors and journal titles, using the Excel workbook (VonVille, 2015). Data were compiled and consensus reached. Articles considered for inclusion were independently reviewed using the same process until a consensus was reached.

Systematic review selections were conducted in four phases: identification, screening, eligibility, and inclusion of the relevant articles. Figure 1 (Appendix 3) shows the PRISMA flowchart, listing the number of records identified; number of titles and abstracts reviewed; duplicates and full-text articles excluded, and reasons for exclusion. Initially, 126 articles were reviewed, with 74 being excluded based on criteria leaving a total of 52 review articles meeting inclusion criteria. Based on the inclusion criteria, review articles related to SM of chronic diseases and rehabilitation after stroke were included when outcome measures for goal setting and/or goal attainment were identified. However, the ultimate purpose of this review was to identify measures of goal setting and/or goal attainment for stroke risk factor SM. For this reason, a decision was made post hoc to only include studies that: (1) were directly concerned with SM of risk factors explicitly associated with secondary stroke prevention (i.e. exclusion of all chronic diseases/conditions not related to stroke risk), (2) included a goal setting or goal attainment measure, and (3) addressed goal setting, or goal attainment for health behavior change in the SM context. A list of excluded studies post hoc is available by request from the author.

Data Extraction and Quality Assessment

Data to be included in the review according to the PRISMA guidelines were extracted from the articles (Moher et al., 2009 and Moher et al., 2010). Quality assessment was performed, using the AMSTAR guidelines (Shea et al., 2017 and Smith et al., 2011). The AMSTAR tool

identifies 11 items that may affect quality. A score of 0-4 indicates low quality, 5-8 indicates moderate quality, and 9-11 indicates high quality. We reported the review quality of primary studies. If a primary study was reported by more than one review, we reported the quality score from the review with the highest AMSTAR rating.

Data Extraction and Procedures for Coding

Data were extracted from each study using a customized data extraction form (Poonawalla, 2000) to obtain data for the evidence table (Appendix 6). The evidence table included the following information: review authors, year, country, aims and theoretical models, types and number of studies in the review article, number of patients, components and duration of the SM programs, outcome measures, tools used to support goal setting/goal attainment, specific instruments that measured goal setting/goal attainment and psychometric properties of goal setting/goal attainment instruments. See Table 1 (Evidence Table).

Evidence Synthesis

We performed a narrative synthesis of the data, adopted from the framework used by Hurn et al. (2006) and Smith et al. (2011), to assist in the organization of identified studies and their analysis in accordance with recommendations for systematic reviews of systematic reviews.

Results

A PRISMA diagram presenting search results is shown in Figure 1. An electronic literature search identified 1363 records from all sources, of which 555 duplicates were removed, resulting in 808 titles and abstracts retaining for further review. After applying inclusion criteria, 682 abstracts were excluded and 126 articles were included in the full review with an additional 74 articles being excluded primarily due to no specific outcome measures for goal setting/goal attainment. A total of 52 systematic review articles were identified for in-depth review with

application of the post-hoc criteria. This yielded a total of nine systematic review articles that met post-hoc criteria.

Characteristics of the Nine Review Articles

Among the nine systematic review articles identified for analysis per inclusion criteria, six were systematic review only, one was a systematic review with meta-analysis and two systematic review articles included review of instruments.

Table 1. Evidence Table

	Author Year Country	Aim Theoretical Model	Type and # of Studies, Condition and # of Patients	Components of the Self-Management Programs (specify)	Outcome Measures and Duration	SM Instruments related to goal setting/goal attainment	Goal Attainment Specific Measure	Psychometric Properties of Goal Attainment
1	Heron 2016 United Kingdom	Evaluate effectiveness of intervention and types of HBG techniques Model: Behavioral change techniques based on Michie's	SR and MA RCTs N=4 TIA 674	Comprehensive post- discharge care management Physical activity and lifestyle changes	Improvements in exercise test results reported in one study only Varied from 6 weeks to 2 years depending on study	Goal Setting, Action Planning in all four studies	Not explicitly mentioned	N/A
2	Fryer 2016 Canada	Assess effects of SM interventions on QOL Model: (CCSM) by Loring and Holman	SR (Cochran Review) RCTs N=14 Stroke 1863	Community active/control intervention Improving ADL through problem solving, coping, self-monitoring and decision making	QOL, Self-efficacy, Activity scores for SM, also impairment scores such as mood and anxiety Varied greatly across the studies	Goal Setting, Action Planning	Not explicitly mentioned	N/A
3	Parke 2015 United Kingdom	Evaluate evidence of SM support interventions with stroke survivors Model: CCSM by Loring and Holman	SR MA RCTs N=13 (101 individual trials) Stroke Over 20.000	Various SM interventions, patient centered, including caregivers, improving health outcomes, setting realistic goals, match goals of all stake holders	SM support at all stages of recovery. Improvements in basic and extended ADL Immediately after stroke and up to 12 months post-stroke	Goal Settings and problem solving	Not explicitly mentioned	N/A
4	Boger 2015 United Kingdom	Identify which generic outcomes of SM were targeted and used Model: SCT focusing on improvements of long term conditions framework	SR N=41 (31 qual), one RCT, two q-exp, one case analysis, one think aloud, inter 17 1620 but only two studies on stroke	Various SM interventions focusing on recovery and adaptation to ADL after stroke focusing on knowledge and re-gaining independence	Improvements in knowledge, independence and achievement of optimal health Immediately after discharge to 12 months	Goal Setting mentioned as key skill	Not explicitly mentioned	N/A

	Author Year Country	Aim Theoretical Model	Type and # of Studies, Condition and # of Patients	Components of the Self-Management Programs (specify)	Outcome Measures and Duration	SM Instruments related to goal setting/goal attainment	Goal Attainment Specific Measure	Psychometric Properties of Goal Attainment
5	Warner 2015 Canada	Identify how many and what SM strategies were included in SM interventions and describe their influence on outcomes such physical function and participation outcomes Model: CCSM by Loring and Holman Lorig and Holman, SCT	SR Pre-post, q-exp and RCT N=9 Stroke pts # Range from 13-155	Heterogeneous components focusing on setting goals and action planning for stroke risk factors control	QOL, active patient participation, functional ability, psychosocial symptoms, knowledge, adherence, self-efficacy, satisfaction with intervention, lifestyle changes Varied between 6-12 weeks to 6-12 months; Duration = 2 hours	Goal Setting and follow up, individual approaches with structured information and professional support	Not explicitly mentioned	N/A
6	Stevens 2013 Netherlands	Identify patient specific measurement instruments used in process of goal-setting and to assess its feasibility Models: Goal-setting and action planning framework by Scobbie et al. 2011	SR of instruments 218 studies included 25 instruments used in goal setting Stroke	25 patients-specific instruments were identified and 11 included in the review. Only four applied in stroke	Disease specific SM goals	Goal negotiation, goal setting, planning, appraisal and feedback	GAS and COPM instrument achieved best outcomes	Only objective feasibility such as time to administer, instructions, training and availability, scoring was difficult
7	Lennon 2013 Australia	Examine evidence base underlying SM programs Models: SCT, Health Belief Model and CCSM by Lorig and Holman	SR RCTs and non-RCTs N=15 Stroke 1233	Various SM interventions for stroke risk factors control	QOL, management of risk factors, self-efficacy Varied from 6 weeks to 6 months	Goal setting, take charge sessions	Not explicitly mentioned	N/A
8	Boger 2013 United Kingdom	Evaluate outcome measures adopted in SMs (methodology and psychometric properties) Model: SCT, and CCSM by Lorig and Holman, Chronic Care Model, Orem's Self-care theory	SR Various studies N=13 Stroke	43 different measures identified, and 21 demonstrated some properties	Health related QOL, self-efficacy, physical functioning, feasibility but none measured stroke SM as a discrete concept 5 weeks to 6 months 4 weeks to 52 weeks	Goal setting and goal attainment (one study)	Not explicitly mentioned	N/A

	Author Year Country	Aim Theoretical Model	Type and # of Studies, Condition and # of Patients	Components of the Self-Management Programs (specify)	Outcome Measures and Duration	SM Instruments related to goal setting/goal attainment	Goal Attainment Specific Measure	Psychometric Properties of Goal Attainment
9	Sugavanam 2013 United Kingdom	Appraise evidence of effects and experiences of goal setting in rehabilitation SCT, Goal Setting Theory and Self-Regulation Theory	SR Non-randomized studies N=17 332 193 142 71 goal attainment Stroke	Only in rehabilitation context so may not apply	Evaluation of goal setting effects and goal attainment (GAS) Varied from 6 weeks to 12 months	Goal setting and goal attainment	GAS Evaluated earlier in 10 22-24 COPM	No psychometric properties assessed

HBG = health behavior goal; SR = systematic review; MA = meta-analysis QOL = quality of life; CCSM = chronic care self-management; ADL = activities of daily living; SCT = social cognitive theory; Q-exp = quasi-experimental; GAS =goal attainment scaling; COPM = Canadian Occupational Performance Management; SM = self-management

The AMSTAR tool was applied to all nine reviews (Appendix 7). Seven reviews were rated as high quality and two were rated as moderate quality. Details concerning results of AMSTAR ratings are available upon request from the author. All nine reviews were published in the U.S. after 2006. Aims for each review were clearly stated and theoretical frameworks were well-described. Theoretical frameworks included: The Chronic Care SM model by Lorig and Holman (2003), Social Cognitive Theory by Bandura (1997), Health Belief Model by Rosenstock, (1974) and Health Behavior Change Techniques by Michie (2016).

The number of studies included in each systematic review varied widely from four to 41. Three systematic review articles included randomized clinical trials only, the remaining six systematic reviews include randomized and non-randomized controlled trials and quasi-experimental studies. Only two systematic review article included studies with instruments that measured goal setting/goal attainment. The number of patients included in the review articles ranged from several hundred to over 20,000. The component of the self-management interventions included in the review articles consistently included goal setting and action planning as a process for stroke risk factor management. Some incorporated goal setting focused on re-gaining independence and adaptation to ADLs. In terms of outcome measures, most of the reviews concentrated on the SM skills to improve QOL, active patient participation, functional ability, psychosocial symptoms, knowledge, and adherence, and on building self-efficacy to promote long-term sustainable lifestyle changes. The duration of self-management interventions ranged from six weeks to two years and were applied in the population of stroke survivors immediate after hospital discharge up to 12 months post stroke event. Tools used to support SM skills typically included goal setting and action planning as defined by Lorig and Holman (2003) in the Chronic Care Self-Management (CCSM) program. One review used a goal setting and

action planning framework based on Scobbie et al., 2011. Goal attainment specific measures and some psychometric properties were only mentioned in two reviews articles (Stevens et al., 2013 and Sagavanam et al., 2013) Thus, we only include these two review articles in the final analysis.

Final Analysis of Review Articles

Stevens et al. (2013) published a systematic review of instruments used to measure goal-setting. A total of 25 patient-specific instruments were identified, and 11 were included in the review. Ten of the instruments were applied to guide processes of goal negotiation, goal-setting and goal evaluation. Only one instrument was used to specifically measure goal attainment, the Goal Attainment Scale (GAS). Feasibility parameters such as time to administer, instructions, training and availability were established for the GAS but psychometric properties were not reported. The GAS facilitated goal setting in a client-centered approach, but was found to be time consuming and difficult to use for patients with cognitive problems. Steven's review also included a study that described an instrument designed to measure improvements in activities of daily living (ADL) within the context of stroke rehabilitation, The Canadian Occupational Performance Management (COPM). Based on Steven's review no instruments were used to specifically measure goal attainment as related to stroke risk factor SM. Therefore, the impact of goal attainment for effective SM of stroke risk factors has yet to be assessed in research or clinical practice.

Sugavanam et al. (2013) performed a systematic review of studies that included measurement of goal setting in the context of stroke rehabilitation. Seventeen studies were included in the review and none described measures specific for goal setting/goal attainment of stroke risk factor SM. While the GAS and COMP were included in the review, neither were

describes as instruments for the measurement of goal setting/goal attainment for stroke risk factor SM but rather were described as a measures for stroke rehabilitation.

Sugavanam et al. reported that goal setting appeared to improve recovery, performance, and goal achievement, and to positively influence patients' perceptions of self-care ability and engagement in rehabilitation. However, to what degree patients were involved in the goal-setting process was not described. In addition, patients and health care providers differed in how they approached goal setting and in their perception of goal attainment. In conclusion, the authors identified that more rigorous research is needed to established valid and reliable measurement of goal setting and goal attainment and to determine the influence of goal setting/attainment on effective SM and stroke rehabilitation. On the basis of this synthesis, the GAS and COPM can be applied to measure goal setting/attainment in the context of stroke rehabilitation. Conversely, neither instrument has been used specifically within the SM context to measure patients' attainment of a health behavioral goal. The GAS, when used in the rehabilitation setting to measure improved physical functioning, achieved good outcomes. However, only objective feasibility was described and other psychometric properties were reported.

Discussion

We undertook the first systematic review of systematic reviews to identify goal setting/attainment measures applied in SM of chronic conditions in research and clinical settings and to identify current evidence for the impact of goal attainment measures in effective SM of chronic conditions that are also stroke risk factors. The last published review with a similar focus was conducted by Hurn et al., 2006. However, Hurn and colleagues provided a comprehensive update on the use of goal setting as an outcome measure in geriatric stroke survivors participating in post-stroke rehabilitation. While the view specifically emphasized the reliability and validity of instruments used to measure goals related to functional recovery after stroke,

findings cannot be directly applied to the measurement of goal attainment in the context of stroke risk factor SM. The authors concluded that there was strong evidence of the reliability, validity and sensitivity of goal-attainment scaling but suggested that further work needed to be carried out with goal attainment to establish its reliability and sensitivity as a measurement instrument.

In our review, we identified that no reliable and valid instruments had been specifically applied to measure goal setting/goal attainment in SM interventions for stroke risk factor reduction. This may in part be related to the inconsistent application of the concepts goal setting and goal attainment. For example, goal setting as an outcome measure was referred to as goal attainment and goal attainment was referred to as action plan implementation or completion. To guide our review process we established clear definitions of terms, with goal setting defined as “the process of establishing priorities and setting criteria for learning and performing a new behavior or for modifying behavior.” Action planning as “the steps that facilitate goal setting and attainment by breaking down a goal to a behavior that is measurable, achievable, realistic and time specific (what, how much, when, and how often?).” Thus, based on these definitions, goal attainment is defined as “achievement of the behaviors detailed in the action plan”.

The lack of consistent use and agreed upon definitions for goal setting and goal attainment has been well described (Letter to the Editor - Hurn, 2007). Being aware of this, we initially searched for review articles that applied the goal setting/goal attainment concepts broadly so that we did not omit important literature on the topic. Results of this approach revealed a multitude of studies that included the concepts of goal setting and goal attainment within the context of behavior changed for chronic disease self-management (Appendix 8) . We then further narrowed our search to identify reviews that included goal setting conceptualized as an outcome: goal attainment defined as achievement of a goal or action plan for behavior

changes related to SM of chronic conditions that are also stroke risk factors. For example, achievement of a goal related to improving hypertension, diabetes, hyperlipidemia, obesity, inactivity etc.. While this approach identified indirect measures of goal attainment quantified as improvement in the blood pressure and/or blood sugar values or increases physical activity, no specific instruments were identified that measured attainment of the specific behavior goals applied to achieve improved blood pressure, blood sugar, or physical activity.

We then established clear definitions of terms, with goal setting defined as “the process of establishing priorities and setting criteria for learning and performing a new behavior or for modifying behavior.” Action planning is “a set of “behavior-specific” steps that will help to realistically accomplish actions within a specific period of time (what, how much, when, and how often?).” Goal attainment is defined as “achieving a set of behaviors leading to attainment of a specified goal, using action planning.” Articles that are concerned only with narrower conditions such as diabetes or hypertension-based stroke were excluded.

This systematic review of systematic reviews advances the field and provides an update on measuring goal attainment in the context of the health behavioral change with an emphasis on chronic conditions that are also stroke risk factors. In the sequel, we recommend which additional research is needed to better understand the definitions and concepts’ operationalization to develop more reliable and valid measures. These measures will enable researchers to design more effective SM programs.

Strengths and Limitations

The study was conducted and reported according to the PRISMA guidelines. Given the complexity of the goal setting and goal attainment concept as applied in the health behavior

change domain in SM of stroke, we were able to use two independent reviewers at every stage of the project for data extraction and synthesis. We also tested the reliability and provided additional training to the reviewers achieving moderate reliability. In addition, we established AMSTAR ratings and studies included in the review were of the highest quality. Our study was also strengthened by its broad inclusion criteria reducing the possibility of missing relevant systematic reviews. However, there are limitations of our systematic review of the systematic reviews due to the considerable variation of included reviews in terms of broadly defined concepts and inclusion criteria. Lack of outcome measures reported and essential details of the impact of goal attainment on the SM interventions also contributed to study limitations resulting in considerable difficulty in synthesizing the information and performing subsequent analysis. Another limitation might be that we included studies published in the English language only which might contribute to omitting important research. Finally, we have not examined individual studies within each systematic review, as this would exceed the scope of the project and its timely completion.

Conclusions

To our best knowledge, this is the first systematic review of systematic reviews evaluating the use of goal attainment measures in the research and clinical contexts. We identified several strengths, but also limitations significantly influencing what evidence-based inferences can be drawn from this review. We have not found any measures in studies that specifically measure goal attainment of stroke risk factors SM. This review demonstrates an absence of outcome measures that specifically measure goal attainment in SM of stroke in the research and clinical setting. It also confirms that, while SM appears to offer significant improvements in patient outcomes, a consensus as to the SM process and its quantitation is just

beginning to emerge (Riegel et al., 2000). As previously reported (Boger, 2015) this might be due to the lack of clear concept definitions and their operationalization. Psychometric properties were not specified, therefore, we can comment on neither their strengths nor weaknesses. This systematic review of systematic reviews demonstrates an absence of measures that adequately assess goal attainment through SM techniques applied in the stroke risk reduction domain. Consequently, the underlying mechanisms that affect behavior change are not fully understood. The use of goal attainment measures is minor and not clearly understood, but the review reveals that this concept is a growing field of research in the SM domain. Additional research is needed to better understand the definitions and concepts' operationalization to develop more reliable and valid measures. These measures will enable researchers to design more effective SM programs.

Future Research

The purpose of this review was to inform the scientific community and professionals working in the field of chronic diseases and stroke risk factors prevention about the importance of goal setting and goal attainment measures and their impact on SM outcomes. On the basis of the review, we would recommend changes to the study methodologies making sure that clear and consistent terms are used to define goal setting as an outcome measure. Further work on conceptualization of the stroke SM cycle as defined by Scobbie (2011) is strongly recommended to develop and evaluate goal attainment measures. We would also recommend that the theoretical framework be clearly specified in the methodological section of each review including the behavioral change model used. These suggestions will better inform researchers and clinicians about development of these measures. Better outcome measures will enable researchers to improve evaluations of SM programs.

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Appendix 1 Search Strategies Summary

Table 1: Summary of databases goal attainment search strategies

Table	Vendor/ Interface	Database	Date searched	Database update	Searcher(s)
1a	Ovid	Medline®	3/16/2017	In-Process & Other Non- Indexed Citations; 1996 to March 15, 2017	Helena M. VonVille; Barbara Kimmel
1b	National Library of Medicine	PubMed	3/16/2017	3/16/2017	Helena M. VonVille; Barbara Kimmel
1c	Ovid	PsycINFO ®	3/17/2017	1987 to March Week 2 2017	Helena M. VonVille; Barbara Kimmel

Appendix 2 Search Strategies

Table 1a: Ovid Medline® search strategy

Provider/Interface	Ovid
Database	Medline®
Date searched	3/16/2017
Database update	In-Process & Other Non-Indexed Citations; 1996 to March 15, 2017
Search developer(s)	Helena M. VonVille; Barbara Kimmel
Limit to English	Yes
Date Range	2000-2017
Search filter source	http://libguides.sph.uth.tmc.edu/search_filters/ovid_medline_filters

1	"Outcome Assessment (Health Care)"/
2	psychological tests/ or behavior rating scale/ or psychometrics/
3	(instrument* or inventories or inventory or measure* or scale or scales or test or tests).ti,ab,kw.
4	1 or 2 or 3
5	Goals/ and (achievement or attainment or collaborat* or health behavior or health related behavior or management or prescription or setting).ti,ab,kw.
6	((goal or goals) adj3 (achievement or attainment or collaborat* or health behavior or health related behavior or management or prescription or setting)).ti,ab,kw.
7	(action planning or implementation intentions or self-management or self-monitoring or self-regulation).ti,ab,kw.
8	5 or 6 or 7
9	4 and 8
10	(((comprehensive* or integrative or systematic*) adj3 (bibliographic* or review* or literature)) or (meta-analy* or metaanaly* or "research synthesis" or ((information or data) adj3 synthesis) or (data adj2 extract*))).ti,ab. or (cinahl or (cochrane adj3 trial*) or embase or medline or psyclit or (psycinfo not "psycinfo database") or pubmed or scopus or "sociological abstracts" or "web of science").ab. or ("cochrane database of systematic reviews" or evidence report technology assessment or evidence report technology assessment summary).jn. or Evidence Report: Technology Assessment*.jn. or ((review adj5 (rationale or evidence)).ti,ab. and review.pt.) or meta-analysis as topic/ or Meta-Analysis.pt.
11	9 and 10
12	(11 and (adult/ or aged/ or "aged, 80 and over"/ or frail elderly/ or middle aged/ or young adult/)) or (11 not (child/ or adolescent/))
13	limit 12 to (english language and yr="2000 - 2017")

Table 1b: PubMed search strategy

Provider/Interface	National Library of Medicine
Database	PubMed
Date searched	3/16/2017
Database update	3/16/2017
Search developer(s)	Helena M. VonVille; Barbara Kimmel
Limit to English	Yes
Date Range	2000-2017
Publication Types	http://libguides.sph.uth.tmc.edu/search_filters/pubmed_filters
Search filter source	National Library of Medicine

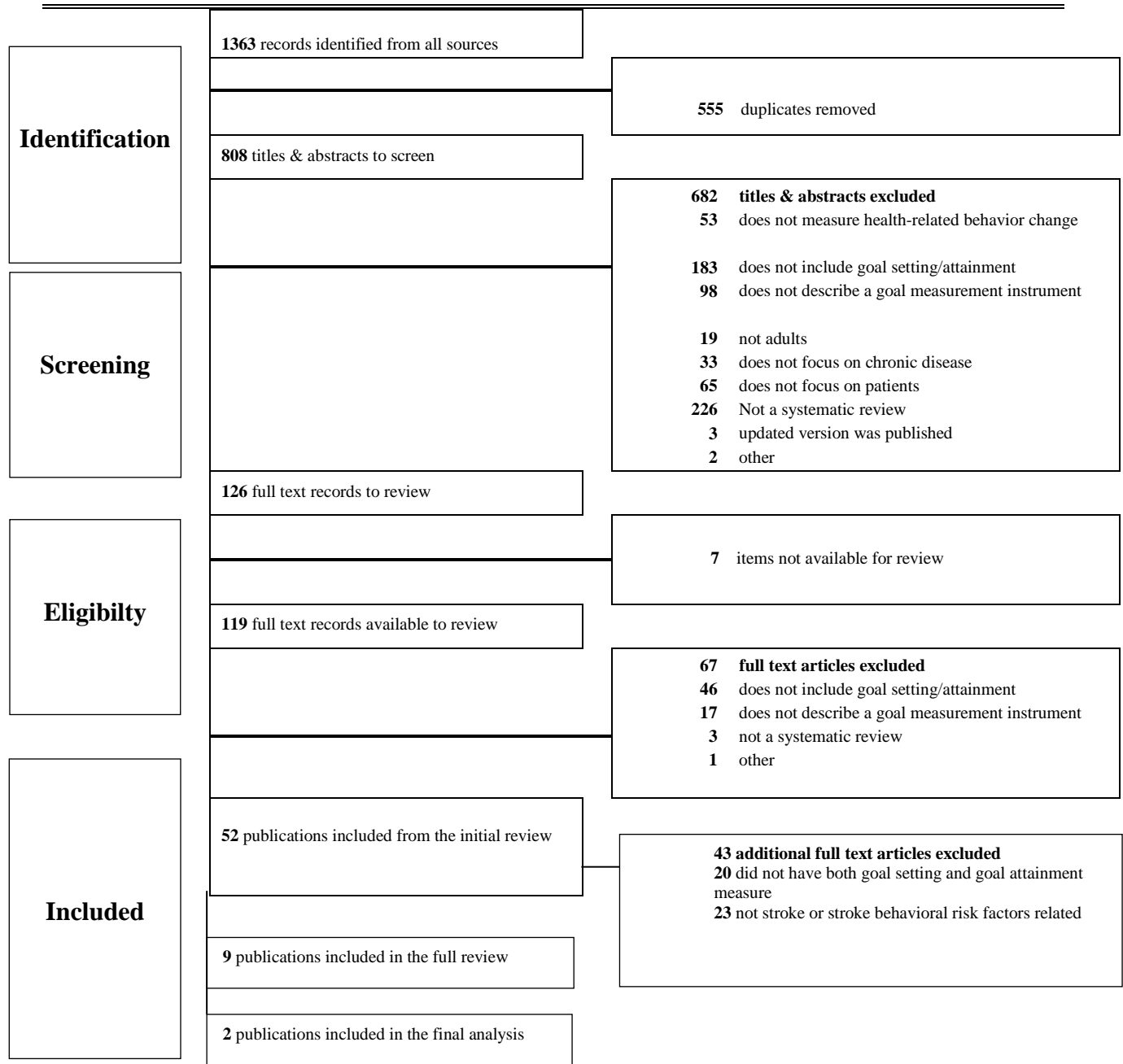
1	"Outcome Assessment (Health Care)"[mesh:noexp]
2	psychological tests[mesh:noexp] OR behavior rating scale[mesh:noexp] OR psychometrics[mesh:noexp]
3	(instrument*[tiab] OR inventories[tiab] OR inventory[tiab] OR measure*[tiab] OR scale[tiab] OR scales[tiab] OR test[tiab] OR tests[tiab])
4	#1 OR #2 OR #3
5	Goals[mesh:noexp] AND (achievement[tiab] OR attainment[tiab] OR collaborat*[tiab] OR health behavior[tiab] OR health related behavior[tiab] OR management[tiab] OR prescription[tiab] OR setting[tiab])
6	((goal[ti] OR goals[ti]) AND (collaborat*[tiab] OR health behavior[tiab] OR health related behavior[tiab] OR management[tiab] OR prescription[tiab] OR setting[tiab]))
7	((action planning[tiab] OR goal achievement[tiab] OR goal attainment[tiab] OR implementation intentions[tiab] OR self-management[tiab] OR self-monitoring[tiab] OR self-regulation[tiab]))
8	#5 OR #6 OR #7
9	#4 AND #8
10	(systematic*[tiab] AND (bibliographic*[TIAB] OR literature[tiab] OR review[tiab] OR reviewed[tiab] OR reviews[tiab])) OR (comprehensive*[TIAB] AND (bibliographic*[TIAB] OR literature[tiab])) OR "cochrane database syst rev"[Journal] OR "Evidence report[mesh:noexp]technology assessment (Summary)"[journal] OR "Evidence report[mesh:noexp]technology assessment"[journal] OR "integrative literature review"[tiab] OR "integrative research review"[tiab] OR "integrative review"[tiab] OR "research synthesis"[tiab] OR "research integration"[tiab] OR cinahl[tiab] OR embase[tiab] OR medline[tiab] OR psyclit[tiab] OR (psycinfo[tiab] NOT "psycinfo database"[tiab]) OR pubmed[tiab] OR scopus[tiab] OR "web of science"[tiab] OR "data synthesis"[tiab] OR meta-analys*[tiab] OR meta-analyz*[tiab] OR meta-analyt*[tiab] OR metaanalys*[tiab] OR metaanalyz*[tiab] OR metaanalyt*[tiab] OR "meta-analysis as topic"[MeSH:noexp] OR Meta-Analysis[ptyp] OR ((review[tiab] AND (rationale[tiab] OR evidence[tiab])) AND review[pt]))
11	#9 AND #10
12	(#11 AND (adult[mesh:noexp] OR aged[mesh:noexp] OR "aged, 80 AND over"[mesh:noexp] OR frail elderly[mesh:noexp] OR middle aged[mesh:noexp] OR young adult[mesh:noexp])) OR (#11 not (child[mesh:noexp] OR adolescent[mesh:noexp]))
13	#12 AND (English[la] AND 2000:2017[dp])

Table 1c: Ovid PsycINFO® search strategy

Provider/Interface	Ovid
Database	PsycINFO®
Date searched	3/17/2017
Database update	1987 to March Week 2 2017
Search developer(s)	Helena M. VonVille; Barbara Kimmel
Limit to English	Yes
Date Range	2000-2017
Publication Types	modified test filter; no change to SR filter: http://libguides.sph.uth.tmc.edu/search_filters/ovid_psycinfo_filters
Search filter source	3/17/2017

1	content analysis (test)/ or "item analysis (test)"/ or "item content (test)"/ or "profiles (measurement)"/ or attitude measurement/ or criterion referenced tests/ or achievement measures/ or attitude measures/ or inventories/ or preference measures/ or questionnaires/ or rating scales/ or individual testing/ or measurement/ or multidimensional scaling/ or needs assessment/ or pain measurement/ or performance tests/ or posttesting/ or pretesting/ or psychometrics/ or response bias/ or test bias/ or test construction/ or test forms/ or test items/ or test reliability/ or test standardization/ or test validity/ or sensorimotor measures/ or statistical measurement/ or subtests/ or surveys/ or testing/ or "22".cc. or ((testing or test or questionnaire* or instrument* or survey* or measurement* or assessment* or scale or scales) and (validation or validity or reliability or internal consistency or psychometric*)).ti,ab,id.
2	goals/ or goal setting/
3	(achievement or attainment or collaborat* or health behavior or health related behavior or management or prescription or setting).ti,ab,id.
4	2 and 3
5	((goal or goals) adj3 (achievement or attainment or collaborat* or health behavior or health related behavior or management or prescription or setting)).ti,ab,id.
6	(action planning or implementation intentions or self-management or self-monitoring or self-regulation).ti,ab,id.
7	4 or 5 or 6
8	1 and 7
9	((comprehensive* or integrative or systematic*) adj3 (bibliographic* or review* or literature)) or (meta-analy* or metaanaly* or "research synthesis" or ((information or data) adj3 synthesis) or (data adj2 extract*))).ti,ab,id. or ((review adj5 (rationale or evidence)).ti,ab,id. and "Literature Review".md.) or (cinahl or (cochrane adj3 trial*) or embase or medline or psyclit or pubmed or scopus or "sociological abstracts" or "web of science").ab. or ("systematic review" or "meta analysis").md.
10	8 and 9
11	limit 10 to (english language and yr="2000 - 2017")

Appendix 3 PRISMA Flowchart: Systematic Reviews of Goal Attainment



Appendix 4 Health-related Behavior Change Theories

1. Schwarzer's Health Action Process Approach (2008)
 2. Health Believe Model (Rosenstock, 1974)
 3. Protection Motivation Theory (Rogers, 1975)
 4. The Transtheoretical Model (Prochaska & Di Clemente, 1986)
 5. Self-Determination Theory (Deci & Ryan, 2001)
 6. Theory of Reasoned Action (Fishbein & Azjen, 1975)
 7. Theory of Planned Behavior (Azjen, 1985)
 8. Goal Setting Theory (Locke, 1996; Latham & Locke, 1991)
 9. Self-Regulation Theory (Carver & Scheier, 2012)
 10. Social Cognitive Theory (Bandura, 1997)
-

Appendix 5 Excell Workbooks

1. Naming Conventions for the Excel SR Workbooks
 2. PRIMARY Excel Workbook for Systematic Reviews
 3. Excel Workbook to Calculate Cohen's kappa
 4. Excel Workbook for Screening Titles and Abstracts
 5. Excel Workbook for Reviewing Full Text Articles
 6. RefWorks RefID, Title, Abstract Style Output
 7. EndNote Tab-delimited style with Record ID Title Abstract
-

Appendix 6 Coding & Data Entry Form for Systematic Review of Systematic Reviews for Goal Setting and Goal Attainment Studies in Stroke

Citation (C), Study (S), Exposure (E), Outcome (O) Levels

ID	Variable Name (Coding Instructions)	Values, Text Codes	
Eligibility Criteria (Note: Must meet all; if any criterion is in doubt, stop and check with the PI.)			
E 1	Must be study in secondary stroke/TIA prevention		Check if “yes.” I.e., not a primary stroke
E 2	Study patients should be engaged in the self-management to control behavioral stroke risk factors		Check if “yes.” Refer to behavioral modifications such for example diet, exercise, smoking and stress reduction
E 3	Must specify types of goal set		Check if “yes.” Note: The report should explicitly state that patients follow the concept of goal setting defined as a making specific action plan for behavioral stroke risk factor control modifications - then DON’T include.
E 4	Must specify names and characteristic of the specific scales for goal setting and goal attainment measures and participants’ self-management intervention program engagement		Check if “yes.” Note: This review will not assess efficacy or effectiveness outcomes related to the self-management program interventions
E 5	Must specify psychometric properties of these measures (reliability and validity scores) if any		Check if “yes.”
Citation Information			
C 1	Ref Works ID (main citation)		
C 2	Name of coder		
C 3	Publication Date		
C 4	Author		
C 5	Type of report		Full text systematic review of the systematic reviews (from journal article)
			Full text systematic review (from journal article)
			Other (specify):
C 6	Secondary cite(s) – Ref Works ID, publication date, author Note: Explain relation to other citations, e.g., “Contains data from later follow-ups.”		

C7	Number of studies reported in this citation		Default=1 N=
Study Level Information			
S 1	Study ID		Default=1. If >1, use additional forms for each additional study with the same citation level information.
S 2	Sponsor (Check one)		Industry
			Govt (Specify)
			Other (Specify)
			Not Reported
S 3	Study design (Use STROBE checklist)		Randomized clinical trial – CONSORT definition
			Non-randomized trial – TREND definition
			Cohort study (prospective) – STROBE definition
			Cohort study (retrospective) – STROBE definition
			Case-control study– STROBE definition
			Cross-sectional survey– STROBE definition
			Other (specify):
S 4	Study Location– City, State, Country		
S 5	Study enrollment years		
S 6	Goal setting domain		Behavior modifications (specify an area of lifestyle changes):
S7	Goal Attainment-- following up on the extent to which the goals are achieved		
S 8	Inclusion criteria (Reverse exclusion criteria, complete all that apply)		
			Other (specify):
S 9	Control or comparison group		Control (check box if applies)
			Comparison (check box if applies)
S 10	Sample size of control/ comparison		
S 11	Behavioral change technique		Check if “yes.” I.e., is a theory –based method for changing one or several psychological determinants of behavior such as person’s attitude or self-efficacy explicitly mentioned?

			If yes- specify which one
S 12	Behavior change interventions		Check if “yes.” I. e. are behavior change methods used in behavior change interventions for example Lorig’s Stanford Chronic Disease Self-Management Program (CDSMP)
S 13	Age (Complete all that apply; Enter # in all study groups)		Lowest age
			Highest age
			Mean (SD) age
			Median age
			Age not described
			Age categories (specify)
S 15	Race/ethnicity (Complete all that apply; Enter # in all study groups)		African American
			Asian
			American Indian
			Hispanic
			Other
			Non-Hispanic White
			Described Otherwise (specify):
			Race/ethnicity not described
S 16	SES (Education, income, SES categories, and/or proxy for SES-specify)		
S 17	Number of exposure/treatment groups		Default=1
Exposure or Treatment Level			
E 1	Exposure/treatment group ID (behavioral interventions)		Default=1. If >1, use additional forms for each additional exposures/treatment group with the same citation and study level information.
E 2	Sample size (group that received intervention)		
E 3	Type intervention (Check all that apply)		In hospital self-management sessions
			Primary care self-management support
			Other (specify):
E 4	Number of outcomes		Default=1

Outcome Level			
O 1	Outcome/subgroup ID		Default=1. If >1, use additional forms for each additional outcome/subgroup, with the same citation, study, and exposure or treatment level information.
O 2	Self-management components (Choose all that apply)		Goal setting
			Action Planning
			Goal attainment/Monitoring/Feedback
O 3	Goal Attainment Measure (Enter mean/median follow-up periods)		Check if “yes.”
O 4	Number of outcomes measured		Default=1
Measurement Level			
M 1	Goal Attainment (check all that apply)		Validity
			Reliability
			Other (specify):
			Specify the measure name:
M 2	How were final results reported?		Description:
M 3	Author’s description of results		

Appendix 7

AMSTAR Data Extraction Template

AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both

<p>1. Did the research questions and inclusion criteria for the review include the components of PICO?</p>		
<p>For Yes:</p> <p><input type="checkbox"/> Population</p> <p><input type="checkbox"/> Intervention</p> <p><input type="checkbox"/> Comparator group</p> <p><input type="checkbox"/> Outcome</p>	<p>Optional (recommended)</p> <p><input type="checkbox"/> Timeframe for follow-up</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>
<p>2. Did the report of the review contain an explicit statement that the review methods were established prior to the conduct of the review and did the report justify any significant deviations from the protocol?</p>		
<p>For Partial Yes:</p> <p>The authors state that they had a written protocol or guide that included ALL the following:</p> <p><input type="checkbox"/> review question(s)</p> <p><input type="checkbox"/> a search strategy</p> <p><input type="checkbox"/> inclusion/exclusion criteria</p> <p><input type="checkbox"/> a risk of bias assessment</p>	<p>For Yes:</p> <p>As for partial yes, plus the protocol should be registered and should also have specified:</p> <p><input type="checkbox"/> a meta-analysis/synthesis plan, if appropriate, <i>and</i></p> <p><input type="checkbox"/> a plan for investigating causes of heterogeneity</p> <p><input type="checkbox"/> justification for any deviations from the protocol</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Partial Yes</p> <p><input type="checkbox"/> No</p>
<p>3. Did the review authors explain their selection of the study designs for inclusion in the review?</p>		
<p>For Yes, the review should satisfy ONE of the following:</p> <p><input type="checkbox"/> <i>Explanation for including only RCTs</i></p> <p><input type="checkbox"/> OR <i>Explanation for including only NRSI</i></p> <p><input type="checkbox"/> OR <i>Explanation for including both RCTs and NRSI</i></p>		
<p>4. Did the review authors use a comprehensive literature search strategy?</p>		
<p>For Partial Yes (all the following):</p> <p><input type="checkbox"/> searched at least 2 databases (relevant to research question)</p> <p><input type="checkbox"/> provided key word and/or search strategy</p> <p><input type="checkbox"/> justified publication restrictions (e.g. language)</p>	<p>For Yes, should also have (all the following):</p> <p><input type="checkbox"/> searched the reference lists / bibliographies of included studies</p> <p><input type="checkbox"/> searched trial/study registries</p> <p><input type="checkbox"/> included/consulted content experts in the field</p> <p><input type="checkbox"/> where relevant, searched for grey literature</p> <p><input type="checkbox"/> conducted search within 24 months of completion of the review</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Partial Yes</p> <p><input type="checkbox"/> No</p>
<p>5. Did the review authors perform study selection in duplicate?</p>		
<p>For Yes, either ONE of the following:</p> <p><input type="checkbox"/> at least two reviewers independently agreed on selection of eligible studies and achieved consensus on which studies to include</p> <p><input type="checkbox"/> OR two reviewers selected a sample of eligible studies <u>and</u> achieved good agreement (at least 80 percent), with the remainder selected by one reviewer.</p>		

AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both

6. Did the review authors perform data extraction in duplicate?		
For Yes, either ONE of the following:		
<input type="checkbox"/> at least two reviewers achieved consensus on which data to extract from included studies	<input type="checkbox"/> Yes	
<input type="checkbox"/> OR two reviewers extracted data from a sample of eligible studies <u>and</u> achieved good agreement (at least 80 percent), with the remainder extracted by one reviewer.	<input type="checkbox"/> No	
7. Did the review authors provide a list of excluded studies and justify the exclusions?		
For Partial Yes:		For Yes, must also have:
<input type="checkbox"/> provided a list of all potentially relevant studies that were read in full-text form but excluded from the review	<input type="checkbox"/> Justified the exclusion from the review of each potentially relevant study	<input type="checkbox"/> Yes
		<input type="checkbox"/> Partial Yes
		<input type="checkbox"/> No
8. Did the review authors describe the included studies in adequate detail?		
For Partial Yes (ALL the following):		For Yes, should also have ALL the following:
<input type="checkbox"/> described populations	<input type="checkbox"/> described population in detail	<input type="checkbox"/> Yes
<input type="checkbox"/> described interventions	<input type="checkbox"/> described intervention in detail (including doses where relevant)	<input type="checkbox"/> Partial Yes
<input type="checkbox"/> described comparators	<input type="checkbox"/> described comparator in detail (including doses where relevant)	<input type="checkbox"/> No
<input type="checkbox"/> described outcomes	<input type="checkbox"/> described study's setting	
<input type="checkbox"/> described research designs	<input type="checkbox"/> timeframe for follow-up	
9. Did the review authors use a satisfactory technique for assessing the risk of bias (RoB) in individual studies that were included in the review?		
RCTs		
For Partial Yes, must have assessed RoB from:		For Yes, must also have assessed RoB from:
<input type="checkbox"/> unconcealed allocation, <i>and</i>	<input type="checkbox"/> allocation sequence that was not truly random, <i>and</i>	<input type="checkbox"/> Yes
<input type="checkbox"/> lack of blinding of patients and assessors when assessing outcomes (unnecessary for objective outcomes such as all-cause mortality)	<input type="checkbox"/> selection of the reported result from among multiple measurements or analyses of a specified outcome	<input type="checkbox"/> Partial Yes
		<input type="checkbox"/> No
		<input type="checkbox"/> Includes only NRSI
NRSI		
For Partial Yes, must have assessed RoB:		For Yes, must also have assessed RoB:
<input type="checkbox"/> from confounding, <i>and</i>	<input type="checkbox"/> methods used to ascertain exposures and outcomes, <i>and</i>	<input type="checkbox"/> Yes
<input type="checkbox"/> from selection bias	<input type="checkbox"/> selection of the reported result from among multiple measurements or analyses of a specified outcome	<input type="checkbox"/> Partial Yes
		<input type="checkbox"/> No
		<input type="checkbox"/> Includes only RCTs
10. Did the review authors report on the sources of funding for the studies included in the review?		
For Yes		
<input type="checkbox"/> Must have reported on the sources of funding for individual studies included in the review. Note: Reporting that the reviewers looked for this information but it was not reported by study authors also qualifies		<input type="checkbox"/> Yes
		<input type="checkbox"/> No

AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both

11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	
<div style="border: 1px solid black; padding: 5px;"> RCTs For Yes: <div style="display: flex; justify-content: space-between; align-items: flex-start;"> <div style="width: 60%;"> <input type="checkbox"/> The authors justified combining the data in a meta-analysis <input type="checkbox"/> AND they used an appropriate weighted technique to combine study results and adjusted for heterogeneity if present. <input type="checkbox"/> AND investigated the causes of any heterogeneity </div> <div style="width: 35%;"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No meta-analysis conducted </div> </div> </div>	
<div style="border: 1px solid black; padding: 5px;"> For NRSI For Yes: <div style="display: flex; justify-content: space-between; align-items: flex-start;"> <div style="width: 60%;"> <input type="checkbox"/> The authors justified combining the data in a meta-analysis <input type="checkbox"/> AND they used an appropriate weighted technique to combine study results, adjusting for heterogeneity if present <input type="checkbox"/> AND they statistically combined effect estimates from NRSI that were adjusted for confounding, rather than combining raw data, or justified combining raw data when adjusted effect estimates were not available <input type="checkbox"/> AND they reported separate summary estimates for RCTs and NRSI separately when both were included in the review </div> <div style="width: 35%;"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No meta-analysis conducted </div> </div> </div>	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	
<div style="border: 1px solid black; padding: 5px;"> For Yes: <div style="display: flex; justify-content: space-between; align-items: flex-start;"> <div style="width: 60%;"> <input type="checkbox"/> included only low risk of bias RCTs <input type="checkbox"/> OR, if the pooled estimate was based on RCTs and/or NRSI at variable RoB, the authors performed analyses to investigate possible impact of RoB on summary estimates of effect. </div> <div style="width: 35%;"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No meta-analysis conducted </div> </div> </div>	
13. Did the review authors account for RoB in individual studies when interpreting/ discussing the results of the review?	
<div style="border: 1px solid black; padding: 5px;"> For Yes: <div style="display: flex; justify-content: space-between; align-items: flex-start;"> <div style="width: 60%;"> <input type="checkbox"/> included only low risk of bias RCTs <input type="checkbox"/> OR, if RCTs with moderate or high RoB, or NRSI were included the review provided a discussion of the likely impact of RoB on the results </div> <div style="width: 35%;"> <input type="checkbox"/> Yes <input type="checkbox"/> No </div> </div> </div>	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	
<div style="border: 1px solid black; padding: 5px;"> For Yes: <div style="display: flex; justify-content: space-between; align-items: flex-start;"> <div style="width: 60%;"> <input type="checkbox"/> There was no significant heterogeneity in the results <input type="checkbox"/> OR if heterogeneity was present the authors performed an investigation of sources of any heterogeneity in the results and discussed the impact of this on the results of the review </div> <div style="width: 35%;"> <input type="checkbox"/> Yes <input type="checkbox"/> No </div> </div> </div>	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	
<div style="border: 1px solid black; padding: 5px;"> For Yes: <div style="display: flex; justify-content: space-between; align-items: flex-start;"> <div style="width: 60%;"> <input type="checkbox"/> performed graphical or statistical tests for publication bias and discussed the likelihood and magnitude of impact of publication bias </div> <div style="width: 35%;"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No meta-analysis conducted </div> </div> </div>	

CHAPTER 4

PAPER #2

Veteran Stroke Survivors' Lived Experiences After Being Discharged Home:

A Phenomenological Study

Abstract

Background

Stroke is a leading cause of disability in adults and the fifth leading cause of death in the United States. Stroke survivors experience multiple challenges after hospital discharge in adapting to their new life conditions and in self-managing stroke risk factors such as hypertension or diabetes. Stroke survivors experience physical and cognitive disabilities as well as emotional comorbidities (e.g., depression and anxiety), which can adversely affect their quality of life. Patient self-management (SM) is critical to prevent a second stroke, but we know little about stroke survivors' lived experiences in performing SM behaviors.

Aims

The purpose of this study was to describe stroke patients' lived experiences of SM following hospital discharge.

Methods

Phenomenology was the guiding qualitative methodology of the study. Participants, who experienced stroke or transient ischemic attack (TIA), within one year after hospital discharge and with two or more stroke risk factors, were enrolled in the study. Interviews were conducted in a large Veterans Affairs Medical Center in the southern United States. An inductive analysis was used to describe the patients' phenomenological experience of being involved in an SM program and their subsequent use of goal-setting and goal-attainment behaviors. Data on patients' post discharge experiences were analyzed deductively to identify themes. Repeated

transcript review was used to identify essential themes regarding perceptions of SM and strategies used to accomplish SM.

Results

Hour-long interviews were conducted with eight patients (six men, two women; mean age, 62; range 45-80 yrs.) over seven months. Analysis revealed three major lived experiences of post stroke patients: 1) immediate uncertainty about life, 2) anger and frustration, and 3) challenges with the Veterans Health Administration healthcare system. Patient perceptions about SM focused on stroke as a debilitating disease that affects all aspects of life. Reported SM strategies focused on improvements in physical function, coping skills, and cognitive resilience (i.e., staying determined and positive). Applying coping skills and setting goals to manage stroke risk factors were critical determinants of improved physical and emotional functioning.

Conclusions

SM coping behaviors and goal setting aided stroke survivors' recovery process and improved their quality of life. These findings indicate that SM support interventions hold promise in assisting stroke survivors to regain physical and emotional function.

Veteran Stroke Survivors' Lived Experiences

After Being Discharged Home: A Phenomenological Study

Introduction

Stroke is the number one cause of disability, number two cause of dementia, and number five cause of death in developing countries (Centers for Disease Control & Prevention, 2018). It is a major cause of epilepsy, falls, and depression, representing a substantial economic and societal burden (Mukherjee & Patil, 2011). In 2007, the American Heart Association (AHA) estimated the cost of stroke in the United States to be around \$40 billion. Estimates of total stroke cost between 2005-2050 in U.S. dollars, is projected to be \$1.52 trillion for non-Hispanic whites, \$313 billion for Hispanics, and \$379 billion for blacks. Lost financial earnings are expected to be the highest cost contributor in each race/ethnic group (AHA, 2012). Although rates in stroke incidence decreased by 42% in high-income countries, they have doubled in low-to-middle income countries (Feigin, Lawes, Bennett, Barker-Collo & Parag, 2009). It is estimated that about one third of people who survived stroke are entirely dependent due to various post stroke disabilities (Simeone, Savini, Cohen, Alvaro & Vellone, 2015). Stroke survivors experience major challenges associated with adjusting to a new phase of life, managing expectations for recovery and attempting to reclaim independence, with survivors rating their quality of life as poor (Sprigg et al., 2012). Physical and cognitive disabilities as well as emotional comorbidities (e.g., depression and anxiety) adversely affect stroke survivors' quality of life. Often depression and anxiety are related to slow physical and emotional recovery and fear of being a burden to their family (Damush, Plue, Bakas, Schmit & Williams, 2007; Evans-Hudnall et al., 2017; Lincoln et al., 2013).

A large body of evidence shows that addressing the health, social and environmental issues associated with life after stroke may improve life for post stroke patients (Jones, 2006;

Jones & Riazzi, 2011; Jones, Riazzi & Norris, 2013). This is specifically important in the context of managing behaviors that contributed to first stroke and have the potential to increase the possibility of stroke recurrence. For example, tobacco smoking, alcohol abuse, physical inactivity, and poor diet constitute behaviors that may contribute to stroke but could be successfully managed. In addition, hypertension, atrial fibrillation, and diabetes, which account for over 60% of all first-ever strokes, if under control, could reduce stroke recurrence (Lawes, Vander Hoorn & Rodgers, 2008). Every effort should thus be made to control modifiable stroke risk factors.

Risk-factor control could be achieved by engaging patients in self-management (SM). SM is a set of behaviors based on the mastery of certain skills. However, how people implement and maintain a behavioral regimen based on those skills is not a simple matter. Stroke survivors are faced with multiple challenges after hospital discharge in adapting to their new life conditions and in self-managing risk factors such as hypertension or diabetes. Even though patient SM is critical to prevent a second stroke, we know little about stroke survivors' lived experiences in performing SM behaviors.

Several studies address patients' experience after stroke; however, few have addressed the post stroke experience in the Veteran population, with particular emphasis on patient SM of behavioral stroke risk factors. Furthermore, studies concerning the use of goal setting and attainment resulted in a problematic theoretical framework, methodology and generalizability (Simeone et al., 2015). Some studies addressed patients' experiences after their hospital discharge and in the context of rehabilitation immediately after the acute event (Simeone et al., 2015). We also found studies that examined patients' lived experience during the prolonged rehabilitation period, addressing issues such as stress, adaptation, coping and disability, and poor quality of life. Burton's study, (2000) revealed that recovery from stroke involved restructuring

and adaptation of physical, social and emotional aspects of an individual's life. Negi (2014) conducted an interpretative phenomenological study of the experiences of stroke patients and their caregivers. Three major themes emerged: reality adjustment by adapting to the new normality, the grown self and limited support for caregivers. McKevitt, Redfern, Mold & Wolfe, (2004) conducted a systematic review of qualitative studies that addressed a wide range of issues related to the impact of stroke on individuals and caregivers and to the organization and delivery of services. The authors concluded that problems still exist with high-quality stroke care delivery that could be solved by improving collaboration between nonclinical and clinical scientists and healthcare providers.

Another study examined patients' perception of quality of life after surviving the first episode of stroke (García-Moriche, Rodriguez-Gonzalo, Muñoz-Lobo, Parra-Cordero & Fernández-De Pablos, 2009) and concluded that the patient perception of the stroke is not that of a disease but rather of a momentary event in health. Patients noted that they had to adjust to a new identity, as well as to a new social context. Based on this review, we have not found any mention of the SM component, either as a description of the method or in program implementation. None of these studies referred to any intervention programs in which SM goal-setting concepts were used.

To understand the gap, a more precise investigation of patients' physical and emotional experience while engaged in the SM of stroke risk factors is needed after surviving a stroke. Knowing the patient's stroke experiences following the stroke may enable healthcare providers and caregivers to view stroke survivors from a broader and more humanistic prospective. It may also add valuable perspective to intervention programs designed to improve patients' physical and emotional status after stroke.

Purpose and Aims

A qualitative phenomenological study was conducted to describe the lived experience of Veteran stroke survivors engaged in the SM of stroke risk factors following hospital discharge. We sought to establish what the patients' experiences immediately are after stroke. We also investigated patients' strategies and perceptions with goal setting and attainment, using the action plan process to achieve stroke risk-factor management.

Design and Methods

A descriptive phenomenological qualitative study has been conducted to describe the core of the lived experience of Veterans who have suffered a stroke and are engaged in SM. This qualitative approach intends to offer insight into how a given person in a specific context makes sense of the given phenomenon (Wagstaff & Williams, 2014). The phenomenological method is a particular way of thinking about what life experiences are like for people experiencing the event under investigation, and it is primarily concerned with interpreting the meaning of these experiences (Powers & Knapp, 1995). Therefore, the theoretical framework of the study is based on the principles of phenomenology first introduced as a research method by Husserl in 1962. The phenomenological research approach in this study allows patients to describe, in their own words, their experience surviving the stroke and applying SM concepts, as described by the study aim. Furthermore, phenomenology research focuses on capturing the whole meaning of experience without dividing it into parts (De Castro, 2003). The goal of the method is to capture the common or shared experience of the phenomena, a concrete daily life experience after stroke, without losing the meaning that the person is trying to convey. A phenomenological approach allowed us to explore the meaning of human experience, to answer the questions, "What was the experience like?" and "How did s/he experience it?" as well as to create a "life-text," resulting in an individual story that generates study data to be clarified and interpreted by performing the

final analysis. The final product presents “the essence of the lived experience,” with the “essence” defined as: “Now I understand what it is like to have experienced that particular phenomenon” (De Castro, 2003, p. 54).

The methodological approach of this study was guided by the previous work conducted by Wagsstaff and Williams (2014) and Norlyk and Harder (2010). It was conducted in two parts. In the first part, Veterans’ lived experiences with stroke were examined. Patients were driving the interview, which consisted of open-ended questions and kept very close to the principles of the phenomenological approach described earlier. In the second part, we used semi structured interviews to answer sub aims of the study related to SM, using goal setting and goal attainment concepts. This part of the research interviews was guided by the interview guide developed specifically for this study. We conducted individual, in-person, semi structured interviews with patients who agreed to participate.

Settings and Patient Population

The study was conducted at the Stroke Clinic and Primary Care Clinics at the Michael E. DeBakey Veterans Administration Medical Center (MEDVAMC) in Houston, Texas.

The MEDVAMC has a large, active stroke program with more than 300 stroke and transient ischemic attack (TIA) admissions annually. Patients receiving stroke care at MEDVAMC reside in the Houston metropolitan area, as well as in neighboring counties. MEDVAMC is a state-of-the-art facility, with 580 hospital beds, a 40-bed Spinal Cord Injury Center, and a 141-bed Community Living Center. It also has a 40-bed domiciliary residence for homeless Veterans.

Patient Sample

To achieve a common understanding of patients’ experiences, we recruited a purposive sample of participants who had experienced stroke or TIA by virtue of its being an integral part of their life experience (Cohen et al., 2007; Smith, 2009). Therefore, the Veterans were not

recruited on a representative basis, but rather because of their expert knowledge of the phenomenon “under inquiry” (Green & Thorogood, 2005).

To meet the clinical inclusion criteria, data on the severity of stroke for Veterans considered for the study were extracted from the Computerized Patient Record System (CPRS), as cognitive and language screenings are standard assessments for stroke patients and are accessible via CPRS.

The determination of the study sample size was based on the guidelines published by Pietkiewicz and Smith (2012). As stated previously, the main goal of the phenomenological approach is to give full attention to each participant’s case; therefore, a sample of eight patients taking part in the lengthy in-depth interviews was adequate. Eight patients was also a manageable group with which to perform comprehensive and in-depth interviews.

Protection of Human Subjects

We obtained study approval by the Baylor College of Medicine Institutional Review Board (IRB) and The University of Texas Health Science Center IRB (See Appendix H). Patients were informed about background, objectives, potential benefits, and risks of the study. Patients’ rights to withdraw from the study at any time were clearly stated, and description of the potential loss of confidentiality and ways to mitigate this were included. We made sure that all personal identifiers, except the patients’ code numbers, were kept in the password-protected database on the VHA secure server. The digital recordings and transcripts were also securely transmitted and stored. Any hard copies of documents were stored in a locked file cabinet. Patients were provided with contact information for the study Principal Investigator (PI) to call in case they had any questions or concerns.

Study Procedures

Screening and recruitment. The study was advertised for patient recruitment in the MEDVAMC Neurology in-patient stroke unit, using the IRB-approved study pamphlets. In addition, we conducted an in-service for providers to inform them about the study (Appendices A and B). Potential participants were identified by providers caring for patients admitted to the MEDVAMC Neurology unit with stroke or TIA. Providers were given the Study Recruitment Flyers to share with their patients during in-hospital care, and they subsequently informed the PI of the names of patients who expressed an interest in participating (Appendix G).

Patients qualified for the study if they received care at the inpatient Neurology unit and outpatient follow-up (within one year post discharge) at the Stroke Clinic and/or at the Primary Care Clinics at the MEDVAMC in Houston, Texas. The patients were 18 years of age or older and had two or more uncontrolled stroke risk factors (i.e., BP > 140/90; HgA1C > 7; LDL-C > 100) and had other risk factors, such as being a current smoker, or obese, with a BMI of 30 kg/m² or higher.

In addition, patients were required to read and speak English at a sixth-grade level or above and to be willing to sign the consent form to participate. Patients with severe cognitive impairment and aphasia as determined by their CPRS medical records were excluded from the study. The IRB approval to conduct the study was obtained in April 2017. Eight patients were recruited over the seven-month period. We coordinated interview study sessions around patients' regularly scheduled clinical appointments. This was very beneficial to patients in terms of their time commitment. All eight interviews were conducted either before or after regularly scheduled visits at MEDVAMC.

Data-collection procedures and interview-guide development. Patients were interviewed at the MEDVAMC over a seven-month period. The interviews were conducted

individually and in-person with each patient and digitally recorded. Each lasted approximately one hour. Demographic information for each patient was collected prior to the interview (See Table 1).

Interview Guide

Development of initial questions. To understand stroke survivors' lived experiences, we posed two initial questions in the following fashion: "In general, please tell me what was your experience right after you had the stroke"; and "Tell me about how it was when you first went home from the hospital after your stroke." In some cases, when the patients' responses were a bit ambiguous, we followed-up with probe questions, such as: "Can you tell me more about this experience?," "Can you give me more examples of what was challenging for you?," "Can you give me more details on what you mean was difficult?," or "Can you tell me more about....?"

Development of follow-up questions. To further clarify initial answers, follow-up questions were developed for the interview guide. We also asked additional questions to further explore original areas of information not previously explored by the patients. We wanted to assure that patients' voices were fully represented and that we gave them the opportunity to fully share their daily life experience (Sprague, Armstrong-Schultz & Branen, 2006). During the interviews we listened actively, providing prompts and probes to make this experience enjoyable for patients. A multidisciplinary team composed of the study author, qualitative methods specialist, advanced practice nurse, and psychologist, based on their clinical and research experience as well as on existing literature in the field, developed the follow-up set of questions and developed a semi structured interview guide informed by the aims of the study (Table 3). To help with the interview and discussion, open-ended questions were asked. Most patients who received their stroke inpatient care at the MEDVAMC also received SM stroke education (prior to their discharge and as a part of their "usual care"). This consisted of an SM course, which

included stroke education, measures for setting stroke risk–reduction goals, action planning; and goal-attainment and problem-solving techniques to control stroke risk factors and to prevent another stroke (*Patients' Self-Management Guide*, Anderson and Wilson, 2010). Following the approach of Handley et al., (2006), Bodenheimer, and Handley (2009), providers and patients developed a specific action plan toward attaining the stated goal in a collaborative fashion and on the basis of the confidence level goal achievement (Table 4).

Data Collection and Analysis

Each interview was audio-recorded, and a verbatim transcription of each interview was produced. Each interview was securely sent to a reliable transcription service. We proofread and made necessary corrections to the transcribed text, based on the original audio recordings for each transcript. All eight interviews were used to conduct data analysis (see Tables 1 and 2 for demographic and clinical characteristics of the study sample). The analyses were performed by two independent reviewers (Johnson, 2012; Wagstaff & Williams, 2014) and guided by the method developed by Giorgi, (2009). Reviewers were trained in the principles of the Giorgi method, making sure that they are able to remove any personal experience while conducting analyses.

Both reviewers reviewed transcripts independently and coded each interview in the applicable sections. To arrive at the consensus, the codes were compared and discussed between the reviewers. If needed, we went back and recoded after reaching consensus. Major themes from the research were discussed, as well as subthemes.

Part 1 analysis: Veterans' lived experiences with stroke. An inductive approach was employed to learn about Veterans' post stroke experience. Staying true to the phenomenological method (Norlyk & Harder, 2010; Omery, 1983), we used no a priori codes when analyzing Veterans' descriptive accounts of their own post stroke experience. This completely inductive

method aimed to describe as accurately as possible the phenomenon, refraining from any pre-given framework, but remaining faithful to the participants facts (Groenwald, 2004). The individual Veteran's lived experience was defined in the study as experience leading into the phenomenon in preparation (Norlyk and Harder, 2010). In general, we used a descriptive method of the experience, focused on intentionality, and searched for the essence.

We employed the Giorgi method, developed based on four major principal characteristics originally introduced by Marleau Ponty in 1962 (Giorgi; Phillips-Pula, Strunk & Pickler, 2011). This phenomenological method's principles state that it is descriptive, that it uses reductions, that it searches for essence, and that it is focused on intentionality (Giorgi, 1985, pp. 42-43). This "scientific" method means having established sets of steps and procedures that obtain findings able to be replicated. In valuing this scientific sensibility, Giorgi is critical of more personal, idiosyncratic approaches in which methods are fluidly or randomly applied

In the first step, we read and reread descriptions of experience to get a sense of the whole experience and to make sure that any a priori opinions of each researcher did not misrepresent the participants' description. To better manage the data, in step two, descriptions were divided into meaning units, based on significant terms used by the participants. In step three, we described the meaning of each unit and related each unit to the topic of study. We kept only units related to the study's topics and discarded all others. In the next step, the units were synthesized into a consistent description of the phenomenon. In step five, we transformed analyzed units, with a focus on participants' intentionality. This step allowed us to develop a description of the common experience, achieving the essence of the phenomena under investigation.

Part 2 analysis: Veterans' strategies and perceptions. A deductive approach was carried out to assess Veterans' strategies and perceptions of post stroke SM. The themes were deductively derived to answer our specific research questions. We used ATLAS.ti 8 (Atlas.ti

Scientific Software Development, GmbH, Berlin, GDR), a qualitative data management software that facilitated our ability to identify meanings and relationships among themes and related quotes necessary not only for the analysis but also for the final discussion. After repeated reading and rereading of the transcripts, coding, and determining how the codes fit into larger themes, several major themes and common experiences emerged.

Findings

Demographic Characteristics

Participants' mean age was 62 years (age range, 45-80); six were men, and two were women. Six participants were white and two black. Education level was mixed, with five participants having a high school degree, two having a college degree, and one having a graduate degree. Half of participants were married. In terms of participants' employment status, three were employed, two collected disability insurance, and three were retired. Living status was as follows: two lived alone, four lived with one person, and two lived with more than one person. Only three participants did not have a caregiver. All but one participant had suffered a stroke, and one had experienced a TIA. Over half of the participants were discharged home (five), and the rest (three) were admitted to the inpatient rehabilitation unit at the MEDVAMC (Table 1).

Clinical Characteristics

In terms of functional disability, two participants could not walk and used a wheelchair. Each participant suffered from several chronic illnesses, such as hypertension, diabetes, chronic obstructive pulmonary disease, back pain and elevated cholesterol. Regarding modifiable behavioral stroke risk factors, six participants were obese, several suffered from anxiety and depression, one smoked cigarettes, and over half expressed frustration with lack of physical activity (Table 2).

Based on the descriptive synthesis, three major lived experiences emerged. The most common theme, ordered by frequency of occurrence, were 1) uncertainty about life immediately after stroke, resulting in a profound life change, 2) anger and frustration and, 3) challenges posed by the healthcare system. Veterans provided information on SM strategies that focused on improvements in physical function, mastering coping skills and cognitive resilience, such as staying determined and positive. Patient perceptions about SM focused on stroke described it as a debilitating disease that affected all aspects of life.

Part 1

Theme 1: Life uncertainty and profound change. Recovery after stroke was very important to the study Veterans. They provided detailed narrative accounts of the devastating results of suffering a stroke and discussed the stroke's cause and nature. They viewed their stroke as a very sudden and personal experience, something that had never happened to them before, affecting them deeply on the emotional, physical, family and social levels.

They described how they do not know what each day will bring and are unable to plan because of change in their cognitive and physical abilities and uncertainty about the future. For example, one 51-year-old black woman said: "When I came home from the hospital, I couldn't walk....I think I'm on the right track, but the scary part is, what I've been told is, when you're having a mild one, there's usually, usually you have another one, and it's gonna be bigger... That's what I hear, and that's what scares me." (PATIENT 8)

Another noted cognitive change, saying that he had been quite smart growing up and able to multiply two-to-three digit numbers in his head, but that he was unable to do so now.

Participants were aware of profound life change adversely influencing their professional future. One commented that, "With my physical limitations, I won't be employable, even in four or five years." (PATIENT 1) Another expressed frustration that he had experienced a mini-

stroke before, but this time he had a full stroke, which affected his speech and ability to write. Participants also noted how physical changes specifically affected their lives: “Having to rely on my wife to do everything: I think she’s getting to the point of, you gotta get up, and do something yourself.” (PATIENT 2) Another added, “. . .I had to learn to use the toilet all over again, how to back up to it, and sit down. (PATIENT 3) Another mentioned that he had had to quit driving.

Theme 2: Anger, frustration and depression. Several participants expressed deep frustration and anger regarding physical and psychological effects of stroke. Frustration regarding physical limitation was specifically related to body movements. Sudden inability to perform daily functions was clearly apparent and very shocking, as illustrated by the following example: “I get pretty frustrated. Um, you know, get sharp tongued every once in a while, you know, just, not meaning to, you know, it’s just. . . . I remember being frustrated because I can’t do anything. I’m still a little wobbly on the walking.” (PATIENT 3)

The same participant, who had been employed prior to the stroke, expressed his anger: “And I have to pay other people to do what I normally do, and so that causes some stress. And just being able to sit there, day after day, either sleepin’ in bed, eatin’, playin’, a game, or watchin’ TV. That’s all I could do. That’s very frustrating to somebody who, for all intents and purposes, is fairly energetic.”

Another said: “The biggest emotion that I have is anger. ‘Cause I can’t do what I want to do.” (PATIENT 2)

Participants also shared how depression affects their post stroke life and recovery. One said, “I have depression anyway. But I can get real depressed. And I won’t move. Other than go to the bathroom. I won’t leave the house.... you know, that is a very hard thing to fight. Because I hurt anyway.” (PATIENT 1) Depression and frustration were apparent in the statement made

by another, when he mentioned putting in a lot of effort and not getting results and then shutting off from everybody.

Finally, post stroke depression was well described by another, who recalled his experience after being discharged home: “When I came home from the hospital, I couldn’t walk. It made me feel depressed. I’m goin’ through a lot. I’m still depressed. I’m really depressed. I cry all the time.” (PATIENT 8)

Theme 3. Challenges with healthcare system. During the interviews, participants expressed their struggle with healthcare systems and delivery of healthcare services. They described their experience immediately after stroke and during recovery. This theme was quite common, as illustrated by two examples based on one participant’s challenges, such as comorbidities in addition to stroke: “And I hurt very bad. Uh, I had a lot of physical injuries that I had rehab done, so I have a torn rotator cuff, took two or three years of therapy on that, well, you know, the muscles don’t remember what they’re supposed to do, so now it wants to hang down and it hurts”. (PATIENT 1) He also complained about not getting what he felt was sufficient coverage of his service-connected disabilities, which prevented him from receiving as many benefits as he felt he deserved.

During the recovery process, participants described their struggle with obtaining rehabilitation services such as physical therapy. One seemed somewhat perplexed that he had not been automatically prescribed physical therapy, mentioning that he had been stumbling lately and that his wife had had to keep him from falling a couple of times (PATIENT 7) Another observed, “And I couldn’t understand why they didn’t give me therapy. I still haven’t gotten therapy, but they have ordered it.” (PATIENT 8) We also found examples of patients’ being stressed with healthcare coordination, noticing gaps in multiple risk-factor control. One explained, “I think the number one thing for me is, hopefully, they’re tryin’ to figure out my bloodwork and

what's going on and CAT scans... I really believe I'm takin' too much medication, or it's just not workin' together." (PATIENT 8) Another said, "Yeah. I feel like, in a sense, you know, I haven't always had the support of the VA. It's just not me. It's a lot of Veterans. And, you know, they need to look at the, to look at it, you know, and just try to correct it." (PATIENT 3)

Overall, the interviews revealed that life was uncertain; lack of physical independence and loss of control were the new reality. The need for lifestyle changes and strong coping mechanisms was recognized as a major challenge for participants. We investigated these challenges in the second part of the study.

Part 2

We used the study-specific interview guide while conducting the semi-structured interviews to investigate specific strategies and perceptions of Veterans engaged in goal setting and goal attainment while self-managing their post stroke risk factors. It became very apparent that their "road to recovery" included setting individual and realistic goals and working with providers to prevent another stroke. Some actions would include improving physical functions, developing strong doctor-patient relationships, improving communication with family members, and maintaining compliance with the physical treatment regimen, using religion or faith to cope, and maintaining strength and determination to stay positive and set recovery goals. We identified the following major themes related to SM strategies: improving physical functions, learning to cope, and staying determined and positive.

Improving physical functions. All participants expressed opinions as to how different aspects of stroke changed their bodies, resulting in physical and functional limitations. These changes directly influenced their ability to interact with family members and profoundly affected their psychological well-being and coping abilities. However, all expressed their willingness and strong determination to improve their physical abilities and try to get better. Despite many

challenges, one man, who really wanted to return to work, stated: “I’m not gonna give uPatient There’s gotta be something I can do.” (PATIENT 1) They also pursued additional therapies to improve their speech and physical strength, as illustrated by the statement of a 68-year-old man: “I was in physical therapy, occupational therapy, and they gave me these rubber bands, you know, so I’m working with those. I want to get to where I can lift weights because I’ve lost two sizes on my watchband.” (PATIENT 2)

Participants also took charge to improve their diet and medication compliance for better control of their hypertension and diabetes, which also helped them with physical recovery. One noted: “I take blood pressure medicine, I take cholesterol, I take an aspirin or two, that’s two diabetes, an aspirin is three, cholesterol is four, heart medication is five. The doctor said, ... if I didn’t start takin’ my medicine, it was gonna kill me.” (PATIENT 3)

In addition, a male Veteran in his 60s who lives with his wife said: “Yeah. I’m taking blood pressure medication, and I take my blood pressure each morning. We eat a lot of chicken, uh, fish from time to time, pork. We eat very little red meat and, um, green vegetables, salads for lunch.” (PATIENT 2)

They also used their own exercise regimen in addition to medication compliance, as illustrated by the following SM strategies shared by a 45-year-old woman: “I continue to take my medicine. I take it every day, all day. And I continue to exercise. I work out at least three times a week....I am at war in my body. But, um, it’s mostly doin’ a lot of exercise and tryin’ more, uh, a little bit more intensified, tryin’ to keep my stress level real low. I have difficulties with that because of my job.” (PATIENT 5)

Learning to cope. It was very apparent that Veterans engaged in various coping strategies to deal with post stroke reality. They often referred to their in-hospital stroke education and SM patients’ workbook, which described tips for developing coping skills and healthy

habits. One participant in his 60s, who is still employed, shared his strategy: “Well, I think that the thing is, it’s the way you live. The first thing is, you have a stroke, some people just kind of like, okay, it happens, whatever. Where I’ve taken this pretty seriously. Maybe sometimes I think not serious enough, but um, stress started with work, started at home, when you feel like that’s overcome, you, you kind of walk away from it. Take a little walk; take a breather. I’ve never done that, and now I kind do”. (PATIENT 7)

Participants also engaged in mental exercises: “So, I don’t know, some exercises, mental exercises would help a lot. I’d lay in bed doing that, you know, thinking of puzzles and what have you.” (PATIENT 2)

Frequently they used religion as a coping mechanism to help in recovery. One described weakness in his right side and speech difficulties but said that he was going to continue and that it was “in God’s hands.” (PATIENT 7) Anger and frustration were frequently observed, but one man (PATIENT 3) gave an example of using support from his pastor to cope with that: “But, um, I’ve been workin’ on the anger. It’s something that I’ve discussed with my minister, and I don’t know if I’m gonna get there, but I’m tryin’.” Another mentioned using faith as a coping mechanism as he was trying to rehab his muscles and his body to work together, but there encountering difficulty.. “Just have faith,” he said. “Just try to have faith.” (PATIENT 7) Finally, a powerful statement came from another (PATIENT 4) about coping with post stroke depression: “I was raised never to give up, never taking anyone’s life or your life, so when I get down and very depressed, I know God is not going to put more on me than what I can bear. So I think that he is, uh, testing me. I just see him, He knows I can handle it. He knows I can run, like I mean, sometimes my body just gives out....” (PATIENT 7)

Staying determined and positive. Most participants indicated that, to make real progress, they needed to stay positive and set recovery goals toward specific behavior to prevent another stroke.

“I want to get better physically and emotionally as one goes with another” commented one of the participants and then he added: “You know, I want to not only extend my life but do something with it”. I want to listen to the music, play games and be with my grandkids.”

(PATIENT 3)

We have learned from the interviews that developing a strong doctor-patient relationship helped patients to stay positive and set recovery goals. One patient shared his experience: “Let’s attack what the problem is. Let’s attack, in other words I’m sick. I have diabetes. What causes that diabetes? Why can’t you fix it?” (PATIENT 3) Several mentioned that strong family ties helped them to stay positive. Their plans toward recovery were well illustrated by two statements: “I’m fortunate in the respect I have a family, and we’re not getting a divorce or anything like that. So I consider myself lucky. Yes, my wife, that’s a big, big, big part of it, getting’ over this thing and getting’ past it.” (PATIENT 4) Another said, “Yeah, I really need support at this point of my life. I need, uh, somebody to lean on. And I think my daughter is that person. And she doesn’t mind. She wants to grow closer, and I, my grandson is down there, too. Uh, you know, I want to spend time with him.” (PATIENT 8)

Participants also described setting goals and motivating themselves to move forward and improve their quality of life. A 62-year-old male Veteran stated, “You know, I’m not concerned with dying. I’m concerned with trying to do what I can to continue. If I was in the middle of a rain forest and I needed a fire, I would find two dry sticks somewhere and try to make a fire.” (PATIENT 1) He also talked about motivation being provided by his desire to get out of his wheelchair and trying to lose weight in small increments.

Strategies and Perceptions

Participants were concerned regarding the fact that stroke is a very debilitating disease, affecting all aspects of life. One mentioned some days having slurred speech and poor coordination in his hands and legs, stumbling and falling down, but said, “But it’s comin’ around.” (PATIENT 8) They described how stroke affected them deeply on the emotional, physical, family and social levels. “Um, nothin’s easy,” noted one.. “If it was, I could’ve done it a long time ago. It’s very difficult. . . .”, He continued, “ I look at it this way. Do I want to continue with my life the way it is, or do I want to try and improve it, hopefully stay around for my kids and grandkids?” (PATIENT 3) They shared their experience of needing to evaluate new life circumstances and face the reality after the stroke. They described new challenges and talked about coping mechanisms to deal with the post stroke reality. They also talked about their goals for recovery. One participant shared his very powerful personal experience: “So I made peace with God, and I said to go where I have support and somebody to help me with my illness. But..I can walk. I just decided I’m not gonna give uPatient If it means I have to crawl, I don’t want to depend on nobody like that. I don’t. . . I saw my grandmother die from just giving up and becoming bedridden.. I want to change that. I want to get better. I don’t wanta be mad at everybody. I want my joy back. You know, I’m a happy person.” (PATIENT 8).

Others shared their plans towards recovery as well. Now since they survived stroke, they described how to take charge of their lives and work on attainable goals toward stroke risk-factor control. One said: “Right. I’m not interested in having another stroke. I don’t know what caused the first one, so.Yeah, yeah. I think I’m headed in the right direction. I think I’m doing everything I can, probably not everything I can do, but...”. (PATIENT 6) They also realized that post stroke recovery is a long process with many small steps: “You try to take too much, you don’t succeed. I always believe in taking small steps. So if you take those small steps, uh, you

can succeed, and then you get rewarded just by succeeding yourself, so, uh, so I'm tryin' to watch myself more often. "(PATIENT 7)

Discussion

The purpose of this study was twofold: 1) to describe the lived experience post stroke and 2) SM experiences. Phenomenology guided only the first part of the study.

Various narrative and descriptive approaches have been used to explore the complexity of living with stroke(Nasr, Mawson, Wright, Parker & Mountain, (2016), van der Riet, Dedkhard and Srithong, (2011) and Simeone et al., (2014)). Participants in this study (Veterans) shared their detailed experience about how stroke affected their lives on the individual and family levels. Patients described their cognitive and functional struggles post stroke. They were able to use SM concepts, based on the stroke education received upon hospital discharge and their SM workbook with tips, and goal-setting and problem-solving techniques. Based on the descriptive synthesis, the essence of the phenomenon that emerged from this investigation is "new life challenges after stroke." Specifically, three major lived experiences of post stroke patients emerged: 1) immediate uncertainty about life, 2) anger and frustration, and 3) challenges posed by the healthcare system.

Reported SM strategies focused on improvement of physical function, coping skills, and cognitive resilience, such as staying determined and positive. Applying coping skills and setting goals to manage stroke risk factors were critical determinants of improved physical and emotional functioning. Patient perceptions about SM focused on stroke as a debilitating disease that affected all aspects of life. Participants described the feeling of lost body after the stroke and a sense of hopelessness. Life uncertainty and decreased quality of life were at the center of each interview. Participants described how, from one day to another, their lives had changed and how many things taken for granted before the stroke no longer existed. Life had now been changed,

becoming unfamiliar and uncomfortable, and leading to frequent anger and frustration. In addition, challenges posed by the healthcare system caused much anxiety and were described as impediments to the recovery process. Lack of physical independence was seen as one of the major problems after surviving a stroke, especially for the participants with limited physical function. Dependence on other people was a new reality that was difficult to accept. New life challenges and development of coping mechanisms to move forward from the acute stage to recovery from stroke were also apparent. This was linked to individual behaviors, such as evaluation of the new life circumstances and use of various coping skills to improve physically and cognitively. Strong will to regain physical independence and ability to perform daily functions rooted in the military ethos were at the core of the recovery. Faith and religious beliefs emerged as a strong coping mechanism. This has been demonstrated in other studies, such as the one published by Moorley, Cahill and Corcoran (2016). Family dynamics and communication with loved ones were also a new reality that post stroke patients had to deal with. Overall, participants' views were to concentrate on the physical and social issues of the process of getting better. This was also reported by Sprigg et al., (2012) and Lincoln et al., (2013). Strategies of risk-factor control were mostly related to keeping a positive attitude and setting recovery goals. Participants wanted to improve medication adherence, keeping doctors' appointments and following a rigorous treatment regimen. It has been shown in other studies that medication compliance was related to increased self-efficacy and social support (Rimando, 2013). These experiences are similar to the findings in other qualitative studies demonstrating that the strong desire to get better and taking control over one's health might mean increased self-control, leading to improved health outcomes (Kendall, Ehrlich, Sunderland, Muenchberger & Rushton, 2011). In summary, the interviews collected revealed an overall essence of experience after stroke: recovery from stroke involves restructuring and adaptation in physical, social, and

emotional aspects of individuals' lives. Engagement in SM and taking control of the illness lead to improvements in the rehabilitation process and prevention of a subsequent stroke.

Strengths and Limitations

To our best knowledge, this is the first study addressing Veterans' lived experience; and it describes stroke patients' lived SM experiences following hospital discharge.

This study recognizes an important fact that many concepts should be considered to understand current thinking related to the SM content, process, method of delivery, patient lived experience and valid and reliable measure of the process of goal setting and goal attainment for stroke patients. This understanding may assist clinicians in designing effective SM programs aimed to improve patients' clinical outcomes, as well as in conducting proper program evaluations in this area of research (Boger, Demain & Latter, 2013 ; Lennon, McKenna & Jones, 2013; Wade, 2009). Our research revealed similar themes reported in other studies but also uncovered fragmentation of care delivery for Veterans. Several important implications for clinical practice also contribute to study strength. Concluding, as a result of this research, we outline important issues for future research to advance the field. Some of these might lead to immediate practical recommendations for improvement of Veterans' care (described below).

In regards to study limitations, the participants included in the study were Veterans from only one medical center located in the Southern state. These were mostly men (six of eight), which might influence the reported experience. It has been found that women experience worse post stroke quality of life than men (Carod-Artal, Egidol, González & Varela de Seijas, 2000; Roth et al., 2011). This sample also represents a limited group in terms of ethnicity and race. We also recognize that this small group of participants represents the viewpoint of a limited number of individuals who survived stroke. On the other hand, staying truthful to the phenomenological approach, we chose a purposive sample to include Veterans who received care at the VHA. They

are close in terms of age, socioeconomic status, and stroke risk factors, such as hypertension and diabetes. Upon discharge, the majority of them went home and to their wives and/or caregivers. In addition, they received SM stroke education as a standard of care and the SM workbook on behavioral risk-factor control. Findings may be transferable to other VHA settings with similar patient populations, but findings are not sufficient for transferring themes and concepts to the full range of settings and services outside the VHA system.

Implications for Clinical Practice

Several implications for clinical practice were identified. Providers should acknowledge Veterans' challenges and struggles after their stroke. More emphasis should be given to the individual's family dynamics; caregivers' availability and willingness to help with loved one's recovery; patient's post stroke work status and financial struggles. Also, recognition of the importance of the social context of the recovery after a stroke is important, as the nonmedical social context of recovery is often overlooked. Providers should help Veterans with social interaction as a distraction from stroke, reestablish social identity; enhance self-esteem and improve mood. Lastly, based on the Veterans' experience, their access to additional resources for post stroke care should be improved. We suggest that providers work with social workers and therapists to arrange for more aggressive inpatient or outpatient treatments. Social workers should help with home visits to check on patients' recovery. Stroke survivors should be encouraged to attend preventive programs, such as diabetes education classes, smoking cessation programs, and various weight-loss programs offered free of charge to Veterans within the VHA system. Finally, in addition to focusing on the acute stage of the disease and on immediate rehabilitation services, healthcare providers should focus more on helping patients and their families adapt to life after stroke. Utilization of stroke support groups for stroke survivors and

Veterans' engagement in the SM programs available within the VHA system are strongly encouraged.

Conclusions

This study describes patients' physical and emotional experience after surviving a stroke and reinforces that recovery from stroke is a long, complex, and challenging experience for Veterans. However, it is among the first to document details concerning the mechanics of health loss and recovery, based on individual accounts. Veterans' accounts of life immediately after stroke, description of new challenges associated with recovery, and strategies for improvement seem to play major roles in this study. Themes revealed how patients' involvement in SM strategies corresponding to goal setting and attainment may help with the recovery process and improve quality of life after stroke.

Physical, psychological, social, and family struggle after stroke are the main challenges for Veterans. Strategies targeting post stroke recovery are oriented around Veterans' ability to accomplish goal setting/action planning, based on the SM teaching skills received as a standard of care at the MEDVAMC. Perceptions assessing their situation are to never give up, move forward, and with the help of families work on getting better, preventing another stroke and ultimately improving Veterans' quality of life.

Healthcare providers should offer more interventions to assist post stroke patients with coping and adaptation to overcome daily limitations. Knowing patients' stroke experiences may enable healthcare providers and caregivers to view stroke survivors from a broader and more humanistic perspective. It also adds valuable insight about the design of SM support interventions for stroke survivors, using SM concepts and the goal-setting model. This review contributes to the body of knowledge that explores the experience of living with effects of stroke and examines what improvements may be made to post stroke healthcare delivery. These

findings confirm what we have learned from other studies in regard to the functional and emotional aspects of post stroke recovery. They generated additional knowledge in terms of using SM skills to improve recovery.

Future Research

Future studies to understand the post stroke experience should include additional concepts from the ecological model, such as family relationships, and the role of the community and society in stroke recovery. This is particularly important in the context of professionally active people affected by a stroke. Losing jobs and financial stability has been the cause of depression and anxiety as a result of a stroke. Therefore, more emphasis should be given to help Veterans deal with loss of income and financial hardship. More emphasis should also be given to the role that caregivers play in their loved one's recovery. It has been shown that unreasonable expectations and limitations in a Veteran's struggle during the recovery process may create family tensions. Although the VHA provides caregiver support (helpful website information and a caregiver support line), none of the interviewees were aware of these services. In addition, more consideration should be given to improve coordination of services provided to Veterans who suffer a stroke, not only during the acute stage of the disease but also during the chronic stage. More studies should be conducted to better understand Veterans' lived experience after the stroke and the caregivers' roles and struggles caring for the loved one. Better understanding of the healthcare providers' role and patient-centered coordination of services might also help Veterans recovering from stroke.

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Results Tables

Table 1. Patient Demographic Characteristics

Measure	N	%
Mean Age: 62 Range: 45--80		
Gender		
Men	6	75
Women	2	25
Race		
White	6	75
Black	2	25
Other	0	0
Ethnicity		
Hispanic or Latino	0	0
Non-Hispanic or Latino	8	100
Unknown	0	0
Living Status		
Live Alone	2	25
Live With 1 Person	4	50
Live With >1 Person	2	25
Education		
Graduates High School	5	63
Some College	0	0
Graduated College	2	25
Graduated Degree	1	12
Employment Status		
Employed	3	37.5
Self-Employed	0	0
Retired	3	37.5
Disable	2	25

Table 2 Clinical Characteristics

Patient ID	Stroke or TIA	Functional Disabilities and Cognitive Impairment	Chronic Illness	Behavioral Stroke Risk Factors Identified	Action Plan Made Upon Hospital Discharge	Discharged Home or Inpatient Rehab	Caregiver Yes/No
1	Stroke	Trouble with walking- using walker	Diabetes, Hypertension Back pain	Obesity, depression and lack of physical activity	Start exercise program	Inpatient Rehab	No
2	Stroke	Trouble with walking-using walker	Diabetes, Hypertension	Obesity	Increase water drinking	Home	Yes (wife)
3	Stroke	Trouble with walking and memory problems	Diabetes, Hypertension and COPD	Obesity and poor diet	Decrease sugar intake	Home	No
4	Stroke	Trouble with walking	Elevated Cholesterol, Hypertension	Poor diet	Decrease salt intake	Home	Yes (wife)
5	Stroke	Trouble with walking and memory problems	Diabetes, Hypertension	Depression and obesity	Increase Exercise Level	Inpatient Rehab	Yes
6	Stroke	Trouble with walking, balance and memory problems	Diabetes, Triple vessel disease of the heart	Stress and obesity	Increase Exercise Level	Inpatient Rehab	Yes (mother)
7	Stroke	Memory and concentration problems	Hypertension , Hyperlipidemia	Smoking, anxiety and depression	Decrease smoking	Home	Yes (wife)
8	TIA	Trouble with walking and memory problems	Diabetes, Hypertension and back pain	Obesity and depression	Increase Exercise Level	Home	No

Table 3 Patient Interview Guide

Introduction	Thank you for agreeing to participate in this interview. Your participation is completely voluntary. Today we will discuss your experience, and your responses will help us to better understand issues around setting goals for post-stroke risk-factors management. Specifically, we are interested how you are using the action plan process to assess the goal-attainment measure. We will be recording this session, and we will not use any identifying information.
Purpose of the study	The purpose of this interview is for you to describe your personal experience surviving the stroke and your perspective on setting goals to improve your health post-stroke and to deal with your personal stroke risk factors
Warm up question	<p>As a whole-- How do you feel today?</p> <p>Tell me about how it was for you when you first went home from the hospital after you had a stroke.</p> <ul style="list-style-type: none"> - What were the challenges going back home? - What is was it like to be back at your own place? - Tell me more about your daily living after stroke. <p>What have you found to be the hardest part of your post-stroke care?</p> <p>What is the easiest part of post-stroke care for you?</p> <p>In what way did you use the patients' SM book to help you avoid having another stroke?</p>
Next step	Now we can start the session-- we will ask set of questions; but if at any time you decide not to continue the interview, you may stop, as you are not under any obligations to complete the interview.
Open-ended questions	<p><i>Characterizing stroke experience</i></p> <p>1. In general, how would you describe your stroke experience?</p> <p><i>Characterizing (SM)</i></p> <p>2. In general, tell me what managing stroke risk factors means to you?</p> <ul style="list-style-type: none"> - How would you describe or characterize stroke management? - Where you thought in stroke education how to set goals? <p><i>Goal setting</i></p> <p>3. In the context of SM, how is your experience with planning to do something about improving your risk factors?</p> <ul style="list-style-type: none"> - What does goal setting mean to you? - How have you used it? - What were your goals after you went home from the hospital? - What could be some challenges in setting up these goals? <p><i>Action Planning (AP)</i></p> <p>4. Tell me about your experience with AP.</p> <ul style="list-style-type: none"> - What have you learned from doing this? - What contexts or situations have typically influenced or affected how you do this? - What makes this easy to do? - What makes this hard to do?

Open-ended questions	<p>5. Tell me about your experience with using the AP to set goals for your health. How do you set goals? What do they mean to you? What are the challenges?</p> <ul style="list-style-type: none"> - What have you learned from doing this? - What contexts or situations have typically influenced or affected how you do this? - What makes this easy to do? - What makes this hard to do? <p>6. Tell me about your experience with using the AP to decide if you have met your health goal.</p> <ul style="list-style-type: none"> - How do you decide when goals are met? What have you learned from doing this? - What contexts or situations have typically influenced or affected how you do this? - What makes this easy to do? - What makes this hard to do? <p>7. Tell me what strategies you may apply using the AP process to attain your goals for SM of stroke risk factors?</p> <ul style="list-style-type: none"> - Can you explain to me what you mean by planning to reach your goals concerning a specific AP? - What examples can you provide to demonstrate following this plan? <p>8. How do you view self-assessment of goal attainment using the AP process for SM of stroke risk factors?</p> <ul style="list-style-type: none"> - Please provide an example of the plan in one particular area that you decided to work on and how you were able to get it done. - Tell me more about this experience. - What has worked for you?
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Table 4 Action Plan Form

ACTION PLAN WORKSHEET									
<u>What action</u>	do you want to select to reduce a specific stroke risk factor? (Pick something you want to do).								
<u>How much</u>	of the action do you plan to do?								
<u>When do</u>	you plan to do the action?								
<u>How often</u>	do you plan to complete the action?								
<u>How</u>	confident are you that you can complete this action plan?								
1	2	3	4	5	6	7	8	9	10
Not Confident						Extremely Confident			

Tabale 5

Goal Attainment Measure for Stroke (GAM-S)

<p>Instructions: This form is used to track your success with accomplishing the specific details of the Action Plan you made last week. In the space provided below for EACH QUESTION, write “Action Plan” details and check the best response that applies to each question about your specific action status.</p>		
<p><u>What</u> - action did you select to do?</p> <p>_____</p>	<p>I completely did the action I selected (I did it).</p> <p>I partially did the action I selected (I did some of it).</p> <p>I did not do the action I selected (I did none of it).</p>	<p>2</p> <p><input type="checkbox"/></p> <p>1</p> <p><input type="checkbox"/></p> <p>0</p> <p><input type="checkbox"/></p>
<p><u>How much</u>- of the action did you plan to do?</p> <p>_____</p>	<p>I completely did the action I planned to do.</p> <p>I partially did I planned to do/</p> <p>I did not do any of the action I planned to do.</p>	<p>2</p> <p><input type="checkbox"/></p> <p>1</p> <p><input type="checkbox"/></p> <p>0</p> <p><input type="checkbox"/></p>
<p><u>When</u> - did you plan to do the action?</p> <p>_____</p>	<p>I completely did the action “when” I planned to do it.</p> <p>I partially did the action “when” I planned to do it.</p> <p>I did not do any of the action “when” I planned to do it.</p>	<p>2</p> <p><input type="checkbox"/></p> <p>1</p> <p><input type="checkbox"/></p> <p>0</p> <p><input type="checkbox"/></p>
<p><u>How often</u>- did you plan to complete the action?</p> <p>_____</p>	<p>I completely did the action “How often” I planned to do it.</p> <p>I partially did the action “How often” I planned to do it.</p> <p>I did not do any of the action “How often” I planned to do it.</p>	<p>2</p> <p><input type="checkbox"/></p> <p>1</p> <p><input type="checkbox"/></p> <p>0</p> <p><input type="checkbox"/></p>

Overall Action Plan Adherence Score for each Action (to be completed by ...)				
What	How Much	When	How Often	Total Score

Confidence Level

Please select **Confidence Level** to achieve Action Plan and by circling the correct number below
(1 = no confidence at all and 10 = complete confidence)

1 2 3 4 5 6 7 8 9 10

CHAPTER 5

PAPER #3

The Goal Attainment Measure (GAM-S) for Secondary Stroke Risk Factors Management:

Pilot Test and Psychometric Analysis

Abstract

Background

Having a stroke is the strongest predictor of a subsequent stroke; yet most strokes can be prevented through patient awareness and self-management (SM) of stroke risk factors. Goal setting has been frequently used as an outcome measure to assess post-stroke improvements of physical function. However, there is a dearth of psychometrically valid instruments to measure goal attainment through the SM of risk factors for stroke (e.g. hypertension, diabetes).

Purpose

The purpose of this study was to pilot the Goal Attainment Measure-Stroke (GAM-S) scale with stroke patients and primary care providers and test the scale for usability, content validity, and internal consistency.

Methods

Ten registered nurse dyads and 44 stroke patients were recruited from the Neurology Department at the Michael E. DeBakey Veterans Administration Medical Center in Houston, Texas. In a pre-experimental pre/post design, the nurses delivered one-on-one educational sessions to patients admitted with stroke and set goals and action plans in patients' medical records. Nurses in the primary care clinic phoned patients 2-weeks post-hospital discharge and evaluated goal attainment with GAM-S scores of 2 (fully attained), 1 (partially attained), and 0 (not attained). Content validity was based on expert rating by 7 stroke SM experts, content validity ratio (CVR), and content validity index (CVI) statistics. Patients and providers rated the GAM-S on usability

parameters of ease of use, understandability, credibility, motivational appeal, and perceived impact of attaining the goal. Cronbach's alpha was calculated to estimate internal consistency of GAM-S items.

Results

Participants comprised patients (N=44; 95% male; 36-81 yrs.; mean age 67), providers (N=20), and clinician and researcher experts in the field (N=7) of SM. Forty two patients (95%) completed the GAM-S to assess action plan attainment. Most experts (71%) specified that each item GAM-S is essential, indicating content validity based on CVR and CVI values. Patient responses on GAM-S usability were analyzed descriptively according to a list of survey items; detailed results will be presented. Overall, provider usability of GAM-S was scored high with the mean score 3.7 (SD 0.24) on the 4 points scale. The coefficient of variation representing the measure of dispersion around the mean value was 6%. Cronbach's alpha for 42 respondents based on 4 items was 0.962 indicating strong reliability.

Conclusion

This pilot test established acceptable ratings for the GAM-S for use in the clinic setting by patients and providers and demonstrated content validity and internal consistency. These findings suggest future efficacy of the GAM-S to determine its impact on patient goal setting behavior.

The Goal Attainment Measure (GAM-S) for Secondary Stroke Risk Factors Management:

Pilot Test and Psychometric Analysis

Introduction and Background

Stroke survivors face many challenges after hospital discharge including the adoption of lifestyle changes to control stroke risk factors that increase their risk for a second stroke and other cardiovascular events. Having a stroke or transient ischemic attack (TIA) is the strongest predictor of a subsequent stroke; yet most strokes that occur each year, including second strokes, can be prevented through patient awareness and stroke risk factor control (Jones, 2006). Thus, preventative efforts that target lifestyle approaches are needed during hospital care and after discharge home to help stroke survivors reduce risk of second stroke.

Patient self-management (SM) of stroke risk factors is critical to prevent second stroke (Rotheram-Borus et al., 2012; Jones & Riazi, 2011). SM interventions using collaborative action planning are designed to help people manage their health problems more effectively and can improve patients' self-efficacy, coping mechanisms and quality of life following stroke (Lorig and Holman, 2003). Goal setting and collaborative action planning are parts of the SM process where patients first identify a goal they want to accomplish and then a healthcare provider collaborates with the patient to develop a specific action plan to attain patient's stated goal. Defined as an outcome measure, goal setting is operationalized as a quantitative assessment of the action planning where patients are being followed up on their specific action to assess goal attainment. It has been showed that several factors such high self-efficacy, motivation, effort, persistence, skills and knowledge as well as goal commitment can relate to goal attainment (Bandura, 1986; Bandura 1988; Schunk, 1990; Horkin et al., 2016). Nurses have been identified as the frontline health care providers responsible for not only providing stroke education but also engaging patients in the SM skills and setting up specific goals. In this study at the Michael E.

DeBakey VA Medical Center (MEDVAMC) nurses on the stroke ward and in primary care participated in the study and worked in tandem as nurse dyads (ND) to support stroke patients in setting and achieving goals to manage risk factors using an action planning. NDs worked with stroke patients to achieve and sustain their behavioral stroke reduction goals through teamwork and collaboration across services lines.

GAM-S Prototype Description

The Goal Attainment Measure in Stroke (GAM-S) prototype was theoretically established based on the on the self-regulation models (Schunk, 1990), Social Cognitive Theory (Bandura 1988), health behavior change (Lorig et al., 2001) and self-management interventions (Rotheram-Borus et al., 2012). Patients and healthcare providers used the GAM-S to assess patients' goals in the SM of stroke risk factors control (Anderson et al., 2011). The GAM-S measure serves two purposes when used in the clinical setting. It helps patients and providers to collaboratively set goals toward specific behavioral change and assess goal attainment. It also helps to cue the patients' goal -directed behavior change outside the clinic setting. In this study, we tested the usability of the GAM-S and explored its psychometric properties. Testing was conducted at the Michael E. DeBakey Veteran Administration Medical Center (MEDVAMC), where patients work collaboratively with their providers to develop action plans for accomplishing a stated health-related behavioral goal (HRBG). Collaborative goal setting allows patients to become more involved as decision makers in their care (Handley et al. 2006; Lorig, 2006). Patients are taught skills to overcome barriers to their goal attainment and problem solving. Action plans are documented on the "Action Plan" form in the following format: "what" action the patient will take to reduce a specific stroke risk factor, "how much" of the action he/she will do, "when" he/she will complete the action, and "how often" he/she will do it

(Appendix C) (Anderson et al., 2011). Patient's confidence level to complete the planned action is recorded and ranges from 1-10, where 1 = low confidence, and 10 = complete confidence.

The GAM-S is an assessment measure that patients use to collaborate with the provider to measure how well they accomplished the goal that they set for each step of their action plans (Appendix D) (Anderson et al., 2011). Specifically, a provider asks the patient to recall the details in the action plan he/she developed previously and whether he/she accomplished each step of the plan (i.e., what action he/she took to reduce a specific stroke risk factor, how much of the action he/she completed, when he/she completed the action, and how often he/she completed the action). Each action plan attainment step is graded by the provider (what, when, how much, and how often), using the form. The form includes a 3-point scale for scoring each action plan step, where 2 = met, 1 = partially met, 0 = not met. An action-plan attainment score is obtained by summing the points given for each action plan step. Total scale scores range from a high of 8 to a low of 0, with higher scores indicating greater action plan attainment. Previous studies conducted by Anderson et al., (2013 and 2014) demonstrated that results from action plan attainment provide a measure of participants' progress in developing sustained behavior change for SM of stroke risk factors in the six weeks' course intervention.

To achieve the study objectives, the study was conducted in three steps. In step one, we examined how patients rate the GAM-S on usability parameters of ease of use, understandability, credibility, motivational appeal, and perceived impact to attain goals. In step two, we examined how providers rate the GAM-S on the same usability parameters. In step three, the GAM-S content validity and reliability was tested.

Purpose and Aims

The purpose of the study was to conduct a pilot test with stroke patients and primary care providers, who are using the Goal Attainment Measure-Stroke (GAM-S) prototype for collaborative assessment of goal attainment during clinical encounters, to establish the usability, content validity and internal consistency of the GAM-S.

Specific Aims

- I. Conduct a usability study with patients, using the GAM-S
- II. Conduct a usability study with healthcare providers, using the GAM-S
- III. Examine content validity and internal consistency of the GAM-S

Research Questions

- I. How do patients rate the GAM-S on ease of use, understandability, credibility, motivational appeal, and perceived impact in assessing goal attainment? Specifically, what is the patients' perception of the GAM-S on
 - a) ease of use and understandability to assess their goal attainment?
 - b) credibility to assess their goal attainment?
 - c) effectiveness to motivate patients to achieve their goals?
 - d) capability to impact goal attainment?
- II. How do healthcare providers rate the GAM-S on ease of use, understandability, credibility, motivational appeal, and perceived impact in assessing goal attainment? Specifically, what is the providers' perception of the GAM-S on
 - a) ease of use and understandability to collaboratively assess patients' goal attainment?
 - b) credibility to assess collaborative patients' goals attainment?

- c) effectiveness to motivate providers to collaboratively work with patients to achieve patients' goals?
- d) capability to impact patients' goal attainment?

Usability Study Hypotheses

Usability H_A:

Patient and provider rating of the GAM-S will indicate acceptable usability
(Items 1-4 in questionnaires: Appendix E and F)

Credibility H_A:

Patient and provider rating of the GAM-S will indicate acceptable credibility
(Items 5-6 in questionnaires: Appendix E and F)

Motivation H_A:

Patient who use GAM-S in the clinic with providers will report acceptable motivation
(Items 7-9 in questionnaire: Appendix E)

Providers who use GAM-S in the clinic with patients will report acceptable motivation
(Items 7-8 in questionnaires: Appendix F)

Impact H_A:

Patient who use GAM-S in the clinic with providers will report acceptable impact
(Items 10-12 in questionnaire: Appendix E)

Providers who use GAM-S in the clinic with patients will report acceptable impact
(Items 9-11 in questionnaire: Appendix F)

Acceptable usability level is defined a-priori with responder's agreement of 70%. (Shegog et al., 2013).

III. What are the preliminary psychometric properties of the GAM-S?

- c) What is the content validity of the GAM-S among a sample of N=7 clinical experts?
- d) What is the reliability of the GAM-S among a sample of N=44 patients using the GAM-S?

Methods

Study Design

A pre-experimental pre/post design was applied to answer research questions. Upon the IRB approval of the study, we conducted patients' and providers' usability testing of the GAM-S. Based on Shneiderman's study (2006), multiple factors may influence the quality of an end user's experience when interacting with the measure. The major feasibility parameters on GAM-S use include: "*ease of use*", defined as "easy process to follow and can be completed in a reasonable amount of time"; *understandability*: "questions are clearly stated, complete and easy to follow"; *credibility*: "information in the GAM-S can be trusted and was helpful to assess goals and where I need to be with my goals"; *motivational appeal*: "will help with moving forward with my goals and influence overcoming barriers"; *perceived impact to attain goal*: "will help me to self-assess goals, make plans to manage my goals in the future and help me to talk to my doctors about goals." *Validity* of the measure refers to a test's ability to measure what it is supposed to measure. *Content validity* of the measure assesses whether the measure is effective, based on end users' assessment (patients, providers and other people who decide to use it) (Shadish, Cook & Campbell, 2002). In other words, do the questions included in the measure really assess the construct in question, or are the responses by the person answering the questions influenced by other factors? *Reliability of the measure* determines the extent to which the measure distinguishes distinct ability levels (items difficulty and person ability) (Hamon & Mesbah, 2002; Allen & Yen, 2002)

Procedures

The GAM-S testing was conducted to measure the instrument's functionality from the perspective of patients receiving care at the MEDVAMC. We conducted the study at the Primary Care Clinics during regular clinic visits with a sample of patients receiving their post-stroke care.

We have worked with providers and nurses in the clinic to identify patients who meet the inclusion criteria. Potential participants were called and asked to take part in the study at their next regularly scheduled clinic visit. Collaborative goal setting and action planning are considered a part of the SM model of multiple risk factor control and used in the MEDVAMC as standard care. However, a systematic measure of goal attainment has not been implemented yet in the MEDVAMC clinics.

Description of the telephone clinic encounter:

Eligible providers were given an orientation on the use the GAM-S in conjunctions with the previously developed “Action Plan” for the goal-attainment assessment. Providers were instructed to ask patients on the phone to recall in detail action plans they developed previously before the discharge and whether they accomplished each step of the plan (i.e., what action they took to reduce a specific stroke risk factor, how much of the action they completed, when they completed the action, and how often they completed the action). Each step of the “Action Plan” available in the patient s medical records was graded by the provider (what, when, how much, and how often) for attainment, using the GAM-S paper prototype. Upon completion of the telephone clinic encounter, 16 patients agreed to respond to the posttest questionnaire, using an adapted 12-item questionnaire modified to correspond to the GAM-S function (Shegog et al., 2013) (Appendix E).

In addition, health care providers evaluated GAM-S functionality by completing the usability questionnaire and open-ended questions. Then providers agreed to evaluate the GAM-S. The 11-item questionnaire developed by Anderson et al., (2010) was used to complete the evaluation (Appendix F).

The GAM-S Content Validity Testing

To establish content validity of the GAM-S, we assembled the Content Evaluation Panel composed of persons who are experts in the domain being studied. All experts were identified and recruited from the Neurology Inpatient Unit, Stroke Outpatient Clinic and Primary Care Unit at the MEDVAMC. Normally, a panel of 5-10 experts is preferred. The use of more than 10 experts is most likely unnecessary (Lynn, 1986). We recruited seven experts representing a range of professionals and subject matter experts, at various specialized levels comprising PhD level nurse researcher focusing on the implementation of the self-management programs (n=1), nurse practitioner serving as a stroke coordinator in the inpatient neurology unit (n=1), diabetic education nurse (n=1) and other experts who have been involved in the stroke management programs at the VAMC (n=4) to participate in the content validity evaluation of the GAM-S. We sought to be certain that panel constitutes a suitable opinion leaders group with the theoretical knowledge not only on the goal setting concepts, but also on the goal attainment theory and practice in the domain of stroke prevention. We provided each member of the panel with the list of items from GAM-S that represent chosen construct or skill, to independently rate each of the items.

The GAM-S Reliability Testing

a) Setting and Participants

We conducted the reliability study at the Inpatient Stroke Unit and at the Primary Care Clinics at the MEDVAMC in Houston, Texas. The MEDVAMC is a health care facility that provides primary health care, both inpatient hospital care and outpatient services in specialty clinics. MEDVAMC is a state-of-the-art facility, with 580 hospital beds, a 40-bed Spinal Cord Injury Center, and a 141-bed Community Living Center. It also has a 40-bed domiciliary residence for homeless Veterans. Recently awarded Magnet Recognition for Excellence in

Nursing Services, it serves as the primary healthcare provider for more than 116,000 Veterans in Southeast Texas. In addition, the MEDVAMC has a large, active stroke program and treats more than 300 stroke patients annually. Stroke follow-up care is generally provided in outpatient clinics and is delivered by attending and resident physicians, nurse practitioners, and physician assistants in the specialty areas of neurology, primary care, and rehabilitation medicine.

Prior to the testing of the GAM-S, we formed a team of nurses to recruit patients and to work as nurse dyads (NDs) to improve patients' engagement in their treatment and SM decisions. The Nurse Manager at the Neurology Inpatient Unit was contacted to discuss using the GAM-S measure for the collaborative goal-setting among nurses and stroke patients. Next, we organized multiple meeting with inpatient nurses to present the project using the GAM-S. Major emphasis was to point out that using the GAM-S may improve patients' perceptions toward involvement in their treatment decisions because nurses would use the GAM-S with their patients for collaborative goal-setting and goal-assessment during patient education encounters. Following that, we established a team of staff nurses who were routinely involved in providing stroke education to help develop a specific implementation plan. We also organized "Lunch and Learn" meetings and invited staff nurses from both inpatient and primary care units to help them build nurse dyads teams and participate in the study. This was carried out to develop a plan that could expand the stroke education protocol in the inpatient hospital unit to the outpatient setting and reinforce what was taught during patients' in-hospital care.

The training protocol to ensure that all the criteria to follow the protocol are met was established as follows: 1) The nurse dyads (NDs) met for the initial introduction meeting in early February of 2017. We prepared a formal presentation, obtained copies of selected SM evidence-based research papers and distributed these to all team members who attended. The initial meeting was designed to provide essential evidence-based knowledge of goal setting theory to all

team members. We also presented literature showing that health behavior changes and health-related behavior goals (HRBG) are integral for effective patient self-management. 2) We presented the underlying precepts that goals are motivation factors for human behavior, and that collaborative goal setting between clinicians and patients can enhance patients' motivation, adherence, and autonomy, and improve their satisfaction. 3) We also explained that extensive research has been done regarding goal setting, but assessment and measures of goal attainment had not been extensively studied.

b) Sample Size

To test the measure's reliability, inpatient and outpatient nurses were invited to participate. A total of 20 nurses signed the informed consent and were enrolled to participate forming 10 NDs (Asare & Wright, 2001). Forty-four patients were recruited from the in-patient unit at the MEDVAMC. A sample of 44 participants is considered sufficient to establish the GAM-S reliability (Bartholomew et al., 2006; Anderson et al., 2010; Shegog et al., 2013). Patients were recruited to represent diverse socioeconomic status, as well as distribution of gender, age and ethnicity. Seven experts in the field have been recruited to the study to establish content validity (Lynn, 1986; Teherani & Obrien, 2016). Finally, usability testing was performed with 16 patients and 10 nurses (Anderson et al., 2010; Shegog et al., 2013).

c) Protection of Human Subjects

An IRB approval from Baylor College of Medicine and the UT Health was granted to conduct the study prior to the enrollment of all study participants. The identities of the participants and the test results have been kept confidential. Study participants were informed about the study protocol and details and assured that participation was voluntary and that they were free to withdraw from the study at any time and for any reason. Upon signing the consent forms, participants were enrolled in the study (Appendix I).

d) Screening and Recruitment Procedures

The study has been advertised for patients' recruitment in the MEDVAMC Neurology inpatient unit using IRB approved study brochure (Appendix N "Study Brochure"). Additionally, the study has been discussed at the Primary Care Clinic monthly meetings, focusing on quality-improvement projects in health prevention and in SM health education. To ensure that the desirable sample size has been reached, we have also consulted with the Houston VA Health Prevention Hospitalist and advertised the study being open for recruitment. Potential study patients had also been identified from providers' referral. Patients who expressed interest in participating in the study were screened for inclusion criteria which consisted of: (1) being ≥ 18 years old; (2) having a stroke and/or TIA; (3) having ≥ 2 or more uncontrolled stroke risk factors (i.e., BP > 140/90; HgA1C > 7, LDL-C > 100, being a current smoker, BMI of 30 kg/m² or higher); (4) reading and speaking English; (5) having access to a telephone; (6) being willing to engage in a goal setting/action planning/goal attainment SM program offered by the VA (documented in the CPRS) and (7) being willing to sign the consent form to participate in the semi-structured interviews. Upon provider's permission, patients who met inclusion criteria were invited to participating the study. Patients with severe cognitive impairment and aphasia, as determined by their medical records in CPRS, were excluded from the study.

e) Minimization of Attrition

To minimize participants' attrition, participants were called to remind them two days prior to their follow up interviews. We have also worked around providers' schedules to assure that the study did not cause any disruption with clinical care.

f) Consenting Procedures

Patient participants were identified by providers caring for patients admitted to the MEDVAMC with stroke or TIA. Providers received the Study Recruitment Flyers to share with

their patients during in-hospital care. Providers contacted the Co-PI with the names of patients who express an interest in participating in the study (Appendix G: Study Recruitment Flyer). Patients who meet the inclusion criteria and signed the consent form were enrolled in the study. Prior to the consent form signing, patients were also informed about their rights to refuse to participate or to withdraw anytime from the study. They were also informed that study withdrawal will not adversely affect their medical care at the VAMC. Following that, nurse participants from the neurology stroke care unit (NU-2A) and primary care clinic at the MEDVAMC have worked as a dyad to develop action plan and follow up on attainment with each enrolled patient.

Data Collection and Measurement

Upon obtaining consent forms, patient and provider demographic data were collected prior to the study interview. After completing the action plan and evaluation of goal attainment, the usability of the GAM-S was evaluated by patients and providers, using questionnaires adapted for each group. In addition, participants were asked to answer the open-ended questions as described in the Procedures section.

Patient usability rating scale

The 12-item patient questionnaire was used to assess patient perceptions of usability of the GAM-S. Usability parameters on ease of use, understandability, credibility, motivational appeal, and perceived impact on attaining the goal were scored on a 3-point Likert scale, ranging from 1=Yes to 2=No and 3=Do Not Know (Shegog et al., 2013). Patients also assessed whether the time it took to use GAM-S was too quick, just right or too long. Finally, each patient was asked to provide any additional free comments regarding the GAM-S usefulness.

Provider usability rating scale

The 11-item providers' questionnaire was used to assess providers' perception of the usability of the GAM-S in facilitating the goal-attainment measure and was scored individually on a 4-point Likert scale, ranging from strongly agree to strongly disagree, where 4=strongly agree, 3= agree, 2=disagree and 1= strongly disagree (Anderson et al., 2010).

Content validity interviews

Content validity allows determining how well the GAM-S measures the behavior for which it is intended. Seven experts in the field were interviewed to establish content validity. The interview included the following general question "How well does the wording of each question in the measure tap into measuring the goal attainment in the patient's specific goal-setting domain" (Shadish, Cook & Campbell, 2002). We provided each member of the previously established Content Validity Panel with the GAM-S items that represent a construct or skill. Working independently of each other, members of the panel were asked to rate each of the items as "essential," "useful," or "not necessary". Outcome data was collected on rating as well as demographic data on all members of the Content Validity Panel (Tables 3 and 6).

Reliability testing

To test the GAM-S reliability, we worked with the nurses from the primacy care unit and administered the GAM-S paper prototype to 44 participants from the VAMC. Data were collected and entered into the study data base for further data analysis.

Data Analysis

The GAM-S patients' usability testing

The assessment of patients' perception of GAM-S usability was established based on the percentage of agreement with positive statements and disagreement with negative statements (80% respondent agreement) on items such understandability, credibility, motivational appeal

and perceived impact. If 70% participants rated GAM-S as understandable then that would meet a-priori usability criteria. Patients' responses to the open-ended questions were tabulated and categorized to identify emerging themes regarding all respective categories.

The GAM-S providers' usability testing

Providers' usability questionnaire responses on the GAM-S were descriptively analyzed by computing means, standard deviations and frequencies for each individual questionnaire item. The two negatively phrased questions were reverse scored. An overall usability score was determined. Providers' responses to the open-ended questions were tabulated and categorized to identify emerging themes concerning four specific usability measures.

The GAM-S content validity assessment

Content validity analyses were carried out by verifying agreement among raters regarding how essential a particular item was in the measure. Lawshe (1975) proposed that each expert in the field respond independently to the following question for each item: "Is the skill or knowledge measured by this item 'essential,' 'useful, but not essential,' or 'not necessary' to the performance of the construct?" Responses from all panelists were pooled, and the number indicating "essential" for each item were determined. Greater levels of content validity correspond to greater numbers of panelists agreeing that a particular item is essential. Specific judging criterion is as follows: If more than half the experts specify that an item is essential, then the item has at least some content validity.

Two validity ratios can be calculated and used to determine whether to keep or remove the item from the measure (Content Validity Ratio) and whether the entire measure has acceptable content validity (Content Validity Index) (Gilbert & Prion, 2016). Content validity ratio (CVR) is a value assigned to each rating. The CVI statistic is useful in rejection or retention of individual items and is internationally recognized as the method for establishing content

validity (Wilson, Pan, & Schumsky, 2012). Content Validity Index is calculated as the mean of the CVR values for all items not lower than the CVR threshold of 0.7 and retained for the final instrument (Gilbert & Prion, 2016). In many situations, it is more efficient to report the overall CVI score than each individual item CVR (Gilbert & Prion, 2016).

To establish CVR, any item performance on which is perceived to be “essential” by more than half of the panelists, has some degree of content validity. The more panelists (beyond 50%), perceive an item as “essential”, the greater the extent or degree of its content validity. The CVR is calculated using the expression:

$$CVR = \frac{n_r - \frac{N}{2}}{\frac{N}{2}}$$

where:

n_r is the number of panelists identifying an item as “essential” and N is the total number of panelists ($N/2$ is half the total number of panelists)

The CVI is calculated as an average value of the CVR over the number of items in the survey. Outcomes of the analysis carried out using these quantitative measures to determine the GAM-s content validity are presented in the Results section.

GAM-S reliability study

The analysis of the GAM-S reliability was conducted in two parts.

In Part 1, we examined mean scores for the scale and performed correlation analysis to test the strength and direction of the relations among the GAM-S variables. The correlation coefficient varies between -1 and 1. Strength of the correlation is its absolute value, which varies from 0 to 1. The correlation is stronger when the value is farther from 0. Zero correlation indicates no linear relation, 0.1 a small effect, 0.3 a medium and 0.5 a large effect.

In Part 2, we assessed internal consistency of the GAM-S. We performed Cronbach α analysis on the entire sample and for the subgroups to assess the internal consistency of the measure. Cronbach α (or coefficient α), has been developed by Cronbach in 1951 to assess how closely related are α items from a set as a group. Coefficient alpha ranges from $\alpha = 0$ to 1, with $\alpha = 0.7$ or greater, which is considered adequate for research purposes, while for making decisions on individuals, a higher threshold 0.85 is recommended (Allen & Yen, 2002).

Results

Demographics

Patients usability study

Sixteen patients agreed to participate in the GAM-S measure evaluation. The sample included 14 males (87.5%) and two females (12.5%). The average age of all participants was 67 years ranging from 36 - 81. In terms of ethnicity, nine patients were White (56%), three were Hispanic (10%) and four were Black (25%). Eleven patients had a caregiver (69%) and five patients did not (31%). In terms of the marital status, seven patients were married (44%) and nine patients were not (56%). Majority of patients suffered a stroke (75%) and 25% were diagnosed with TIA (Table 1).

Providers usability study

In terms of the providers, all 10 providers were female registered nurses working at the Prime Care Clinic at the MEDVAMC (Table 2).

Experts from the field engaging patients in the self-management to control stroke risk factors

Evaluation of content validity was performed by seven experts in the field. The average age of all participants was 41 years ranging from 36 - 62 years. All seven participants were female with an average of an approximately 18 years of the clinical practice experience providing care for the post-stroke patients (Table 3).

Usability Outcomes Evaluation

Patients' survey outcome

To answer the study research questions, the survey described earlier was administered to assess patient perceptions of the GAM-S parameters on ease of use, understandability, credibility, motivational appeal, and perceived impact of attaining the goal. The data on patients' responses were analyzed descriptively. Patients rated GAM-S favorably in terms of ease of use. Specifically, most patients (75%) felt comfortable to use the measure. Only 6% stated he/she did not feel comfortable using the measure and 19% stated that they did not know the specific answer to questions included in the measure. Ten patients (62%) reported that the time to use the measure was just right, 19% stated that the time was too short and 19% stated the survey was too long.

Remaining questions on the survey concerned assessing understandability, credibility, motivational appeal, and perceived impact on attaining the goal. Fifteen patients (94%) stated they were able to understand very well the words being used in the survey and 6% did not provide feedback. Seven patients (44%) needed help to answer some questions but 44% did not need any help. Only two persons (12%) did not know how to answer these questions.

Credibility of GAM-S was established based on the answers to three questions concerned with whether the GAM-S would help patients to think carefully about stroke risk factors, whether it could be trusted and whether the GAM-S stimulated them to consider reliable ways to achieve health related behavioral goals. Thirteen patients (81%) stated that the GAM-S was helpful to think about management of stroke risk factors and that the measure can be trustworthy. Only three patients (19%) did not know how to answer this question. Credibility of the measure was also assessed by asking participants if they have been prompted to consider reliable ways to achieve their goals. Ten patients (63%) answered yes to this question and 6 (37 %) said that

using the measure did not prompt them to think about achieving goals on their previously set action plans

Motivational appeal was assessed based on how likely patients would use the measure as a part of their self-management program and if they could recommend it to others to use during the clinic visit. Patients responded overwhelmingly that they would use GAM-S in self-management programs (94%) and only one person was not sure if they would like to use it. Similarly, 94% said that they would recommend the measure to other people and 6% did not offer feedback. When asked if patients would use the GAM-S again in a clinic visit, 88% indicated that they would use it in the future and 12% said that they did not know about the future use of the GAM-S.

The final set of questions in the survey was concerned with perceived impact of the GAM-S. Eleven patients (69%) responded that the questions helped them to talk to the doctor or nurse about their stroke risk factors. One patient (6%) said that the measure was not helpful to improve discussion about stroke risk factors and 4 patients (25%) did not offer feedback and stated that they did not know if this would make a difference in their self-management of the stroke risk factors. In addition, patients were asked if the questions provided in the GAM-S would help them to think about how to overcome barriers to effectively manage stroke risk factors. Majority of patient thought that they might benefit in terms of overcoming barriers to stroke risk factors while using GAM-S (69%). The remaining participants did not provide feedback on this question (31%). The final survey question was concerned with patients assessment related to what extent the questions provided in the GAM-S will help them manage stroke risk factors better in the future. Thirteen patients (81%) believed that using this measure would improve their stroke risk factors control in the future. The rest of the patients (19%) indicated that they did not know if this would help them in stroke risk factors control (Table 4).

Emerging themes concerning patients' answers to the open-ended questions:

Due to the low frequency of the open-ended questions, we were unable to conduct a more in – depth analysis of the emerging themes.

Providers survey outcome

All 10 providers responded that they strongly agree that questions included in the measure were clear. All but one provider (90%) responded that they strongly agreed that the measure was easy to use, the time to use the measure was reasonable and they felt comfortable using the measure. In terms of the effectiveness of the measure to help providers discuss goal attainment outcomes, 90% of providers strongly agreed that the GAM-S was effective. Also 90% of providers strongly agreed that the measure was helpful to discuss patients' barriers to the goal attainment and they would use the measure in their clinical practice.

Half of the providers strongly agreed that the measure prompted them to consider other evidence-based interventions. Two negatively phrased questions were related to whether the measure “did NOT use familiar terminology “and “did NOT help to discuss goal-attainment barriers”. All but one provider (90%) strongly disagreed that the measure used unfamiliar terminology. Four providers (40%) agreed that the measure did not help them to discuss goal attainment barriers with the patients.

Overall usability for GAM-S was derived from the mean of the sum of scores for each item on the GAM-S usability questionnaire. Two items were reverse coded. Of the maximum 4 points score, usability scored high (Mean, 3.7 [SD, 0.24]) (Table 5). The coefficient of variation representing the measure of dispersion around the mean value was 6%.

GAM-S content validity results

The content validity study results were assessed based on the Lawshe method (1975). We established content validity based on the experts rating, content validity ratio (CVR) and content validity index (CVI) statistics. More than half of the experts (71%) specified that each item is essential; therefore, an item has at least some content validity (Table 6).

For more precise assessment, the CVR for each item was calculated according to the formula adopted from Gilbert and Prion (2016) and presented in Table 7. The threshold of 0.7 has been considered acceptable for individual items to be retained (Gilbert & Prion, 2016).

The analysis also revealed that only the items 1 and 2 have been rated “essential” by all raters and items 3, 4, and 5 received mix ratings. To take this into account, the CVI for the entire measure was established by calculating the overall mean based on the CRV for all items included in the measure (Mean CVI= 4.14/ 5= 0.83).

The CVI value of 0.83 indicates that the GAM-S had a high level of content validity as rated by the panel of content experts (Gilbert & Prion, 2016) (Table 7).

Reliability Outcome Study Results

Participants Characteristic

Forty-four patients agreed to participate in the reliability study, completed the goal setting/action plan survey. and provided follow-up data on the goal attainment using GAM-S. The sample included 42 males (95%) and two females (5%). The average age of all participants was 67 years ranging from 36-81. During the recruitment process, majority of patients (41/44 or 93%) were hospitalized with stroke/TIA in the neurology section of the hospital and only three (7%) patients were hospitalized in the rehabilitation section. In terms of the ethnicity, 23 patients were White (52%), 10 Black (23.5%), 10 Hispanics (23.5%) and one of the “Other” category (1%). Out of the 44 patients enrolled in the study, 42 patients completed GAM-S (95% follow-up

rate) and provided follow-up data on the goal attainment using GAM-S. The data were entered into the Excel spreadsheet for the analysis.

Part 1

Patients set up action plans to address control of modifiable stroke risk factors such as diet, exercise, and reduction in cigarette smoking and alcohol consumption. In addition, some patients decided to improve their blood pressure and diabetes medication compliance. Specifically, 12 patients out of 42 (29%) decided to increase their physical activity, 17 patients (40 %) wanted to make healthy improvements in their eating habits. Eight patients (19%) were willing to reduce smoking and three patients (7%) decided to reduce alcohol intake. Finally, two patients (5%) made improvements in their medication compliance. Twenty-three patients (52%) achieved maximum total score equal to 8 indicating that these patients fully achieved each of the specific Action Plan goals in the respective domains. The remaining score values ranged from 0 to 7 with the total of 5 patients (11%) not achieving any of their previously set up goals. The mean score of goal attainment was 6.2 (Table 8).

Total Sample Score Calculations

We calculated mean scores, SD and variance by GAM-S subscales and a summary score for the total sample (Table 9).

Correlation Analysis for the Entire Sample

We conducted correlation analysis for the entire sample to test the correlations among four items.

Table A. Correlation analysis of four items.

j = 2	j = 3	j = 4	
0.878	0.878	0.853	i = 1
	0.901	0.878	i = 2
		0.877	i = 3

Table A depicts direct correlation coefficients among the 4 items from the GAM-S:

- 1) What action did you select to do?
- 2) How much of the action did you do?
- 3) When did you do the action?
- 4) How often did you do the action?

As evident from Table A, all items appear to be similarly highly positively correlated.

Part 2.

GAM-S reliability results

We use the Cronbach's α analysis. The value of α computed for the entire sample $N = 42$, based on 4 items, is equal to 0.962. This high value indicates strong internal consistency of the GAM-S.

Discussion

Goal attainment is a theoretical construct central to the goal setting/goal attainment theory. It is also incorporated in many other health behavior change theories and applied in SM intervention programs. The absence of reliable and valid measures of stroke survivors' goal attainment creates a critical methodological gap in the assessment of SM stroke risk factor control and advancement of research outcomes. In this study, we pilot tested and established preliminary psychometric properties of GAM-S, which may fill this gap and be applied in the

clinical practice. The GAM-S scale was tested with participation of stroke patients and primary care providers to assess patient perceptions of GAM-S parameters with respect to ease of use, understandability, credibility, motivational appeal, and perceived impact of goal attainment.

Patients' rating of GAM-S was favorable across all feasibility parameters indicating justification for the measure to be used in SM behavior change interventions. Specifically, the usability study suggests that 75% of patients felt comfortable with the measure and 62% reported that the time required to use the measure was just right. However, 25% did not feel comfortable suggesting that the measure does not suit a fraction of the users. Some patients may have experienced post-stroke fatigue following stroke which may have contributed to difficulties related to comfortably use the measure. As we have reported in the phenomenological study, frustration and fatigue was salient symptoms for patients similarly to outcomes reported by Young, Mills Gibbons and Thornton (2013). To mitigate this barrier, additional coaching as to how to use the measure may help.

Assessment concerning understandability, credibility, motivational appeal, and perceived impact on attaining the goal was also promising. Patients were able to understand very well the words being used in the survey, with 94% indicating that the survey was easy to complete and patients could complete the survey by themselves. Most of the patients felt that GAM-S helped them to think carefully about stroke risk factor SM control. Thirteen patients (81%) stated that GAM-S was helpful for their thinking about management of stroke risk factors and that the measure was trustworthy. Credibility of the measure was also assessed and 63% of the patients said that were prompted by GAM-S to consider reliable ways of achieving goals within their previously set action plans. However, 27% of the users did not find the value in GAM-S helping them to successfully get to the previously set goal. It is possible that for this fraction of users, more simplified language should be used to assess whether GAM-S prompted patients in a

reliable way to achieve their goals. We may revise the question as follows: “GAM-S helped me identify better ways to achieve my goals”.

The GAM-S was also highly rated in terms of motivational appeal. Patients responded overwhelmingly that they would use GAM-S in self-management programs. Ninety-four percent of patients stated that they would use the measure as a part of their self-management program and they would recommend it to others to use during clinic visits. The final set of questions in the survey was concerned with perceived impact of the GAM-S and 69% responded that the questions helped them to talk to the doctor or nurse about their stroke risk factors. GAM-S was also favorably rated when used as a tool to overcome barriers to effectively manage stroke risk factors. Majority of patients (69%) felt that they might benefit in the terms of overcoming barriers to stroke risk factors while using GAM-S. The GAM-S was also highly rated in the terms of future use in stroke risk factor control. Eighty-one percent of patients believed that using this measure would help them to achieve their behavioral goals. Patients also provided free-response comments on the experience of using GAM-S. Some of participants expressed their appreciation of the measure helping them to specifically discuss their health-related behavior goals and of the opportunity to motivate them to attain their goals. One participant stated the intent to continue to work with the provider and follow up on the exercise regime, which would help to achieve a specific weight loss goal and subsequently keep the weight off. Another participant indicated that reviewing his goal attainment with the provider helped to continue to monitor his daily salt intake to improve blood pressure, which is the single most important stroke risk factor control.

Providers' ratings of GAM-S were also favorable across all parameters. All providers strongly agreed that questions included in the measure were clear, time to complete questions was reasonable, and they felt comfortable using the measure. Providers also felt that the measure

was effective in the assessment of specific goal attainment. Moreover, 93% of providers strongly agreed that the measure was helpful in discussing patients' barriers to goal attainment and that they would use the measure in their clinical practice. In addition, half of the participants stated that using GAM-S prompted them to consider other evidence-based interventions. This might be considered not entirely satisfactory. Based on the mean score evaluation, GAM-S scored high, indicating that the measure will perform well when used in clinical settings for SM risk factor control. Patients' and providers' positive ratings of GAM-S when used in SM goal setting assessment are encouraging. Our study demonstrated that using a measure that specifically asks the level of complete responses in each domain (what, when, how, and how much) is perceived as a clear, credible, motivational, and effective way to assess goal completeness. Successful goal completes build patients' self-confidence, which is a critical factor to stroke self-management. The GAM-S also enhanced patient-doctor communication and was recommended for use in evidence-based stroke risk factor control.

The current study also evaluated content validity of the measure. Ratings were provided by the panel of content experts and we used a quantitative measure to assess content validity (Gilbert & Prion, 2016). Based on the CVR value above 0.8 we concluded high content validity of the measure.

The final step in the preliminary psychometric assessment of GAM-S included reliability assessment. As previously mentioned, the absence of instruments to reliably measure stroke risk factors goal attainment based on the "Action Plan" creates a methodological challenge gap in the self-management research framework (Teal et al., 2012). The GAM-S prototype has been developed based on the answers to four questions included on the "Action Plan" (Lorig & Bodenheimer, 2001). Collaborative action planning is a process where patients first identify a goal they want to accomplish and then a healthcare provider collaborates with the patient to

develop a specific action plan to attain patient's stated goal. Action planning lists the steps that facilitate goal setting and attainment by breaking down a goal that is specific, measurable, achievable, realistic and time specific (what risk factor do you want to improve, by how much, when, and how often). Therefore, the prototype of the goal attainment scale measures the achievement of four steps detailed by the patient in the Action Plan.

In this study, the goal attainment completion scores were collected by the RNs in Prime Care, which means that the Investigator was blinded to the scores outcome. Nurses contacted patients by phone and collected self-reported data using the GAM-S two weeks after patients set up an Action Plan immediately after the acute event. Patients set up action plans to address modifiable stroke risk factor controls such as diet, exercise, reduction in cigarette smoking, and reduction in alcohol consumption. In addition, some patients have decided to improve their blood pressure and/or diabetes medication regimen. The GAM-S completion rate was very high, with a 95% completion rate (Table 8). Overall, more than half of the participants achieved a total score that indicated that patients fully achieved every section of their action plans. The remaining score values ranged from zero to seven with only 11% not achieving any of their previously set up goals. However, we observed low variability based on the outcome scores. We noted that half of the participants self-reported the perfect score resulting in a low variability sample (the scale did not have much variance). Revisions to the GAM-S (version 1) may be needed to address the low variability. The factors potentially responsible for this may include selection bias, self-reporting bias, and score scale.

1) Selection bias: The sample included VA patients who had low National Institute of Health stroke scale (NIHSS) severity score, specifically in the area of level of consciousness, ability to follow simple commands and no impairments in language or speech (as per study inclusion criteria and determined by the neurologist at the inpatient unit). The low variability in

the scores may be a reflection of the low variability in the stroke severity. Patients with low stroke severity tend to be willing and able to set achievable goals and comply with their plans to achieve the goals. In addition, VA patients are generally more educated and engaged in self-management programs offered by the system as standard care than the average. Therefore, the study sample is not representative of the general population of secondary stroke survivors. We hypothesize that administering the measure to non-VA patients with wider NIH score severity would yield higher score variability. We may propose to test this hypothesis in future studies.

2) Self-reporting bias: As with all self-reported measures, the chance of bias on the part of the responders is more likely than a no self-reported measure because of the inherent difficulty to introspectively and objectively assess oneself. It has been documented in the literature, that self-reported scores are less reliable as compared to the direct monitoring of patients responses on the surveys (Shadish, Cook & Campbell, 2002; Streiner & Norman, 2004). We have no reason to believe that the participants were not honest or that they desired to manage how they appear to the nurse collecting the attainment data. However, because of the high motivation level discussed in item 1 above and a positive association between monitoring and goal attainment (Harkin et al., 2016 and Bee et al., 2016), patients may have over-estimated their achievements which resulted in the more 50% of patients achieving perfect score. To address a potential bias, we propose to improve the measure by:

a) Establishing face validity in addition to the already conducted content validity to show that the measure demonstrate the construct and help provide further evidence that we measuring what is supposed to be measured.

b) Revising the instructions to the users to emphasize that all responses are valid and useful irrespective of the numerical score. In addition, we propose to use the measure in conjunction with monitoring of the goal progress (for example by using technology such I-Pads

or incorporating it to the MyHealthVet computerised system offered at the VA to measure activity) and measuring clinical outcomes such as blood pressure, hemoglobin A1c, and cholesterol.

3) Score scale: The low variability in the overall score may be due to 1) the formulation of the first question, and 2) the options provided to assess the partiality of the actions taken in each item. Specifically, it is possible that patients are more likely to answer, “Completely did the action” to all items if they selected that option as answer to the first question. Since the first question is qualitative in nature, we suggest changing the response options to “yes/no”. As a result, in subsequent questions we expect the patients to be more likely to objectively quantify the extent to which they attained the goal in specific domain.

In addition, the low variability of the overall score may be related to the insufficient assessment of the degree of partiality of the attainment of the goal. In the current version, the second question is formulated as: “I partially did the action...” and equal weight (1) is given to the answer irrespective of the degree of partiality. One possibility to improve the measure and its variability is by giving the patient the option to more accurately describe the degree of adherence by providing the following options as answers to the question: “completely”, “most of the time”, “some of the time”, and “not at all”. The terms “most of the time” and “some of the time” would be intended to capture what was completed more or less than 50% of the time.

Reliability Study

We utilized Cronbach’s analysis to determine GAM-S internal consistency. The value computed for the entire sample, based on four items, was equal to 0.962. This high value indicates strong internal consistency of GAM-S.

Limitations

Our assessment of the reliability study is not without limitations. The study participants are a part of the VA population exposed to the goal setting, action planning and goal attainment SM concepts and stroke risk reduction education provided by the VA health system. Participants with more knowledge, better SM skills, and stronger commitment are more likely to achieve the goal (Prah, Richards, Griggs & Simpson, 2017). For this reason, GAM-S should be also tested in the non-VA population.

We provided a brief training to the nurses regarding how to set the goals with patients and how to use GAM-S in clinical practice. Even though the usability testing revealed acceptable time to complete the GAM-S, other health care providers may not be able to easily utilize and complete GAM-S due to their busy practice.

While the GAM-S should be further examined for additional psychometric properties such as construct or external validity, or in different populations and settings, the measure performed well for our specific sample in terms of the good usability outcomes evaluated by patients and providers . In addition, we established good content validity and internal consistency. Notwithstanding the limitations, our study provides useful information for intervention program designers who would like to include a goal attainment measure in their programs.

One observation is that a future study might be planned to better distinguish among individuals. In the current study, 28 out of 42 (67%) participants achieved either a perfect score or all zeroes. It seems desirable to be able to measure intermediate degrees of goal attainment in the “partial category”. Observed biases, such as small sample size, predominantly male population and various comorbidities, might be contributing to the distribution of scores observed.

Conclusions

Having a stroke is the strongest predictor of a subsequent stroke, yet most strokes can be prevented through patient awareness and self-management (SM) of stroke risk factors. Goal attainment assessment has been used in rehabilitation studies, but not in the assessment of health behavior goals to control stroke risk factor self-management (Hurn, Kneebone & Cropley, 2006). It has been showed that patients' active involvement in goal-setting tends to result in a positive association between the goal-setting process and treatment outcomes (Bodenheimer and Handley, 2009; Glasgow et al., 2005 and Naik et al., 2011). However, there is a dearth of psychometrically valid instruments to measure goal attainment through the SM of risk factors for stroke (e.g. hypertension or diabetes). This study provides preliminary conclusions as to how to measure goal attainment in patients who experienced stroke and who are engaged in self-management of stroke risk factors. Preliminary psychometric testing of GAM-S demonstrates high usability scores assessed by patients and providers, good content validity, and reliability for goal setting attainment evaluation. Cronbach's α , which quantifies the extent to which all the items are measuring the same content, is high in this study. The study addresses a critical gap and provides researchers with valuable preliminary knowledge to guide future research in the area of reliable goal-attainment measures. In addition, the present framework can be later expanded as a model for developing goal-attainment measures for other chronic illnesses in the general population.

Implications for Clinical Practice

The GAM-S holds promise of goal attainment assessment in the context of clinical practice. With revisions suggested in the Discussion, it can be used as a reliable measure in intervention programs utilizing SM concepts, such as goal setting and action planning to help patients more effectively manage their behavioral risk problems. It may improve patients' self-

efficacy, coping mechanisms, and quality of life following stroke (which should be more thoroughly tested in the future studies). GAM-S is easy to use and it can be completed in a timely manner by patients and providers. It facilitates the patient-shared decision process in terms of complicated risk factor control following stroke. Providers and patients can be easily trained in GAM-S scoring to monitor patients' goal-setting progress. We recommend GAM-S use in future studies for further psychometric evaluation and in the context of behavioral change techniques directly targeting other chronic diseases such diabetes or hypertension. Finally, more research should be conducted to improve goal attainment and better understand goal attainment interventions in chronic illness self-management.

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Results Tables

Table 1. Demographics of Usability Testing

Patient Sample (N=16)		
Age	Range (years) 36-81	Percent (%)
Mean Age	67	
Gender	Male: 14	87
	Female: 2	13
Race/ethnicity	White: 9	56
	Hispanic: 3	19
	Black: 4	25
Marital status	Yes: 7	44
	No: 9	56
Stroke	N=12	75
TIA	N=4	25
Caregiver	Yes: 11	69
	No: 5	31

Table 2. Demographics of Usability Testing

Provider Sample (N=10)		
Age	Range (years) 32-62	Percent (%)
Mean Age	48	N/A
Gender	Male : 0	0
	Female: 10	100
Primary Care Nurse	N= 9	90
Specialty Nurse (diabetes educator)	N= 1	10
Type	Nurses (RNs)=9	90
	Advance practice nurses (APNs)=1	10
	Physician assistants (PAs) =0	0

Table 3. Demographics of Experts in the Field (N=7)

Age	Range (years) 36- 62	Percent (%)
Mean Age	41	N/A
Gender	Male: 0	0
	Female: 7	100
Primary Care Nurses	N= 5	71
Specialty Nurse (diabetes educator and stroke care coordinator)	N= 2	29
Average years in practice	18	N/A

Table 4. Patient Agreement with Usability Statements

Statements	n (%)
Ease of use	
I think that the time it took to use GAM-S was:	
Too quick	3 (19)
Just right	10 (62)
Too long	3 (19)
I felt comfortable to use the measure	12 (75)
Understandability	
I knew and understood most of the words used in the GAM-S.	15 (94)
I needed help to answer questions in the GAM-S.	7 (44)
Credibility	
I think the questions in the GAM-S will help me to think carefully about my stroke risk factors and can be trusted.	13 (81)
The GAM-S prompted me to consider reliable ways to achieve my goals.	10 (63)
Motivational appeal	
I would use the GAM-S as a part of my self-management program.	15 (94)
I would tell other patients to use the GAM-S.	15 (94)
I would use the GAM-S again in a clinic visit.	14 (88)
Perceived impact	
I think the questions helped me talk to my doctor or nurse about my stroke risk factors.	11 (69)
I think the questions provided in the GAM-S will help me to think about how to overcome barriers to effectively manage my stroke risk factors.	11 (69)
I think the questions provided in the GAM-S will help me manage my stroke risk factors better in the future.	13 (81)

Table 5. Providers usability test outcome of the GAM-S a (N=10) ^a

Usability Item	Score
1. Overall the measure was easy to use.	3.9
2. The time to use the measure was reasonable.	3.9
3. I felt comfortable using the measure.	3.9
4. The questions provided by the measure were clear.	4.0
5. The measure was effective in helping me to discuss with Veterans their goal- setting outcomes.	3.7
6. The measure prompted me to consider other evidence-based interventions.	3.4
7. The measure was effective in prompting me to discuss barriers to goal attainment.	3.7
8. The measure did not use familiar terminology.	1.4
9. The measure helped me to consider additional patients' healthcare problems.	3.2
10. The measure did NOT help me to discuss goal-attainment barriers.	1.4
11. I would use the measure in clinical practice.	3.7
Overall total score	3.7

^a Response score for each item: 0 - 4 (4=strongly agree, 3= agree, 2=disagree and 1= strongly disagree)

Table 6. Content Validity of GAM-S ^a

Participant's Number	Q 1	Q 2	Q3	Q4	Confidence Level
1	Essential	Essential	Essential	Essential	Essential
2	Essential	Essential	Essential	Essential	Essential
3	Essential	Essential	Essential	Essential	Essential
4	Essential	Essential	Essential	Essential	Essential
5	Essential	Essential	Essential	Essential	Essential
6	Essential	Essential	Essential	Useful but not essential	Useful but not essential
7	Essential	Essential	Useful but not essential	Essential	Essential

^a Response set of items: essential, useful, but not essential and not necessary

Table 7. GAM-S Individual Items CVR and Overall CVI

GAM-S Items	1	2	3	4	5
CVR Index	1	1	0.71	0.71	0.71
CVI Index = 0.83					

Table 8. Patients Distribution of GAM-S Total Scores^a

Number of Patients (N=42)	GAM-S Total Score
23	8
3	7
4	6
3	5
4	4
5	0

^aScore range: 0-8

Table 9. Goal Attainment Mean Scores, Standard Deviations (SD) and Variances by Subscales and Total Score

	Subscales				
	What	How much	When	How often	Total Score
Mean Total Score	1.5	1.6	1.6	1.5	6.2
SD	0.7	0.7	0.7	0.7	2.7
Variance	0.5	0.5	0.5	0.5	7.2

Dissertation Conclusions

During the last several decades, the prevalence of chronic illnesses has been on the rise worldwide (AHA, 2011). Stroke belongs to this category and is a leading cause of disability in adults and the fifth leading cause of death in the U.S. Post-stroke care extends over a long period of time and is very costly (Reker, 2005) The VA Stroke QUERI Strategic Plan. After hospital discharge, stroke survivors experience numerous challenges in adapting to their new life conditions and in self-managing risk factors of a recurrent stroke such as hypertension or diabetes. Moreover, physical and cognitive disabilities as well as emotional comorbidities such as depression and anxiety can adversely affect survivors' quality of life.

A large body of evidence exists on self-management (SM) concepts, skills, support and interventions by means of which individuals and health care providers assume greater responsibility for health decisions (Lorig, 2003). SM interventions have been identified as key programs to address the burden of stroke and help Veterans to manage their controllable risk factors (Anderson et al., 2013; Damush et al., 2016). SM involves engagement in a collaborative approach such that patient and provider work together to define problems, set priorities, establish goals, create treatment plans, solve problems and assess attainment. In particular, control of stroke risk factors includes making small but specific health behavior and lifestyle changes leading to a healthier diet or a successful exercise regimen. For example, patients may set specific health behavior goal to monitor daily salt intake to reduce blood pressure, which might be the single most important stroke risk factor control. Modification of risk factors may be effectively managed through lifestyle changes but requires strategies that support complex health related modifications. Consequently, successful implementation of SM goals to control risks remains a challenge. Moreover, the complicated nature of SM goals causes a goal attainment measure to be a difficult task to design and accomplish. The literature does not demonstrate the

existence of a reliable and valid goal-attainment measure. In addition, the use of existing measures is unclear (Ruben & Tinetti, 2012), especially in various intervention programs, of which a goal-attainment measure is a crucial part. Hence, we identified the need for developing a goal-attainment measure and for testing its psychometric properties for stroke survivors in the primary care setting. The study was conducted in three parts.

First, we recognized the necessity to assess the current understanding of goal attainment measures in the health behavior change. Researchers have been using goal attainment to measure the effect of interventions or treatment, but the literature shows that goal setting as an outcome measure has not been systematically reviewed for post-stroke patients (Hurn, Kneebone & Cropley, 2006). To address this shortcoming, we systematically reviewed the literature to evaluate the use of goal attainment measures in research and clinical contexts. We have not found any measures in studies claiming to specifically measure goal attainment in the SM context for secondary stroke risk factors control. This review also confirmed that, while SM appears to offer significant improvements in patient outcomes, a consensus on the SM process and its quantitation is just beginning to emerge (Riegel et al., 2000). As previously reported (Boger, 2015) this might be due to the lack of clear concept definitions and their operationalization. Psychometric properties were not specified; therefore, we can comment neither on their strengths nor on weaknesses. Our review of systematic reviews demonstrates an absence of measures that adequately assess goal attainment through SM techniques applied in the stroke risk reduction domain. Consequently, the underlying mechanisms that affect behavior change are not fully understood. The use of goal attainment measures is minor, but the review reveals that this concept is a growing field of research in the SM domain.

Next we conducted the study in which we recruited Veterans to understand their experiences after the stroke and when engaged in SM. We were particularly interested in the

phenomenon of patients' post stroke experience while self-managing their stroke risk factors. On the basis of the current review, we determined that published papers that systematically obtained and analyzed data related to the increase of patients' everyday activities associated with goal attainment were absent from the literature. We sought to describe stroke patients' lived experiences with SM following hospital discharge. Phenomenology was the guiding qualitative methodology of the study. We obtained a deeper understanding of patients' challenges, strategies and perceptions while working with clinicians to attain their personal goals. Furthermore, SM coping behaviors and goal setting aided their recovery process and improved their quality of life. These findings indicate that SM support interventions hold promise in assisting stroke survivors to regain physical and emotional well-being.

Informed by the findings from the systematic review and Veterans' stroke SM post-stroke experience study, we proceeded to test the GAM-S measure. In this study, we focused on the specific aspect of SM support associated with setting goals and assessing goal attainment to prevent another stroke. Preliminary psychometric testing of GAM-S demonstrated high usability scores assessed by patients and providers, good content validity, and reliability for goal setting attainment evaluation. Cronbach's α , which quantifies the extent to which all the items are measuring the same content, is high in this study. The GAM-S may improve patients' self-efficacy, coping mechanisms, and quality of life following stroke. GAM-S is easy to use and it can be completed in a timely manner by patients and providers. It facilitates a patient-shared decision process in terms of complicated risk factor control following a stroke.

This study provides preliminary conclusions as to how to measure goal attainment in patients who experienced stroke and are engaged in the SM of stroke risk factors. Moreover, this research provides valuable preliminary knowledge to guide future research in the area of reliable

goal-attainment measures. The framework can then be expanded as a model for developing goal-attainment measures for other chronic illnesses in the general population.

Taken together, our findings are among the first tests of goal setting and goal attainment use in clinical setting, Veterans' experience with SM, and pilot testing of psychometric properties of the goal attainment measure. It makes it clear that more research is needed; we summarize our suggestions in the next section.

Directions for Future Research

The present review demonstrates that a goal attainment measure has an important role in precise goal attainment assessment necessary in effective SM stroke risk factors control. It raises a number of questions to be addressed in future research.

First, to improve the quality of future systematic reviews, more precise definition of concepts are needed. We recommend changes to current study methodologies to ensure that clear and consistent terms are used to define goal setting as an outcome measure. Further work on conceptualization of the stroke SM cycle as defined by Scobbie (2011) is strongly recommended in order to develop and evaluate goal attainment measures. Additional research is needed to better understand the definitions and concepts' operationalization to develop more reliable and valid goal attainment measures. We also recommend that the theoretical framework be clearly specified in the methodological section of each review including the behavioral change model used.

Second, future research of the post-stroke experience could be expanded to populations other than Veterans to enable extending our findings to the general population. Further, the scope of study of goal-based interventions could be broadened to include ecological levels of family relationships, and the role of the community and society in stroke recovery. More emphasis could be given to explore the best way to help patients deal with loss of income and financial

hardship. The role that caregivers play in their loved ones recovery could also be incorporated in future studies. It has been shown that unreasonable expectations and limitations in patients' struggle during the recovery process may create family tensions. Finally, better understanding of the healthcare providers' role and patient-centered coordination of services may also help in post stroke recovery.

Finally, we have only conducted GAM-S usability with a sample of Veterans and their health care providers and established GAM-S content validity and reliability. Further evaluations are needed to establish additional GAM-S validities, which will require greater sample sizes.

In conclusion, more research should be conducted to improve goal attainment measures and better understand their application and effectiveness in SM interventions.

APPENDICES

Appendix A: GAM-S Study Presentation for the VA Providers

MEASURING GOAL ATTAINMENT
IN CHRONIC DISEASE SELF-MANAGEMENT:
TESTING
GOAL ATTAINMENT OUTCOME MEASURE
FOR STROKE (GAM-S)

Quality Improvement Project

Participants:

RNs- Neurology Inpatient

RNs- Primary Care

Barbara Kimmel, Department of Neurology

Dr. Jane Anderson, Associate Chief of Nursing Research

MEDVAMC, Houston

OBJECTIVES

- The proposed pilot project tests the usability of the GAM-S tool to measure goal attainment in the self-management risk factors control.
- Knowledge gained from this project will inform researchers and clinicians of best way to measure goal attainment that utilizes GAM-S tool for patient self-management and stroke risk factor reduction.

PROJECT AIM

Pilot test with Veterans and healthcare providers to use CPRS **Action Planning** and **Goal Attainment Measure-Stroke (GAM-S)** prototype for collaborative goal assessment during clinical encounters to establish the tool's usability in the clinical setting.



DESIGN

- Telephone follow up goal attainment improvement project using GAM-S prototype
- Protection for Human Subjects: BCM/VA IRB approvals (in progress)
- Patient/Provider recruitment
 - Eligibility criteria:
 - Providers from Neurology inpatient unit and Primary Care and Post-Stroke Clinic
 - Patients who survived stroke or TIA and developed Action Plan
- Sample size N = up 60 participants

METHODS

- Clinic encounter description: action planning and goal attainment using GAM-S
 - Develop Action Plan upon discharge and document in CPRS using the existing template (standard of care)
 - Make a follow up phone call to evaluate the plan using paper form of GAM-S tool (see handout)

INTRODUCTION -COLLABORATIVE ACTION PLANNING

- Something **YOU** want to do for yourself
- Something you can **ACHIEVE**
- Something **VERY SPECIFIC**
- Something that **ANSWERS THESE QUESTIONS:**
 - **What?**
 - **How Much?**
 - **When?**
 - **How Often?**
- Something you have a **CONFIDENCE LEVEL** of 7 or more on a 1 – 10 scale of accomplishing

Attainment of goals at lower levels permits the attainment of high-level goals

Ref.: Lorig and Holman, 2003; Lorig et al., 2013

ACTION PLAN FORM

My Action Plan

- ☐ What do I want to do? _____
- ☐ How much will I do? _____
- ☐ When will I do it? _____
- ☐ How often will I do it? _____
- ☐ _____

On a scale of 1-10, how confident am I that I can accomplish this Action Plan?

- ☐ 1 2 3 4 5 6 7 8 9 10



CPRS TEMPLATE

Shared Templates

- Neurology Care Line
 - Stroke
 - Stop Stroke Action Plan



SPECIFIC PROCEDURES

STEP I

Upon IRB approval, eligible patient and providers will be recruited in the study at the inpatient unit and asked to complete inform consent

STEP II

- 1) Patient and RN from the Neurology – Stroke Inpatient Unit (2B) discuss behavioral risk factor and jointly develop Action Plan (see Patient Workbook p. 15)
- 2) Action Plan is document in the patient's chart in CPRS using the Action Plan template
- 3) Upon 1 week from discharge, PC RN will call patient who developed Action Plan to follow up on their Action Plan attainment status
- 4) Documentation of attainment will be completed using the GAM-S paper form (see handout)

STEP III

Phase II : Usability testing (f/up surveys completions with the subset of participants)

Goal Attainment Measure (GAM-S)

Instructions: This form is used to track your success with accomplishing the specific details of the Action Plan you made last week. In the space provided below for EACH QUESTION, write "Action Plan" details and check the best response that applies to each question about your specific action status.

What- action did you select to do? 	I completely did the action I selected (I did it).	2
	I partially did the action I selected (I did some of it).	1
	I did not do the action I selected (I did none of it).	0

How much- of the action did you plan to do? 	I completely did the action I planned to do.	2
	I partially did what I planned to do	1
	I did not do any of the action I planned to do.	0

When- did you plan to do the action? 	I completely did the action "when" I planned to do it.	2
	I partially did the action "when" I planned to do it.	1
	I did not do any of the action "when" I planned to do it.	0

How often- did you plan to complete the action? 	I completely did the action "How often" I planned to do it.	2
	I partially did the action "How often" I planned to do it.	1
	I did not do any of action "How often" I planned to do it.	0

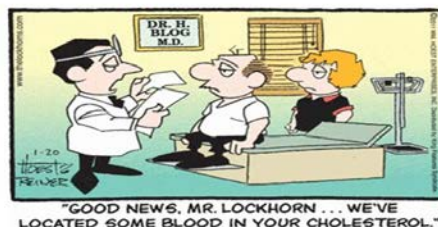
INCENTIVES FOR NURSES

- Opportunity to learn about clinical research.
- Opportunity to obtain clinical research CITI certificate Collaborative Institutional Training Initiative (<https://www.citiprogram.org/>)
- Upon signing the consent form, opportunity to receive certificate of appreciation for research project participation.
- Gift certificates will be offered for participation in the usability testing.
- Consultation and advice for future quality improvement projects will be offered to RNs willing to conduct their own research.

PRELIMINARY TIMELINE

- Obtain project IRB by mid January 2017
- Sign up RNs by January 20, 2017
- Start patients' recruitment - ongoing
- Start GAM-S data collection
- Start GAM-S usability testing

QUESTIONS



Appendix B:

Procedures summary handout provided for nurses during the “In-Service” presentations

MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

Study Procedures

Participant Identification, Screening and Enrollment

- Patient participants will be identified by providers caring for patients admitted to the MEDVAMC with stroke or TIA.
- Providers will be given the Study Recruitment Flyers to share with their patients during in-hospital care. Providers will contact the co-PI with the names of patients who express an interest in participating in the study.
- Patients who sign IC and meet inclusion criteria will be enrolled in the study.
- Nurse participants will be identified from the neurology stroke care unit (NU-2A) and primary care clinic at the MEDVAMC.

Reliability study of the GAM-S

- ☐ Total of 20 nurses will be involved to complete the Goal-setting/Goal Attainment protocol (described below) with N = 44 patients.
- ☐ Each inpatient nurse will be paired with an outpatient nurse as a dyad to provide a partnered approach in teaching the patient goal setting during inpatient care and for assessment of goal attainment during outpatient follow-up care.

- Once a patient is enrolled in the study, the patient will be assigned to a nurse dyad. Each nurse dyad will have up to 8 patients.
- The inpatient nurse will initially meet with the patient to provide education on goal setting using the action plan process.
- The inpatient nurse will work collaboratively with the patient during the hospital stay to establish a risk factor reduction goal.
- The inpatient nurse will document the patient's goal as part of a research note in CPRS.
- The inpatient nurse will send the research note to their respective outpatient partner for co-signature.
- When the outpatient RN signs the goal setting research note in the CPRS, they will schedule a follow-up call with the patient to assess the patient goal attainment, using the GAM-S tool, within up to two weeks of the patient's discharge.

Data collection:

Reliability testing: The "Action Plan" electronic template is currently available in the patient's CPRS record and will be used to collect data on goal settings (See "My Action Plan").

Data on goal attainment will be collected using the GAM-S paper form prototype.

Upon co-signing the CPRS research note, primary care nurse will arrange call with patient (within up to two weeks of discharge) to follow up on their action plan.

Detailed description of the GAM-S paper prototype data collection protocol:

Primary care nurse working on each team will receive notification via CPRS to co-sign the note for patients who completed action plan prior to being discharged home from the inpatient stroke unit. Within up to two weeks' time of patients discharge, primary care nurses will call the patients to follow up with them on their "Action Plan". The nurse will ask patients to recall in detail their previously developed "Action Plan" and whether they accomplished each step of the

plan (i.e., what action they took to reduce a specific stroke risk factor, how much of the action they completed, when they completed the action, and how often they completed the action). Each step of the “Action Plan” will be graded by the provider (what, when, how much, and how often) for attainment, using the GAM-S.

Appendix C: Action Plan Form

“ACTION PLAN” FORM

=====

MY ACTION PLAN

☐ WHAT DO I WANT TO DO?

☐ _____

☐ HOW MUCH WILL I DO?

☐ _____

☐ WHEN WILL I DO IT?

☐ _____

☐ HOW OFTEN WILL I DO IT?

☐ _____

ON A SCALE OF 1-10, HOW CONFIDENT AM I THAT I CAN ACCOMPLISH THIS
ACTION PLAN?

☐ 0__1__2__3__4__5__6__7__8__9__10

=====

Appendix D: Goal Attainment Measure for Stroke (GAM-S)

Instructions: This form is used to track your success with accomplishing specific details of Action Plan you made last week. In the space below for EACH QUESTION, write "Action Plan" details and check the best response that applies to each question about your specific action status.		
<u>What</u> - action did you select to do? 	I completely did the action I selected (I did it). I partially did the action I selected (I did some of it). I did not do the action I selected (I did none of it).	2 <input type="checkbox"/> 1 <input type="checkbox"/> 0 <input type="checkbox"/>
<u>How much</u> - of the action did you plan to do? 	I completely did the action I planned to do. I partially did the action I planned to do I did not do any of the action I planned to do.	2 <input type="checkbox"/> 1 <input type="checkbox"/> 0 <input type="checkbox"/>
<u>When</u> - did you plan to do the action? 	I completely did the action "when" I planned to do it. I partially did the action "when" I planned to do it. I did not do any of the action "when" I planned to do it.	2 <input type="checkbox"/> 1 <input type="checkbox"/> 0 <input type="checkbox"/>
<u>How often</u> - did you plan to complete the action? 	I completely did the action "How often" I planned to do it. I partially did the action "How often" I planned to do it. I did not do any of the action "How often" I planned to do it.	2 <input type="checkbox"/> 1 <input type="checkbox"/> 0 <input type="checkbox"/>

Overall Action Plan Adherence Score for each Action (to be completed by ...)				
What	How Much	When	How Often	Total Score

Confidence Level

Please select **Confidence Level** to achieve Action Plan and by circling the correct number below
(1 = no confidence at all and 10 = complete confidence)

1 2 3 4 5 6 7 8 9 10

Appendix E GAM-S Usability Questionnaire for Patients

GAM-S Patients' Questionnaire

Usability Questionnaire Instructions

Tell us what you think about the “GAM-S.”

This survey is designed to find out what patients think about this paper-based measure. We want to know what you like and what you think could be better.

You do not have to answer any questions that make you feel uncomfortable. Your participation is voluntary. It is **YOUR CHOICE** to answer the questions on this survey.

It is very important that you answer every question as truthfully as you can.

Please circle the answer in each row to describe how you feel about the GAM-S.

1. I think that the time it took to use GAM-S was:	Too Quick	Just right	Too Long
2. I felt comfortable using the GAM-S	Yes	No	Don't know
3. I knew and understood most of the words used in the GAM-S	Yes	No	Don't know
4. I needed help to answer questions in the GAM-S	Yes	No	
5. I think the questions in the GAM-S will help me to think carefully about my stroke risk factors and can be trusted	Yes	No	Don't know
6. The GAM-S prompted me to consider reliable ways to achieve the my goals	Yes	No	Don't know
7. I think the questions helped me talk to my doctor or nurse about my stroke risk factors	Yes	No	Don't know
8. I think the questions provided in the GAM-S will help me to think about how to overcome barriers to effectively manage my stroke risk factors	Yes	No	Don't know
9. I think the questions provided in the GAM-S will help me manage my stroke risk factors better in the future	Yes	No	Don't know
10. I would use the GAM-S as a part of my self-management program	Yes	No	Don't know
11. I would tell other patients to use the GAM-S	Yes	No	Don't know
12. I would use the GAM-S again in a clinic visit	Yes	No	Don't know

Open-ended questions:

How does the GAM-S compare to other measures you have used in the clinic?

How does the GAM-S compare to other goal-attainment programs that you've used in the clinic?

****When you have completed the questionnaire, please turn it in to the moderator as you leave the testing room.***

Appendix F GAM-S Usability Questionnaire for Providers

GAM-S Providers' Questionnaire

Usability Questionnaire Instructions

Tell us what you think about the “GAM-S.”

This survey is designed to find out what you think about this paper-based measure. We want to know what you like and what you think could be better.

You do not have to answer any questions that make you feel uncomfortable. Your participation is voluntary. It is YOUR CHOICE to answer the questions on this survey.

It is very important that you answer every question as truthfully as you can.

Please circle the answer in each row to describe how you feel about the GAM-S.

GAM-S Usability Questionnaire for Providers				
	Strongly Disagree	Disagree	Agree	Strongly Agree
1. Overall the measure was easy to use	1	2	3	4
2. The time to use the measure was reasonable	1	2	3	4
3. I felt comfortable using the measure	1	2	3	4
4. The questions provided by the measure were clearly stated and easy to follow	1	2	3	4
5. The measure was reliable to help me discuss patient goal-setting outcomes	1	2	3	4
6. The measure prompted me to consider other evidence-based interventions	1	2	3	4
7. The measure was effective in prompting me to discuss barriers to goal attainment	1	2	3	4
8. The measure did NOT use familiar terminology	1	2	3	4
9. The measure helped me to consider additional patient healthcare problems	1	2	3	4
10. The measure did NOT help me to discuss goal-attainment barriers	1	2	3	4
11. I would use the measure in clinical practice	1	2	3	4

In addition, one open-ended question: how would you improve the GAM-S?

****When you have completed the questionnaire, please turn it in to the moderator as you leave the testing room.***

Appendix G Study Brochure

Please make time to help improve quality of care for Veterans with Stroke!



Goal Attainment Measure for STROKE (GAM-S)

Stroke risk factors overlap with chronic diseases, such as hypertension, diabetes and lifestyle choices that compound cardiovascular risk, such as smoking, diet, and inactivity. Understanding Veterans opinions and setting and measuring goals to control stroke risk factors is an important part of the recovery after stroke and in the stroke risk factors management.

We would like to invite you to participate in study to obtain your perspective on life after stroke and to determine the best way to measure goal achievement (GAM-S usability). We would like to conduct semi-structured interviews to learn about your personal experience after stroke. The goal of the study is to improve programs for Veterans who survived stroke, improve their lifestyle and help with stroke risk factors control.

To be eligible for this program, you must:

- 1- Be 18 years or older
- 2- Have a history of stroke/TIA within the last 2 years or multiple stroke risk factors
- 3- Be able to read and speak English
- 4- Able and willing to give appropriate informed consent
- 5- Have access to a telephone
- 6- Willing to participate in interviews



For more information please call study coordinator:

Barbara Kimmel: 713 859 6477

Principal Investigator: Jane Anderson, PhD, RN, FNP-BC

Appendix H

IRB Study Approval Letters



Appendix I Consent Forms (Patients and Providers)

A Subject Name: Date:

VA RESEARCH CONSENT FORM

Subject Initials:

Principal Investigator: JANE ANDERSON VAMC:

H-39852 - MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN

CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

Patients Participation

Background

Self-management (SM) to control risk factors after stroke or mini-stroke also called transient ischemic attack (TIA) is an important part in the patient's post-stroke recovery. SM approach includes patient developing specific skills to improve their blood pressure, control diabetes, reduce stress and develop healthy eating and physical activity habits. Goal setting, action planning and evaluation of goals' completion play an important part of the stroke risk factors control. Shared goal setting with nurses helps with patient's motivation, taking medication regularly and self-sufficiency to prevent another stroke. In this study, we would like to learn about patients' experience after stroke when engaged in goal setting/goal completion process. We plan to oversee and measure patients' goal completion using the Goal Attainment Measure for Stroke (GAM-S). We will also evaluate whether the GAM-S measure is sufficiently dependable to be used in the SM programs. You are invited to take part in a research study, because you had a stroke or TIA and you receive care at a hospital that is participating in this project. Please read this information and feel free to ask any questions before you agree to take part in the study.

Purpose

The overall purpose of this research project is to learn about patient experience with goal setting/goal completion after surviving a stroke, to evaluate how patients use and rate GAM-S to assess goal completion and whether this measure is sufficiently dependable to use in the self-management prevention programs. We will learn more about patients' challenges, strategies and perceptions related to goal setting by using the action plan/goal completion process. We will also to evaluate how patients view GAM-S use and how do they rate the GAM-S measure to learn more about goal completion and dependability.

This research will provide valuable preliminary knowledge to guide larger studies that may use the GAM-S to learn more about goal completion for stroke risk factors control. If this proves to be a dependable goal completion measure, it may be expanded as a model for other risk reduction programs.

Procedures

The research will be conducted at the following location(s):

VA FORM

JAN 1990 **10-1086**

Last Amendment: 4/24/2017 **BCM Approval from January 30, 2018 to January 29, 2019**

Chair Initials: G. H. Page 1 of 6

Subject Name: Date:

VA RESEARCH CONSENT FORM

Subject Initials:

Principal Investigator: JANE ANDERSON VAMC:

H-39852 - MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN

CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

Baylor College of Medicine and Michael E. DeBakey Veterans Affairs Medical Center.

We are inviting 50 patients to participate in the study.

If you agree to take a part in this study, you will undergo the following procedures:

You will be enrolled in the study from the hospital where your stroke or mini -stroke (TIA) occurred. You will receive inpatient stroke education to prevent you from getting another stroke. Your inpatient nurse will teach you how to set goals and make plans to work on controlling your stroke risk factors. Your specific action plan will be documented in your medical records. Within two weeks after your hospital discharge, the research nurse working on the study will call you to schedule a follow-up call with you to learn more about your goal completion using the GAM-S measure. Completion of the GAM-S is expected to take no more than 10 minutes. To evaluate how patients use and rate the GAM-S to learn more about goal completion, we will ask you to participate in a one-time data collection to obtain answers to the survey questions evaluating GAM-S. Survey questions will be focused on how easy and understandable the GAM-S was and whether it has a motivational appeal and impact on completing goals. The study co-PI will call you to set up a convenient time to complete the survey with you by phone. Completion of the survey is expected to take no more than 10 minutes. To assess patients' specific post-stroke lived experience using goal setting/action planning and completion process, we will ask you to participate in one-time face to face semi-structured interview to learn about your experience after surviving a stroke. Interview questions will be specifically focused on how you work with your nurse to control your stroke risk factors using the goal setting/action plan process. The semi-structured interviews will be conducted individually and in person with you at the time convenient for you. To reduce the burden of coming to the hospital for the interview, if possible, we will coordinate your appointment around your regularly scheduled clinical visits at the MEDVAMC. We will use conference room in the MEDVAMC Neurology area to conduct the interviews. This room is easily accessible from either the neurology stroke clinic or any of the primary care clinics in the hospital. It is equipped with a comfortable table and chairs. Interviews will be digitally recorded, and should last no more than one hour. The conference room doors will be closed for your privacy. We will collect your demographic information

such as your name, data of birth, age, gender, race, marital and caregivers status prior to the interview. Interviews will be audio-taped and transcribed for analysis. To retain confidentiality only your assigned study number will be included on the tape transcripts and only assigned study personnel will have access to them. Audio recording will be transcribed by the “Lighthouse For The Blind Of Houston” transcription services. The audiotapes will be destroyed 6-years after the closure of the study.

VA FORM

JAN 1990 **10-1086**

Last Amendment: 4/24/2017 **BCM Approval from January 30, 2018 to January 29, 2019**

Chair Initials: G. H. Page 2 of 6

Subject Name: Date:

VA RESEARCH CONSENT FORM

Subject Initials:

Principal Investigator: JANE ANDERSON VAMC:

H-39852 - MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN

CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

You will not have to travel to the Michael E. DeBakey VAMC to participate in the study. Only participants enrolled in the semi-structure interviews will have to meet with the study personnel at the MEDVAMC. The personnel working on the study will call you to complete questionnaires over the phone. You will be assigned a study number that will be used in data collection. This will be done to protect your personal identifying information (for example, your name and address) and help prevent any break in confidentiality. The master list with your name/study code will be kept in a locked file cabinet in a locked research study office. The electronic master list will be password protected and saved in the study folder on the secured computer located at the Michael E. DeBakey VAMC. All data collection forms will be kept in the PI's locked office at the Michael E. DeBakey VAMC and will be secured in a locked file cabinet. Data will be stripped of any identifying information and statistical analysis will be completed at the Michael E. DeBakey VAMC.

Confidentiality

The health information that we may use or disclose (release) for this research includes:

- Information from health records such as diagnoses, progress notes, medications, lab or radiology findings, etc.

- Specific information concerning psychiatry notes

- Demographic information (name, D.O.B., age, gender, race, etc.)

- Partial Social Security # (Last four digits)

- Photographs, videotapes, and/or audiotapes of you

- Other: We will not collect from nurses last four digits of the SS number nor psychiatry notes .

Use or Disclosure Required by Law

Your health information will be used or disclosed when required by law.

Your health information may be shared with a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability and conducting public health surveillance, investigations or interventions. No publication or public presentation about the research described above will reveal your identity without another authorization from you.

Potential Risks and Discomforts

There is a possible risk of breach of confidentiality. We will keep all research records private to the extent

VA FORM

JAN 1990 10-1086

Last Amendment: 4/24/2017 BCM Approval from January 30, 2018 to January 29, 2019

Chair Initials: G. H. Page 3 of 6

Subject Name: Date:

VA RESEARCH CONSENT FORM

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H-39852 - MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN

CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

of the law. Only authorized research personnel will be allowed to view these records and all databases will remain located behind the Michael E. DeBakey VAMC fire walls. All data will be secured in a locked cabinet in a locked office. There is also a risk of discomfort because of discussion about your medical problems and life after stroke. There may be psychological risks associated with some of the research questions regarding quality of life after stroke. These can include depression symptoms, feelings of sadness, and anxiety. At any time you can refuse to answer any question that makes you uncomfortable. Your privacy will always be respected. If at any time you do not feel comfortable participating, you may withdraw from the study. Study staff will update you in a timely way on any new information that may affect your decision to stay in the study.

Questionnaires:

You may get tired when we are asking you questions or you are completing questionnaires .

Study staff will update you in a timely way on any new information that may affect your decision to stay in the study. There is a small risk for the loss of confidentiality. However, the study personnel will make every effort to minimize these risks.

Potential Benefits

The benefits of participating in this study may be: This study may help you to better control your stroke risk factors. There is potential benefit to society if this study is beneficial to individual participants. Specifically, your participation may help the investigators better understand patients individual experience after surviving stroke as well as how to better measure goal achievement after setting action plan to control risks factors. However, you may receive no benefit from participating. However, you may receive no benefit from participating.

Alternatives

You may choose to not participate in this study.

Subject Costs and Payments

You will not be asked to pay any costs related to this research.

You will not be paid for taking part in this study.

VA FORM

JAN 1990 **10-1086**

Last Amendment: 4/24/2017 **BCM Approval from January 30, 2018 to January 29, 2019**

Chair Initials: G. H. Page 4 of 6

Subject Name: Date:

VA RESEARCH CONSENT FORM**Subject Initials:**

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H-39852 - MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN

CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

Subject's Rights

Your signature on this consent form means that you have received the information about this study and that you agree to volunteer for this research study.

You will be given a copy of this signed form to keep. You are not giving up any of your rights by signing this form. Even after you have signed this form, you may change your mind at any time.

Please contact the study staff if you decide to stop taking part in this study.

If you choose not to take part in the research or if you decide to stop taking part later, your benefits and services will stay the same as before this study was discussed with you. You will not lose these benefits, services, or rights.

The investigator, JANE ANDERSON, and/or someone he/she appoints in his/her place will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury related to the research, you may speak with a member of the study staff: JANE ANDERSON at 713-440 4484

(daytime number)

Members of the Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals (IRB)

can also answer your questions and concerns about your rights as a research subject. The IRB office number is (713) 798-6970. Call the IRB office if you would like to speak to a person independent of the investigator and research staff for complaints about the research, if you cannot reach the research staff, or if you wish to talk to someone other than the research staff.

Under Federal Regulations, the VA Medical facility shall provide necessary medical treatment to you as a research subject injured as a result by participation in a research project approved by a VA Research and Development Committee and conducted under the supervision of one or more VA employees. This requirement does not apply to treatment for injuries that result from non-compliance by a research subject with study procedures. If you sustain an injury as a direct result of your study participation, medical care will be provided by the Michael E. DeBakey VA

Medical Center. The Department of Veterans Affairs does not normally provide any other form of compensation for injury. You do not waive any liability rights for personal injury by signing this form.

You may withdraw from this study at any time without penalty or loss of VA or other benefits to which you are entitled. Your participation will not affect the way you now pay for medical care at the VAMC. If you would like to verify the validity of the study and authorized contacts, you may speak with the Michael E. DeBakey Veterans Affairs Medical Center Research Office at 713-794-7918 or 713-794-7566.

VA FORM

JAN 1990 **10-1086**

Last Amendment: 4/24/2017 **BCM Approval from January 30, 2018 to January 29, 2019**

Chair Initials: G. H. Page 5 of 6

Subject Name: Date:

VA RESEARCH CONSENT FORM

Subject Initials:

Principal Investigator: JANE ANDERSON VAMC:

H-39852 - MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN

CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

Signing this consent form indicates that you have read this consent form (or have had it read to you), that

your questions have been answered to your satisfaction, and that you voluntarily agree to participate in

this research study. You will receive a copy of this signed consent form.

Subject Date

Witness

Investigator or Designee Obtaining Consent Date

Date

VA FORM

JAN 1990 **10-1086**

Last Amendment: 4/24/2017 **BCM Approval from January 30, 2018 to January 29, 2019**

Chair Initials: G. H. Page 6 of 6

Subject Name: Date:

VA RESEARCH CONSENT FORM

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Principal Investigator: JANE ANDERSON VAMC:

H-39852 - MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN

CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

Providers Participation

Background

Self-management (SM) to control risk factors after stroke or transient ischemic attack (TIA) is an important component in the patient's post-stroke recovery. Patients work with nurses to develop skills to improve their blood pressure, control diabetes, reduce stress and develop healthy eating and physical activity habits. Collaborative goal setting with nurses helps with patient's motivation, adherence, and self-sufficiency to prevent another stroke. In this study, we would like to learn about patients' experience after stroke using goal setting/action planning process. We plan to work with nurses to administer and measure patients' goal completion using the Goal Attainment Measure for Stroke (GAM-S). We also plan to evaluate whether the GAM-S measure is sufficiently dependable to be used in the SM programs. You are invited to take part in a research study. Please read this information and feel free to ask any questions before you agree to take part in the study.

Purpose

The overall purpose of this project is to determine nurses' perspective of the GAM-S usability and to conduct preliminary assessment and testing of the psychological measure of the GAM-S. The GAM-S is a paper tool to assess patient's goal attainment when used in the self-management intervention programs. The purpose of this study is to determine feasibility, consistency of the psychological measure and the accuracy of the measurement of the GAM-S. This research study will provide valuable preliminary knowledge to guide other studies as to how to further establish psychometric properties of the GAM-S and how to improve goal attainment measure in patients who successfully developed action plan to control their stroke risk factors.

Procedures

The research will be conducted at the following location(s):

Baylor College of Medicine and Michael E. DeBakey Veterans Affairs Medical Center.

We are inviting up to 20 nurses at the Michael E. DeBakey VAMC to participate in the evaluation of the psychometric properties GAM-S paper tool.

VA FORM

JAN 1990 10-1086

Last Amendment: 4/24/2017 **BCM Approval from January 30, 2018 to January 29, 2019**

Chair Initials: G. H. Page 1 of 5

Subject Name: Date:

VA RESEARCH CONSENT FORM

Subject Initials:

Principal Investigator: JANE ANDERSON VAMC:

H-39852 - MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN

CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

Each inpatient nurse will be paired with an outpatient nurse as a dyad (total of 10 dyads) to provide a partnered approach in teaching the patient goal setting during inpatient care and for assessment of goal attainment during outpatient follow-up care. Once a patient is enrolled in the study, the patient will be assigned to a nurse dyad. Each nurse dyad will have up to 8 patients. The inpatient nurse will initially meet with the patient to provide education on goal setting using the action plan process. The inpatient nurse will work collaboratively with the patient during the hospital stay to establish a risk factor reduction goal. The inpatient nurse will document the patient's goal as part of a research note in CPRS. The inpatient nurse will send the research note to their respective outpatient partner for co-signature. When the outpatient nurse signs the goal setting research note in the CPRS, outpatient nurse will schedule a follow-up call with the patient to assess the patient goal attainment, using the GAM-S tool, within up to two weeks of the patient's discharge. Completion of the GAM-S should not take more than 10 min. After completing the tool with patients, we will ask nurses to complete a short survey to establish GAM-S usability. You will be asked to answer 12 items usability questionnaire and open ended questions. This part of the study will take no more than 10 min. In addition, we will seek your participation to establish content validity of the tool. Content validity will allow us to determine how well the GAM-S measures the behavior for which it is intended. The length of the interview will be no longer than 30 minutes. To minimize any burden on you, we will complete interviews either in person or by telephone at a time that is convenient for you. Interviews may be audio taped and only first names will be included on the tape transcriptions to retain confidentiality

Confidentiality

The health information that we may use or disclose (release) for this research includes:

- Information from health records such as diagnoses, progress notes, medications, lab or radiology findings, etc.
- Specific information concerning psychiatry notes
- Demographic information (name, D.O.B., age, gender, race, etc.)
- Partial Social Security # (Last four digits)
- Photographs, videotapes, and/or audiotapes of you
- Other: We will not collect from nurses last four digits of the SS number nor psychiatry notes .

Use or Disclosure Required by Law

Your health information will be used or disclosed when required by law.

Your health information may be shared with a public health authority that is authorized by law to collect or

VA FORM

JAN 1990 **10-1086**

Last Amendment: 4/24/2017 **BCM Approval from January 30, 2018 to January 29, 2019**

Chair Initials: G. H. Page 2 of 5

Subject Name: Date:

VA RESEARCH CONSENT FORM

Subject Initials:

Principal Investigator: JANE ANDERSON VAMC:

H-39852 - MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN

CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF
THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

receive such information for the purpose of preventing or controlling disease, injury, or disability and conducting public health surveillance, investigations or interventions. No publication or public presentation about the research described above will reveal your identity without another authorization from you.

Potential Risks and Discomforts

There is the possible risk of inconvenience due to the interruption of your schedule. All efforts will be made to schedule interviews at your convenience and according to your timetable. Study staff will update you in a timely way on any new information that may affect your decision to stay in the study. There is a small risk for the loss of confidentiality. However, the study personnel will make every effort to minimize these risks.

Potential Benefits

You will receive no direct benefit from your participation in this study. However, your participation may help the investigators better understand This study may help you and your patients to better control their stroke risk factors. It may also help you to better understand how to measure goal attainment in the self-management risk factors control. However, you may receive no benefit from participating.

Alternatives

You may choose to not participate in this study.

Subject Costs and Payments

You will not be asked to pay any costs related to this research.

You will not be paid for taking part in this study.

Subject's Rights

Your signature on this consent form means that you have received the information about this study and that you agree to volunteer for this research study. You will be given a copy of this signed form to keep. You are not giving up any of your rights by signing

VA FORM

JAN 1990 10-1086

Last Amendment: 4/24/2017 BCM Approval from January 30, 2018 to January 29, 2019

Chair Initials: G. H. Page 3 of 5

Subject Name: Date:

VA RESEARCH CONSENT FORM

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CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF
THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

this form. Even after you have signed this form, you may change your mind at any time. Please contact the study staff if you decide to stop taking part in this study. If you choose not to take part in the research or if you decide to stop taking part later, your benefits and

services will stay the same as before this study was discussed with you. You will not lose these benefits, services, or rights. The investigator, JANE ANDERSON, and/or someone he/she appoints in his/her place will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury related to the research, you may speak with a member of the study staff: JANE ANDERSON at 713-4404484 during the day. Members of the Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals (IRB) can also answer your questions and concerns about your rights as a research subject. The IRB office number is (713) 798-6970. Call the IRB office if you would like to speak to a person independent of the investigator and research staff for complaints about the research , if you cannot reach the research staff, or if you wish to talk to someone other than the research staff. Under Federal Regulations, the VA Medical facility shall provide necessary medical treatment to you as a research subject injured as a result by participation in a research project approved by a VA Research and Development Committee and conducted under the supervision of one or more VA employees . This requirement does not apply to treatment for injuries that result from non-compliance by a research subject with study procedures. If you sustain an injury as a direct result of your study participation, medical care will be provided by the Michael E. DeBakey VA Medical Center. The Department of Veterans Affairs does not normally provide any other form of compensation for injury. You do not waive any liability rights for personal injury by signing this form.

You may withdraw from this study at any time without penalty or loss of VA or other benefits to which you are entitled. Your participation will not affect the way you now pay for medical care at the VAMC. If you would like to verify the validity of the study and authorized contacts, you may speak with the Michael E. DeBakey Veterans Affairs Medical Center Research Office at 713-794-7918 or 713-794-7566.

VA FORM

JAN 1990 10-1086

Last Amendment: 4/24/2017 **BCM Approval from January 30, 2018 to January 29, 2019**

Chair Initials: G. H. Page 4 of 5

Subject Name: Date:

VA RESEARCH CONSENT FORM

Subject Initials:

Principal Investigator: JANE ANDERSON VAMC:

H-39852 - MEASURING GOAL ATTAINMENT IN CHRONIC DISEASE SELF-MANAGEMENT WITHIN

CLINICAL AND RESEARCH CONTEXTS: DEVELOPMENT AND INITIAL TESTING OF THE GOAL

ATTAINMENT OUTCOME MEASURE FOR STROKE (GAM-S)

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

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Date

VA FORM

JAN 1990 **10-1086**

Last Amendment: 4/24/2017 **BCM Approval from January 30, 2018 to January 29, 2019**

Chair Initials: G. H. Page 5 of

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Appendix J Interview Discussion Guide

[RUNNING TIME 0:00]

INTRODUCTION (5 minutes)

Hello, my name is Barbara, and I'll be your interviewer today. My role as the interviewer is to direct the conversation to make sure that we cover the main topics.

Today...

Before we begin the discussion, I would like to go over a few basic rules of our conversation. If you haven't already done so, please turn off your cell phones.

This session is being audio taped which allows me to focus on you rather than trying to jot down notes during our chat. Please speak in a voice as loud as mine, so that the microphone can pick it up.

My team and I will prepare a report using the tapes. Our report will not make reference to any one of you by name, so I hope that you will speak openly and honestly.

I strongly encourage you all to share your opinions and, remember, there aren't any right or wrong answers, so feel free to give both positive and negative viewpoints.

The session will take about 45-60 minutes, and we will not be taking any breaks. I ask that you not get up to use the restroom until the session is over.

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