ADHERENCE WITH HOME EXERCISE PROGRAMS 1-6 MONTHS AFTER DISCHARGE FROM PHYSICAL THERAPY BY INDIVIDUALS POST-STROKE

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Submitted to the faculty of the University Graduate School
in partial fulfillment of the requirements
for the degree
Master of Science
in the School of Health & Rehabilitation Sciences,
Indiana University

August 2008

Accepted by the Faculty of Indiana University, in partial
fulfillment of the requirements for the degree of Master of Science.

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Acknowledgements

I would like to thank Indiana University and my faculty thesis committee, Joyce Mac Kinnon, PT, EdD, chair, Rebecca Porter, PhD, PT, and Lisa Riolo, PhD, PT, NCS. I am grateful for their support, patience, guidance and direction throughout this project.

I would like to thank the Stroke Support Groups in Central Indiana and their members for letting me visit and for their participation in this project. I wish to express my gratitude to all of the patients I have had the opportunity to work with in the clinic. Their persistence in the face of personal crisis and their hard won successes have been inspiring and instrumental in developing my vision of hope for recovery after stroke. Finally, I must express thanksgiving to God for His presence, grace and blessing in my efforts as a clinician and researcher.

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Chapter One: The Problem

Introduction

Physical therapists are integral to the rehabilitation of patients that have had a stroke, and home exercise program (HEP) prescription is a routine part of physical therapy care. The HEP is provided at the time of discharge from physical therapy to help the patient maintain functional gains and enhance continued functional progress. The HEP is a tool to help patients assume responsibility for long term management of their disability. Adherence to the HEP and reasons for non-adherence have not been well studied in the stroke population.

Cerebral vascular accident (CVA), or stroke, is a devastating and costly medical condition. Stroke is the third leading cause of death in the United States (US)[1,2] and a leading cause of long term disability.[3-11] Approximately 700,000 individuals have a stroke each year in the US:[2-4,12] 500,000 of them first time incidences.[2] The 2003 prevalence, mortality and hospitalization data, report that there are over 4 million people living in the United States after having had a stroke.[12]

Post-stroke survival rates have increased leaving many individuals who have had a stroke with long term physical and psychological impairments as well as functional limitations.[1,5,13] Patients who have had a stroke have been reported to be the largest single consumer group of rehabilitation services in the country.[6] Consequences of stroke are a major health concern[14] and are believed to be the leading cause of disability world wide.[7] Stroke leads to moderate disability in 40% of individuals who have had a stroke and severe disability in 15%-30%.[15] This frequency of disability has been reported even after the completion of rehabilitation.[15] Stroke has been estimated to cost the US $57.9 billion dollars per year with $3.7 billion being paid for Medicare beneficiaries with short hospital stays.[2] Seventy percent of the total costs are attributed to inpatient hospital costs in the first year after stroke onset.[2]

Background

Rehabilitation services for individuals who have had a stroke were based largely on expert opinion rather than evidence prior to the Balanced Budget Act of 1997.[16] When Congress passed the Balanced Budget Act of 1997 to control Medicare costs, reimbursement for rehabilitation services was limited due to variability between programs and high costs without adequate patient outcome evidence to justify the expenditures.[16] Rehabilitation services for patients after stroke continues to be highly variable between programs and is increasingly shorter in duration.[6] An individual's recovery is seldom complete at the time of discharge from rehabilitation.[6,8] Many patients and their caregivers do not have resources or opportunities for engaging in exercise activities after discharge from rehabilitation services.[8] Sedentary lifestyles due to disability and progressive deconditioning over time as well as normal aging and failure to maximize potential for cortical reorganization contribute to stopped recovery of function. In addition, some patients experience declining mobility skills after discharge from rehabilitation.[13]

Stroke rehabilitation should begin immediately after the medical diagnosis is established.[15] Post-stroke rehabilitation training traditionally focuses on basic mobility and activities of daily living (ADL) in the initial months after insult.[4,8] Preventing a second stroke, managing complications, mobilizing the patient, and encouraging resumption of self care are all integral parts of initial management after stroke.[15] Rehabilitation is focused on remediation of deficits and compensation for persistent deficits once patients are medically stable.[15] Patients typically are discharged home with home exercise programs (HEP) and family support but patients and families are often too overwhelmed to continue with the prescribed exercises at home.[4] Exercise program prescription in rehabilitation clinical practice is often inconsistent with conflicting and unsubstantiated treatment philosophies.[6] Duncan et al [15] have reported that stroke care has developed and changed over time. Post-stroke care is delivered in programs that range from providing individual therapies 1 hour per session 1-3 days per week to inpatient care 5 hours per day 7 days per week by multiple clinical disciplines.[15] Heiss and Teasel[17 (p. 314)] have stated, “Rehabilitation after stroke is undergoing a renaissance of sorts, with growing evidence of rehabilitation’s impact extending from cortical reorganization to its effect on health related quality of life.”

Statement of Problem

Limited reimbursement for therapy services combined with the disabling and chronic nature of impairments expressed after stroke place significant importance on individuals' discharge activities. Appropriate education and exercise prescription along with patient adherence to promote maintenance and/or improvement of functional status after discharge from rehabilitation are significant concerns. Compounding these concerns is the increasingly shorter duration of rehabilitation after stroke leaving patients and their caregivers with more responsibility for managing their disability long term.[6]

Patient adherence with physician recommended exercises has been shown to be low[11] even though recent studies with patients in the sub-acute (3-6 months post-stroke) and chronic (> 6 months post-stroke) stages post-stroke have demonstrated improvements with both impairments and functional skills through structured exercise programs.[6,8,18,19] Additionally, many patients experience poor health related quality of life (HRQL) and decreased life participation 6 months post stroke incident.[1,5,20,21] Factors related to physical functioning and affect have been identified as relating to both HRQL and life participation in the population of those who have had a stroke .[1,5,14,20]

Individuals who have had a stroke are at risk for a decline in functional status after discharge from acute rehabilitation at rates greater than healthy aging individuals.[13,22-24] Some risk factors that have emerged as contributors to such a decline include depression, fatigue, and physical inactivity.[13,24-26] These patients have also been shown to have poor HRQL and low life participation.[1,5,14,20,21,27] Patients in both the sub-acute and chronic stage post-stroke have shown benefits from exercise.[6,8,11,18,28,29,30] Home exercise programs that promote maintenance of gains from rehabilitation and further progression are an important part of discharge planning for rehabilitation professionals.

Home exercise program adherence is a significant issue for physical therapists to consider during patient education and discharge planning. Physical therapists may have the opportunity to influence patients' long-term management of their disability through HEP prescription, education, and follow up. Adherence with exercise recommendations has been shown to be low in other at-risk populations that have also demonstrated benefits from exercise.[25,31-34] These populations include the older adults,[25,31] patients with arthritis,[34-36] and patients with low back pain (LBP).[32-34] Reasons for non-adherence have emerged relative to self efficacy and outcome expectations. Self efficacy is the belief that one can perform the exercises while outcome expectation is the belief that exercises will help.[4] Self efficacy and outcome expectations have been tested with individuals in the chronic stage post-stroke and were found to fit the stroke population.[11] Motivational programs have shown some improvement in HEP adherence in patients with LBP.[32,33] Adherence with HEP prescription from physical therapists has not been specifically documented in the stroke population.

Importance of Study

The goal of stroke rehabilitation is to discharge patients as functional community-dwelling adults. Approximately two-thirds of the individuals that have had a stroke require rehabilitation and retain some persistent deficits.[3,8,12] Understanding and influencing exercise and physical activity level after discharge from physical therapy is an important consideration for discharge planning.

Individuals that have had a stroke are not typically involved in structured rehabilitation programming long term (greater than 1 year post-stroke) even though persistent deficits continue. It is important that patients continue with exercise activity on their own after discharge from physical therapy.[4,6,11,18,19] Home exercise program prescription is part of discharge planning in physical therapy and has the potential to influence post rehabilitation activity levels. To be effective, however, physical therapists need to understand factors that influence HEP adherence and structure their HEP prescription, education, and follow up care to promote adherence.

Purpose of Study

The primary purpose of this study was to determine if individuals that have had a stroke have been adherent with physical therapy HEP after discharge from rehabilitation services. Inherent in determining HEP adherence was confirming that individuals who have had a stroke were provided a HEP at the time of discharge from rehabilitation services. Important secondary aims were to determine reasons for non-adherence and to assess relationships between HEP adherence and reported loss of function since discharge from rehabilitation.

Statement of Hypotheses

The hypotheses for this study can be stated as null hypothesis as follows:

1. Home exercise program adherence rates will be greater than or equal to 80% in patients in the chronic stage post-stroke.
2. Patients in the chronic stage post-stroke will not identify the listed barriers to exercise adherence that have also been identified by other populations including healthy older adults and patients with LBP or arthritis.
    a. Not enough time
    b. Do not know what exercises to do
    c. No one to exercise with me
    d. No place to exercise
    e. Exercise is too hard
    f. Exercises are not helpful to me
    g. Exercise causes pain
    h. Exercise is boring
    i. Afraid of falling while exercising
    j. Concerned about getting hurt while exercising
    k. I do exercises, but not the ones the physical therapist gave me

3. There is no association between PT HEP non-adherence and reported loss of function in individuals in the chronic stage post-stroke.
4. There is no association between PT HEP non-adherence and reported difficulty with depression in individuals in the chronic stage post-stroke.
5. There is no association between PT HEP non-adherence and reported difficulty with fatigue in individuals in the chronic stage post-stroke.
6. There is no association between PT HEP non-adherence and reported physical inactivity in individuals in the chronic stage post-stroke.

Rationale and Theoretical Framework

The theoretical framework behind this study is two dimensional. The first theoretical framework is based on the importance of exercise post-stroke and the second is based on evidence of low adherence to exercise recommendations. The importance of exercise post-stroke is established by evidence on neuroplasticity post-stroke, evidence on the potential influence that repetitive motor practice can have on recovery, and evidence on the role physical inactivity can play in declining functional status, HRQL and life participation. The second rationale is based on evidence of low adherence to exercise recommendations and contributing factors to low adherence to exercise recommendations after discharge from rehabilitation.

The current paradigm of rehabilitation post stroke attributes most motor and functional recovery to the first 3 months after stroke, even though there is growing evidence that suggests that therapeutic exercise can facilitate benefits to motor control, strength, upper extremity (UE) use, mobility, balance, and aerobic capacity in patients in the chronic stage post-stroke.[6] The brain is capable of reorganization post-stroke.[7,9,17,36-39] The brain is ready in the acute phase after stroke for reorganization that supports early rehabilitation, but there is increasing evidence that patients who continue in an active stimulating environment after acute rehabilitation has finished can continue to demonstrate cortical and functional changes into the sub acute and chronic stages.[7,17] Ward[38 (p.725)] has stated,

> It appears that the motor system reacts to damage in a way that attempts to generate motor output through surviving brain regions and networks. There are changes in cortical excitability after stroke that may provide the substrate whereby the effects of motor practice or experience can be more effective in driving long lasting changes in motor networks. This will be particularly important in intact portions of neural networks subserving motor skills learning.

Physical inactivity can lead to disability through deconditioning and learned non-use. Animal studies as well as emerging clinical evidence suggest that task repetitive training can induce adaptive neuroplasticity.[8] Patients that have had a stroke and made good recovery continue to have significant residual disability in hand function, activities of daily living, and physical functioning persisting beyond 6 months post-stroke.[40] Physical conditioning exercises by patients who are in the chronic stage post-stroke have demonstrated improvements with strength, ambulation, mobility, and function.[28] Yet even with the documented benefits from exercise and potential for latent neuroplasticity, some individuals in the chronic stage post-stroke continue to experience a decline in status.[13,22-24] Maintaining an active stimulating environment during the sub-acute and chronic phases post-stroke is challenging in the current paradigm of stroke rehabilitation with limited funding for rehabilitation services especially in the sub-acute and chronic phases of stroke.[17]

Long-term management of disability within the current paradigm of stroke care is dependent on patient adherence with HEP prescription. Poor adherence with exercise recommendations has been noted in the healthy older adult population[25,31] as well as other chronic rehabilitation populations including individuals with arthritis[32,33,35] and LBP.[32-34] One of the models for exercise behavior is self efficacy, which has been shown to impact adherence with physician prescribed exercises in the stroke population.[11] Barriers such as fatigue, depression, self efficacy, and outcome expectation have been shown to be significant contributing factors to non-adherence.[11] Self efficacy and outcome expectations have been assessed with individuals that have had a stroke using the Short Self-Efficacy for Exercise Scale (SSEE) and Short Outcome Expectation for Exercise (SOEE). The SSEE is a patient centered instrument that respondents indicate the degree to which pain, fatigue, depression, and exercising alone impact their belief about their exercise capability.[11] The SOEE is also a patient centered tool that is used to measure respondents belief about potential benefits of exercise regarding enjoyment of activity, improved well-being, mood, alertness, and endurance.[11] Self efficacy and outcome expectation accounted for 33% of the variance in exercise adherence in a sample of individuals in the chronic stage post-stroke.[11] Physical therapists prescribe exercises to patients and educate patients and caregivers on HEP as part of discharge planning. Adherence with exercises prescribed by physical therapists has been shown to be low in populations other than the stroke population.[32,33,34,35] Exercise adherence within the stroke population has been shown to be low with exercises recommended by a physician.[4,11] Adherence with exercise recommendations from a physical therapist within the stroke population has not been documented.

Chapter Two: Review of Related Literature

Overview

The purpose of the study was to gather data from individuals who have had a stroke and have been discharged from physical therapy for 1-6 months. The data gathered reported adherence with rehabilitation HEP recommendations as well as reasons for non-adherence when applicable. Perceived functional changes since discharge from rehabilitation were also collected. Patients who have had a stroke represent a large rehabilitation population. Stroke leads to significant long-term disability. Patients in the chronic stage post-stroke continue to experience significant functional impairments. Loss of function after discharge from rehabilitation has been reported. Appropriate physical activity, however, may be able to prevent loss of function and promote improved function. The current paradigm of clinical care provides limited resources for therapy interventions particularly in the chronic phase of stroke. Therefore, appropriate HEP prescription, good patient and caregiver education, and meaningful follow up to promote HEP adherence after discharge from rehabilitation are all important concepts for discharge planning. Discharge planning that can modify post-rehabilitation behavior for improved HEP adherence and function is desired. The data collected in this study allowed for adherence rate calculations which address the primary purpose of the study. The data also allowed for comparison of reasons for non-adherence with other populations and correlations between non-adherence and other reported information including physical inactivity, depression, fatigue, and mobility decline.

Historical Background

Historically, stroke rehabilitation has been focused in the first 3 months following CVA due to the known complex pattern of brain reorganization occurring during that time.[23] Functional change in the chronic stage post-stroke is not a new revelation, but a relationship between motor area brain activity and outcome in the chronic stage post-stroke is a recent realization.[7] This relationship is of significant interest relative to the possibility of targeted physical therapy having an impact on activity driven cerebral reorganization.[7] Neuroscientists believed as recently as 10 years ago that functional and structural plasticity in the mature brain was not likely, but the discovery of nerve growth factor has led to further investigation which points to neural plasticity in the mature brain due to physical activity.[37] Even though spontaneous recovery after stroke is most active in the affected brain 3 months after stroke, recent evidence suggests that functionally meaningful and measurable recovery can be achieved years after insult with task relevant repetitive training.[41] Central nervous system (CNS) reorganization is now considered to be responsible for much of the functional recovery seen after stroke.[38] Complete understanding, however, of the cerebral network response to focal damage and relationship to recovery is not yet realized.[38] Potential for ongoing plastic changes with repetitive physical activity after stroke is important to physical therapists.

These data make adherence with HEP prescription after discharge from physical therapy not only a fitness issue but also one of ongoing recovery.

Acute stroke rehabilitation ideally occurs in an intense specialized program. These rehabilitation programs have been shown to be effective at facilitating recovery of motor function and physical performance.[18] Inactivity after completion of rehabilitation however, has been shown to contribute to loss of gains made once rehabilitation is ended.[18] A significant decline in physical performance has been reported during the 1 to 5 year post-stroke period with the greatest decline noted in the areas of volitional movement, balance, ambulation, and ADL.[18] Physical inactivity after stroke may contribute to cardiovascular decline, metabolic deconditioning, muscle weakness, gait impairments, and related declines in social and physical functioning.[3]

Many community dwelling elders who have had a stroke experience marked decrease in their physical fitness between the acute phase in the hospital and the maintenance stage after discharge from therapy.[42] Individuals that have had a stroke also experience age related decreases in function at a quicker rate than non-stroke elderly.[23] Exercise capacity has been demonstrated to be compromised 30% one month post stroke compared to healthy individuals that have had a stroke.[12] People who have had a stroke are more likely to be sedentary leading to deconditioning and a higher risk of second stroke and stroke mortality.[12] Cardiovascular fitness in the chronic phase post-stroke is a significant issue with 75% of patients exhibiting some form of cardiovascular disease.[29]

Rehabilitation programming is provided as long improvements are observed but long-term rehabilitation programming is needed to sustain the functional status achieved with rehabilitation.[14] Langhammer and Stanghelle[23] have reported that regular physical training is needed to keep strength, endurance, and postural control gained with acute rehabilitation during the sub-acute and chronic phases. Kernan et al[22] have reported that the current strategy for maintenance of physical function after completion of rehabilitation is education on behavior changes to help decrease risk of a second stroke event even though physical decline has been identified in the absence of an additional neurological event. Individuals that have had a stroke and are finished with post-stroke rehabilitation need more active home based programming after discharge to improve their physical fitness.[42]

Ongoing participation in exercise programs have been shown to be influenced by self efficacy and outcome expectations in both the stroke and healthy older adult populations.[4,11,43] Both have been shown to be strong discouragers or motivators to exercise in chronic stage post-stroke.[11] "The theory of self efficacy states that self efficacy expectations and outcome expectations are not only influenced by behavior, but also by verbal encouragement, physiological sensations and exposure to role models or self modeling."[43 (p.648)] Interventions that have been tried to improve self efficacy include: interventions to improve an individual's believe about the benefits of exercise, interventions to modify the exercise environment, and interventions that provide feedback about the performance of the exercise.[43] This theory has been extensively tested in the healthy older adult population and some in the arthritis and joint replacement populations as well as the stroke population.[43] Shaughnessy and Resnick[11] have found a relationship between self efficacy and outcome expectations for exercise, demographic variables, exercise history, and physician influences on physical activity post-stroke. The goal of exercise interventions for patients after stroke is to improve functional status and HRQL.[27] Health benefits and improvements with ADL activities have been associated with structured exercise programs in people post-stroke.[4] Exercise programs, however, must be appropriately prescribed and adhered to for individuals that have had a stroke to benefit from PT HEP after discharge from rehabilitation services.

Many individuals post-stroke have been shown to be sedentary which when combined with normal aging predisposes people to increasing functional deficits and declining activity tolerance.[4] Decreased mobility after stroke is a significant concern. Loss of ambulatory skills typically leads to increasing dependence with ADL.[24] Mobility status is directly linked to level of independence achieved in the community after stroke.[24] Sources vary in reports of mobility status decline in the chronic stage of stroke after completion of rehabilitation ranging from 12%-43% of the individuals losing mobility skills by 1 year after discharge from rehabilitation.[13] Patients who are physically inactive,[24] depressed,[24,26] cognitively impaired,[24] and suffer from fatigue are more likely to experience a physical decline in the chronic stage post stroke.[24,26] Page et al[10] have reported that motor rehabilitation techniques are heterogeneous in delivery without randomized clinical trials to support efficacy. In the meantime, patients in the chronic stage post-stroke continue to have diminished quality of life. Substantial numbers of patients who have had a stroke have poor HRQL.[1,21] Physical functioning, cognitive functioning, depression, and incontinence are all important factors that have contributed to HRQL.[1] Decreased motor performance has been correlated with declining life satisfaction 4-6 years post-stroke.[18]

Review of Similar Related Studies

Literature used as a foundation for this study includes research related to long-term disability impact of stroke, neuroplasticity post-stroke, HRQL and changing functional status post-stroke, exercise and physical fitness post-stroke, and exercise adherence. Knowledge and understanding of neuroplasticity post stroke has increased significantly placing greater importance on long-term physical activity after stroke. The chronic nature of stroke relative to HRQL and functional status changes long-term post rehabilitation warrants specific attention from rehabilitation professionals. Exercise and physical fitness and how they relate to function in the chronic stage post-stroke are important factors that can influence maintenance of gains made during rehabilitation. Benefit, however, from exercises after rehabilitation can be realized only if patients are adherent with the HEP.

Disability Impact Post Stroke

Pang et al[19] have reported stroke as one of the most common chronic conditions in older adults with incidence doubling each decade after the age of 55. Patients that have had a stroke live with residual physical impairments leading to sedentary lifestyles and low cardio respiratory fitness.[19,29] Motor deficits and physical disability in later life are attributed, to a great extent, to stroke.[10,18] Restoration of normal upper extremity (UE) motor function is achieved in less than 15% of those affected by stroke.[30,37] Pang et al[30] have reported that 25%-53% of those who survive stroke remain dependent with at least one activity of daily living (ADL), and Thom et al[2] have reported 26% are dependent with ADL 6 months after stroke onset. By 6 months post stroke, only 33% of patients recovering from a stroke are independent with community mobility.[44] Patients in the sub-acute and chronic stages post stroke walk an average of 40%-50% less distance as age-matched healthy individuals during the 6 minute walk test (6MWT)[45] and 30% require an assistive device or physical assistance to walk 6 months after stroke.[2] Hemiparesis is the most common persistent impairment post-stroke contributing to physical disability and sedentary lifestyle.[2,4] Sedentary lifestyles after stroke are linked to progressive decline in function and cardiovascular fitness.[11] Fatigue,[26] depression,[2] and learned paralysis[46] have all been reported to contribute to persistent and at times worsening disability in patients in the chronic stage post-stroke.

Neuroplasticity

Initial injury from stroke is typically due to disruption in the efferent pyramidal fibers of the internal capsule with edema contributing to paralysis, but the paralysis continues after the edema resolves due in part to learned paralysis.[46] Patterns of non-use have been reported to negatively affect brain activation and recovery.[3] Data have shown that patients greater than 1 year post-stroke can exhibit substantial motor improvement with task specific motor practice.[10,30,47,48] Furthermore, task-specific practice has been shown to induce lasting cortical reorganization that appears to proceed motor improvement.[10,47] Bilateral movements by patients who have had a stroke have been shown to be able to facilitate cortical neuroplasticity by three mechanisms:

> Motor cortex disinhibition that allows increased use of the spared pathways of the damaged hemisphere; Increased recruitment of the ipsilateral pathways from the contralesional or contralateral hemisphere to supplement the damaged crossed corticospinal pathways; and Up regulation of descending premotorneuron commands onto propriospinal neurons.[37 (p.309)]

Impairment-oriented training, such as the Arm BASIS program, has led to higher motor recovery and a medial motor map shift with better conduction times.[49] Ward et al[50] have indicated that increased attention to a motor task by patients in the chronic stage post-stroke might facilitate better performance by enhancing detection of a discrepancy between predicted and actual consequences. Formisano et al[51] have reported that patients with prolonged periods of flaccidity have greater potential of progress in the chronic phase of stroke.

Electromyography (EMG) and functional magnetic resonance imaging (fMRI) have been used to assess neuromuscular and cortical activation during motor activity. Butefisch et al[36] have noted bilateral cortical activation in patients who have had a stroke with hemiparetic finger tapping while non-stroke participants demonstrated only contralateral cortical activation. This motor cortex activation ipsilateral to the hemiparesis is believed to be an adaptive central nervous system (CNS) response.[36] A relationship between task-related activation of motor cortical areas and outcome have been noted.[39] In patients in the chronic stage post-stroke with focal lesions, outflow of corticospinal fibers from primary motor cortex can be re-organized for functional control through the dorsal premotor cortex.[9] Changes in neurotransmitters, transcollosal inhibition, and dendritic sprouting all contribute to reorganization post stroke.[17] It has not been shown that the secondary motor areas can completely substitute for the actions of the primary motor cortex (MI), but it has been shown that the secondary motor areas can play a greater role with significant damage to the primary motor cortex.[9]

Neural reorganization after stroke has been shown to be influenced by motor practice, somatosensory input, and pharmacological agents.[39] Evidence suggests that motor cortex function changes occur as a result of both injury-related reorganization and motor experiences.[37] Topology changes have occured in the motor cortex with time and could be a key factor in motor cortex reorganization.[49] Motor recovery can be predicted by a medial shift in the motor cortex map of the affected hemisphere.[49] Intensive task specific training has been reported to induce plasticity as well as better functional outcomes in patients in the chronic stage post-stroke.[47] Movement repetition without skill learning can induce neural network changes[52] and plastic changes have been seen in the mature brain during both learning and recovery.[53] Platz et al[49 (p.1363)] have stated,

> Motor recovery after stroke is accompanied by functional reorganization, i.e. a changed pattern of cerebral activity when the recovered limb is moved. Changes in functional cortical organization can but do not necessarily imply adaptive reorganization, i.e. functional changes in the brain with a specific role for functional recovery.

The amount of perfusion in representative areas of the brain has been linked to cortical and functional changes post-stroke.[41,51] Some areas have demonstrated increased perfusion after task-specific hand activity in patients in the chronic stage post-stroke including the precentral gyrus, premotor cortex (Brodman’s Area 6 [BA6]), frontal cortex, and superior frontal gyrus (BA10) in the affected hemisphere and the superior frontal gyrus (BA6), and cingulated gyrus (BA31) in the non-affected hemisphere and the cerebellum bilaterally.[41] Formisano et al[51] have reported that the degree of motor recovery in patients in the chronic stage post-stroke correlates positively with preserved perfusion of basal ganglia, thalamus, and premotor cortex of the undamaged hemisphere. Ramachandran[46 (p.368)] has reported two reasons for a paradigm shift in neurorehabilitation as follows,

> First, there appears to be tremendous latent plasticity even in the adult brain. Second, the brain should be thought of, not as a hierarchy of organized autonomous modules, each which delivers its output to the next level, but as a set of complex interacting networks that are in a state of dynamic equilibrium with the brain's environment.

HRQL & Status Change

Some patients experience poor HRQL in the chronic stage post-stroke. D'Alisa et al[14] administered the London Handicap Scale (LHS) to 73 patients post-stroke and found that physical disability and mood disorders may both independently contribute to limited participation after stroke. Paul et al[21] assessed HRQL using the Assessment of Quality of Life Instrument on 948 patients 5 years post-stroke. Their results were 20% of the subjects demonstrated very low HRQL scores.[21] These researchers have concluded that physical disability must be improved to affect HRQL.[21] Haacke et al[1] found patients 4 years post-stroke have poor HRQL. The poor HRQL was related to physical functioning, cognitive impairment, depression, and incontinence using the EuroQol Index (EQ-5D) and Health Utility Index 2 & 3 (HUI2/3) as preference-based measures and the Barthel index (BI) and modified Rankin scale (mRS) as disability outcome measures.[1] Desrosiers et al[5] compared 46 patients 2-4 years post-stroke to 46 healthy age matched controls using the Assessment of Life Habits (LIFE-H) to determine differences in life participation. The stroke group had greater restriction in ADLs than in social roles compared to the healthy controls.[5]

In addition to poor HRQL, some patients who have had a stroke experience a decline in functional status after discharge from rehabilitation. Kernan et al[22] administered the Physical Performance Test (PPT) at baseline and annually for 5 years in a study of 664 postmenopausal women after stroke or TIA. Sustained improvement or decline was defined by greater than a 3-point change over 2 consecutive years.[22] Thirty-five percent of participants demonstrated a decline in the 5 year period and 15% demonstrated a sustained decline.[22] van de Port et al[24] used the Rivermead Mobility Index (RMI) to demonstrate that 21% of 205 patients having had a first time stroke 1-3 years previous to testing demonstrated a decline in status since the completion of rehabilitation. Inactivity, cognitive impairment, fatigue, and depression were all significant prognostic indicators of mobility decline.[24] Van Wijk et al[13] found that 12% of 148 patients with first time stroke 1 year post-stroke incident demonstrated significant mobility decline as depicted on the RMI. Depression was identified as a significant predictor of the decline.[13] Langhammer and Stanghelle[23] assessed patients with first time stroke at 1 and 4 years post-stroke with the Motor Assessment Scale (MAS), Sodring Motor Evaluation (SMES), Bartel Index (BI), Nottingham Health Profile (NHP), and Berg balance assessment (BBA). A decline was demonstrated between 1 and 4 years post-stroke at a greater rate than would be expected in a healthy aging population.[23] By 4 years post-stroke 40% of the patients were still living in their own homes compared to 60% at 1 year post-stroke.[23]

Exercise & Physical Fitness

Exercise interventions for the sub acute and chronic stages post-stroke after completion of rehabilitation programming have been linked to improved function and reduced impairments. Several studies have considered the sub-acute (3-6 months post-stroke) stage. Duncan et al[6] demonstrated gains exceeding the control group by the intervention group in a randomized controlled single blind clinical trial with 92 participants. The intervention consisted of 36 structured progressive physiologically based therapist supervised home exercises lasting 90 minutes in 12 weeks targeting flexibility, strength, balance, endurance, peak aerobic capacity and mobility in patients 1-4 months post-stroke.[6] Leroux[18] showed significant improvement with BBA, step test, and timed up and go in participants in an 8-week community-based exercise program for patients at least 6 months post-stroke. The exercise program was performed 2 times per week and was designed to address balance, mobility, coordination, walking endurance, and strength.[18] Age and time since stroke were weakly related to improvement.[18] Olney et al[28] divided 72 participants who had a stroke into 2 groups and assessed them with the 6MWT, Human Activity Profile, Medical Outcomes Study Short Form 36 (MOS SF-36), Physiology Cost Index, and lower extremity manual muscle testing. One group participated in a 1-week supervised exercise program followed by 9 weeks of in home exercise and the other participated in 10 weeks of supervised exercise.[28] Subjects in both groups demonstrated physical benefits and self-reported gains that were retained after 1 year, but the supervised group demonstrated greater self-reported gains.[28] Platz et al[49] randomized 28 sub-acute patients that had stroke with severe arm paresis, reduced motor cortex excitability, reduced conduction velocity in the corticospinal system, and symmetrical motor cortex topology into 3 groups: no additional training, Bobath approach, and arm BASIS training. The subjects in the arm BASIS training group demonstrated better improvement than the Bobath group which was better than subjects that did not receive training.[49]

Patient response to exercise in the chronic stage post-stroke has also been considered. Macko et al[8] used an exercise program consisting of 6 months of treadmill aerobic training performed 3 times per week as the intervention and stretching plus low intensity walking as the control group in 61 patients in the chronic stage post-stroke. Participants randomly assigned to the intervention group demonstrated significantly greater improvement in both functional mobility and cardiovascular endurance than subjects assigned to the control group.[8] Within the intervention group greater velocity intensity was correlated to greater VO_2 max while longer session length led to greater improvement with 6MWT performance.[8] In another study, Studenski et al[27] randomized 80 patients at least 1 year-post stroke to either an intervention group participating in a 12-week exercise program or a control group receiving usual care. Participants were assessed with multiple tools including the BI, functional independent measure (FIM), instrumental activities of daily living (IADL), MOS-SF36, and the Stroke Impact Scale

(SIS).[27] The intervention group demonstrated quicker improvements, but the authors concluded that continued adherence to the exercise program after completion of the 12-week program may be needed to continue benefit.[27] Michaelsen et al[47] had patients with arm impairment participate in a therapist-supervised home exercise program 3 times per week for 5 weeks. The 30 participants, all in the chronic stage post-stroke, were randomized into 2 groups, with and without trunk restraint while exercising.[47] Both groups demonstrated improvement in function, but the group with trunk restraint demonstrated increased isolated elbow extension and the group without trunk restraint demonstrated improved function with compensatory strategies.[47] Pang et al[19] divided a group of 63 patients in the chronic stage of stroke into 2 groups. The intervention group participated in a fitness and mobility exercise program (FAME), an exercise program designed to improve cardiorespiratory fitness, mobility, leg muscle strength, balance, and hip bone mineral density.[19] The intervention group performed the exercises 3 times per week for 19 weeks.[19] The control group performed seated upper extremity exercises.[19] Participants were assessed using maximal O_2 consumption, 6MWT, BBA, Physical Activity Scale for Individuals with Physical Disabilities, and femoral neck bone mineral density.[19] Significantly greater improvement was demonstrated by the intervention group in cardiorespiratory fitness, mobility, and paretic leg strength.[19] In another study, Pang et al,[30] used 1-hour sessions of either arm or leg exercises with patients in the chronic stage post-stroke. The authors concluded that UE function can be improved with a community-based exercise program and that there is increasing evidence that both motor and functional changes can occur in the affected UE for years post-stroke with forced use.[30] Exercise therapy is effective for patients in the chronic stage post-stroke[54] and gains from exercise can continue after discharge from rehabilitation.[6]

Physical fitness is important for functional skills and mobility.[55] Patients after stroke have been shown to demonstrate impaired strength and cardiorespiratory fitness.[55] Ambulatory activity and cardiovascular fitness have been found to be low in patients during the chronic stage post-stroke when compared to healthy community dwelling elderly.[3,12] Cardiorespiratory fitness is difficult to assess after stroke due to poor correlation between VO_2 max and 6MWT.[12] This difficulty is believed to be due to impairments affecting gait.[12] Impairments related to gait make cycle ergometry a better option for cardiorespiratory fitness after stroke[12] Body weight supported treadmill training maybe an option in the clinic for gait as a cardiovascular endurance activity but it is not feasible as a home exercise program.[12] Correlations between improved physical fitness and decreased disability in the chronic stage post stroke are inconsistent but improved ambulation measures are reported as a benefit of physical fitness training.[55] Patients participating in rehabilitation and discharged as independent ambulators with a HEP have demonstrated lower anaerobic threshold (AT) than non-impaired controls.[42]

Exercise Adherence

Exercise adherence has been studied minimally in patients with stroke but it has been studied to a greater extent in other populations. It has been shown that older adults are resistant to participating in regular exercise activity.[43] Resnick[56] estimates that 80% of the older adult population has become sedentary. Factors identified as barriers to exercise within the older adult population include lack of knowledge about the benefits of exercise, impaired health, fear of injury, unpleasant sensations associated with exercise, and personality.[56,57] Resnick and Spellbring[58] have also noted correlations between adherence with an exercise program and physical function, FIM score, self efficacy expectations, and reported number of falls in older adults. Resnick[59] reported that healthcare providers should develop strategies to improve self efficacy and outcome expectations relative to exercise to improve exercise adherence in older adults. Self efficacy expectations and outcome expectations have both been reported to directly impact exercise participation in older adults and health status was found to indirectly impact exercise participation due to its direct correlation to self efficacy expectations and outcome expectation.[31] Resnick and Nigg[31] reported that strengthening self efficacy expectations and outcome expectation may be particularly important for individuals with poor perceived physical health. Both the self efficacy expectation scale (SEE)[57] and the outcome expectation scale (OEE)[60] have been validated in the older adult population. McAuley et al[61] have reported links between physical activity and HRQL as well as self efficacy and HRQL. Physical activity has been shown to have long-term impact on well being in the older adult population.[62] McAuley et al[63] has also reported the need for targeting self efficacy in the older adult population before ending a structured exercise program to help improve long-term maintenance of physical activity. In a review by Conn et al,[25] the authors reported that older adults increased their physical activity during experimental interventions but did not increase their activity enough to improve health status. Evidence does not support long-term maintenance of activity.[25]

Patients with both osteoarthritis (OA) and rheumatoid arthritis (RA) have reported significant issues with pain, stiffness, and poor health.[35] There are documented benefits of exercise for patients with both diagnoses but adherence has been shown to be low and motivating these patients to exercise has been shown to be difficult.[35] Barriers to exercise identified by this population include not enough time, pain, boredom, fatigue, fear of falling, fear of getting hurt, too old to exercise, too fat to exercise, no place to exercise, don't see any reason to exercise.[35] Other authors have reported that adherence rates with HEP by patients with arthritis are 40%-50%.[34]

Patients with LBP have also been reported to have poor adherence with HEP.[32,34] Use of technology for patient instruction instead of traditional written instruction has been assessed to determine if technology applications influence compliance in this population.[34] Lysack et al[34] did not find a statistically significantly difference in adherence between HEP with traditional written instructions and HEP with video exercise instruction. Friedrich et al,[32] found improved short term adherence with the LBP population with a motivational program in addition to exercise instruction, but not improved long term adherence. The motivational program consisted of 5 interventions summarized as follows:

> Extensive counseling and education designed to emphasize the importance of exercise and dependence on compliance for success; Positive reinforcement techniques to reward compliant behavior; Written contract to reinforce oral agreement made by patients to comply with HEP; Asking patients to post the written contract in a visible place at home; and directing patients to maintain and turn in an exercise diary.[32 (p.477)]

It has been estimated that between one-third to two-thirds of patients with LBP are non-adherent with exercises prescribed by physical therapists.[32] Data have also shown that exercise adherence decreases quickly after completion of structured rehabilitation.[34] Friedrich et al[33] reported decreased disability, decreased pain intensity, and improved working ability at 5-year follow up in patients with LBP given a HEP and a motivational program before discharge from rehabilitation.

Poor HEP adherence has also been shown in a general physical therapy population.[64] Sluijis[64] has reported a significant difference between short-term supervised adherence and self regulation long term adherence. Three main factors were shown to relate to adherence with PT HEP perceived barriers, lack of positive feedback, and helplessness.[65] Adherence with PT HEP in the stroke population has not been documented. Adherence with physician recommended exercises has been shown to be low in the stroke population.[11] Shaughnessy and Resnick[11] distributed 1200 surveys to individuals in the chronic stage post-stroke through participant lists of the National Stroke Association (NSA) stroke support groups. Returned surveys totaled 321 but only 312 had complete data and were included in the analysis.[11] Data analysis revealed that self efficacy expectations has the greatest impact on increasing exercise behavior in individuals in the chronic stage post-stroke.[11] Outcome expectations and physician recommendation to exercise both indirectly influence exercise behavior through influence on self efficacy expectations.[11] Neither one, however, lead to a significant influence on exercise behavior in individuals in the chronic stage post-stroke directly.[11] Shaughnessy and Resnick [11] concluded that healthcare recommended exercises combined with counseling on the role of exercise for individuals post-stroke may influence long term exercise behavior and warrants further research.[11]

Need Based on Literature Review

Disability from stroke is significant and long term.[4-11] The duration of structured rehabilitation, however, has gotten shorter over time.[4,6,11] Individuals who have had a stroke are at risk for loss of function,[13,22,24] poor HRQL,[1,14,21,27] low life participation,[5,20] and greater changes with aging than the healthy aging population.[23]

Research in the last 10 years has demonstrated neuroplasticity in adult brains after insult even into the chronic stage of stroke.[7,10,37,46,66] The chronic stage of stroke is a time when patients are not typically participating in structured rehabilitation. Patients and their caregivers are assuming responsibility for their own disability management.[4,6,11] Adherence with physician recommended exercises is low due in part to low self efficacy and outcome expectations.[4,11]

Some people post-stroke, in addition to losing functional gains made in rehabilitation, are also struggling with depression,[2,13,24] fatigue,[24,26] and physical inactivity.[23,24] There is growing evidence that patients in the sub acute and chronic stages post-stroke can benefit from regular exercise aimed at strength, flexibility, balance, and endurance.[6,8,18,19,28,29]

Physical therapists, through rehabilitation intervention and discharge planning with patients and their caregivers, have an opportunity to influence post rehabilitation behavior. Data on patient adherence with HEP prescribed by therapists to patients post-stroke is not documented.

Chapter Three: Methodology

Description Approach

Patients in the chronic stage post-stroke typically have ongoing physical impairments without continued involvement in ongoing rehabilitation. Patient adherence with physical therapy HEP is important for maintenance of gains and continued progress after discharge from physical therapy. This study used patient-centered data collected from individuals that have had a stroke and have been discharged from physical therapy in the previous 1-6 months. The data were collected using a written survey. The data collected include whether or not participants recall being provided a HEP when they were discharged from physical therapy. For participants that received a HEP, data on adherence, reasons for non-adherence, perception of loss of function since discharge from physical therapy, and attitude about exercise were gathered. The data were analyzed both descriptively and quantitatively.

Research Design

The primary hypothesis for the study was that patients have a high rate of non-adherence with physical therapy HEP after discharge from therapy services. It was also hypothesized that individuals who have had a stroke will identify barriers to exercise that have also been identified by other populations including the community dwelling older population and patients that have arthritis and LBP. Additional hypotheses were that a correlation would be found between those who report non-adherence with

PT HEP and reported decline in function, difficulty with depression, difficulty with fatigue, and physical inactivity. The design of this study was a cross sectional survey study. This study was basic in its design. Data were collected from subjects without variable manipulation to change the outcome. The study was descriptive and quantitative. The primary outcome measure was adherence to physical therapy HEP prescription provided to persons who have had a stroke. Data were collected on reasons for non-compliance with HEP and patients' perceptions on loss of function since discharge from physical therapy.

Population of Interest/Selection of Samples

The population of interest was people who have had a stroke and not currently involved in structured rehabilitation. Participants for this study were individuals that have been discharged from physical therapy in the previous 1-6 months. Participants were recruited from stroke support groups in Central Indiana. Participants for this investigation completed a survey or designated a proxy to complete the survey for them. The participants completed a survey about exercise activity relative to HEP instruction provided at the time of discharge from rehabilitation.

Instrumentation

The instrument used was a patient-centered tool developed for this study (Appendix). The responses provided nominal data about exercise adherence, reasons for non-adherence, and perceived loss of function since discharge from rehabilitation. The nominal data allowed for measuring frequencies and differences between groups. Demographic information collected included participant age, gender, date of stroke, date of last physical therapy visit, and location of post-stroke rehabilitation. Data were also collected on patient perception of physical inactivity,[24] depression, and fatigue[24,26] because these confounders have been identified as correlating to loss of function in the chronic stage post-stroke after rehabilitation has been completed. Depression and fatigue are parameters that have been used to measure self efficacy for exercise post-stroke.[11] Frequency and duration of exercise were collected due to the documented relationship between these factors and functional improvement [3,6,15,18,19,28,30] and plastic changes[10,36,37,41,48,52,53] in the chronic stage post-stroke. Data on variables that have been linked to poor exercise adherence in other populations were also collected. Some of the items developed for this survey are based on identified barriers to exercise in the arthritis population such as not enough time, too tiring, no place to exercise, and don't see any reason to exercise.[35] Barriers identified within the older adult population including lack of knowledge about the benefits of exercise, impaired health, fear of injury, and unpleasant sensations associated with exercise were also included in items on the survey.[56,57] Pain and exercising alone are also parameters used to measure self-efficacy for exercise post-stroke.[11] Place of rehabilitation was obtained for confirming standard operating procedures relative to HEP prescription at the time of discharge from physical therapy after stroke at the identified facilities.

Procedure

After literature review and survey development, the survey was pilot-tested on a group of three individuals in the chronic stage-post stroke. The survey was also reviewed by 2 experts in neurological rehabilitation. The surveys were provided to 73 participants at 9 stroke support group meetings in Central Indiana. Responses were recorded on an Excel spread sheet and aggregated and analyzed with SPSS 15.0. Rehabilitation facilities identified by participants were contacted to verify standard operating procedures relative to HEP prescription for patients discharged from physical therapy after stroke during the 1-6 months period previous to data collection. Confirmation was received from 9 of 14 facilities identified.

Data Analysis

All data were recorded and maintained in a database using an Excel spreadsheet. Identifying information was not collected on the surveys. Each survey has been identified numerically as a case within the database, and surveys with missing data were not included in the analysis. Demographic data were reported with descriptive statistics. Rates of responses were calculated and reported for all questions. Differences between variable responses were calculated using SPSS 15.0 Chi Square with degrees of freedom 1 and alpha 0.05. Chi Square was used to reject or fail to reject null hypotheses 3,4,5, and 6. Sample size and power calculations were performed using a power and sample size calculator available on line at www.stat.uiowa.edu/~rlenth/Power with prototype data Chi Square statistic

6 and sample size 100.[67] Calculations were made based on alpha .05 and degrees of freedom 1 with the following results. Consultation with a statistician in the Clinical Systems Improvement Department at St. Vincent Health, Indianapolis, Indiana helped facilitate final survey design and decisions about statistical tests to be used.

Chapter Four: Results

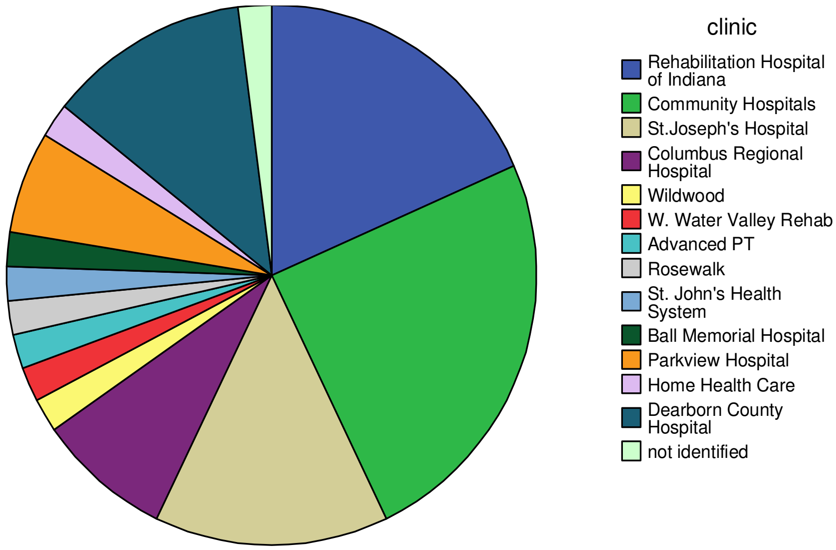
Surveys were distributed and completed at 9 stroke support group meetings in Central Indiana. Fifty-five completed surveys met the inclusion criteria. Six of the 55 participants indicated not receiving a HEP upon discharge from physical therapy. All data analysis was performed on the remaining 49 surveys. The age range of the sample was 32 – 92 years of age. Sixty-three percent of the sample was male. Eighty-two percent of the sample indicated they were greater than 6 months post-stroke and 82% of the sample indicated they completed the survey themselves. A summary of this demographic information is shown in Table 1.

Table 1. - Demographic Data

Variable	Number	Percentage (%)
Male	31	63.3
Female	18	37.7
Self report	40	81.6
Proxy report	9	18.4
<3 months since CVA	0	0.0
3-6 months since CVA	9	18.4
>6 months since CVA	40	81.6

Participants completed physical therapy at 14 clinics in Indiana. Home exercise program prescription as a standard operating procedure (SOP) was confirmed at 9 of the clinics. The other 6 clinics did not respond to my request to confirm SOP. The number of participants that received physical therapy from one of the 9 clinics that confirmed HEP as standard operating procedure was 44, which represents 89.8% of the sample. Clinic distribution of the sample is represented in figure 1.

Figure 1. - Clinic Distribution of Participants



Adherence with HEP was reported by 32 (65.3%) of the participants that received a HEP and non-adherence was reported by 17 (34.7%) of the participants. These results led to rejection of null hypothesis 1. Within the group that reported adherence with HEP, 27 (84.4%) indicated knowledge of how to modify the program and 5 (15.6%) indicated not knowing how to modify the program. Frequency of exercise and duration of exercise responses are shown in Figures 2 and 3. Duration of 30 minutes or less was reported in greater than 70% of participants that were adherent with PT HEP, but frequency was distributed between 1-2x/week, 3-4x/week, 5-6x/week and 7x/week.

Figure 2. - Frequency of Exercise

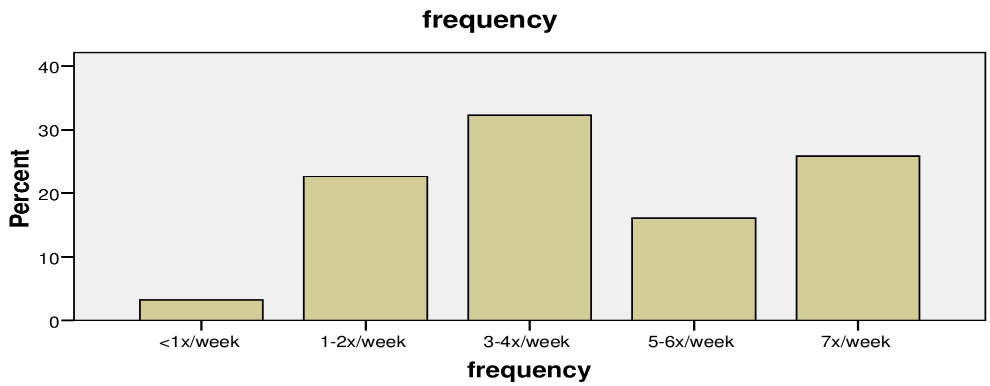
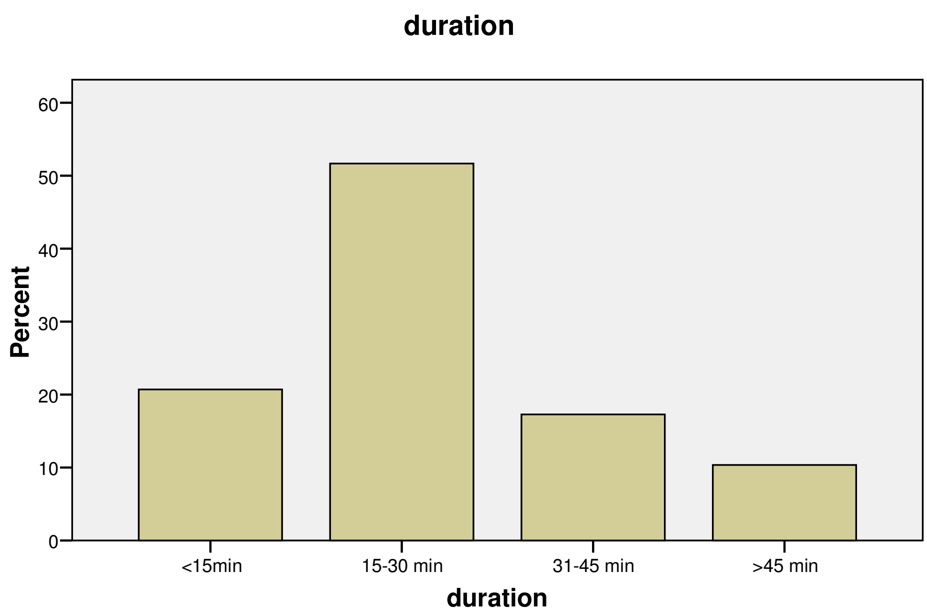


Figure 3. - Duration of Exercise



Reasons for non-adherence were addressed in null hypothesis 2 which states no overlap in identified barriers to exercise between patients that have had a stroke and other populations including healthy older adults and patients who have LBP or arthritis. Reasons for non-adherence were indicated by participants. Each participant was able to check all reasons on the list that applied to them. Participant responses are summarized in Table 2. This sample of individuals post-stroke indicated reasons that were consistent with reasons reported by other chronic patient populations and community-dwelling elders.[35,43,56,57,65] The only reason not selected was not enough time and the most frequently selected reason was doing other exercises. The results failed to reject null hypothesis 2a since "not enough time" was not selected as an option by any of the respondents but the results rejected null hypotheses 2b-2k since the rest of the options were selected by at least one respondent.

Table 2. - Reasons for non-adherence with PT HEP

Reason	Frequency
Not enough time	0
Do not know what exercises to do	1
No one to exercise with me	2
No place to exercise	1
Exercise is hard	2
Exercises are not helpful to me	1
Exercise causes pain	3
Exercise is boring	3
Afraid of falling while exercising	4
Concerned about getting hurt while exercising	2
I do exercises, but not the ones the physical therapist gave me	9
Other	3

The written responses reported for "other" included the following: "Told to type and write, which I do; My own routine; and Only thing now is some walking – arthritis in knee is bothering him."

Null hypotheses 3-6 were tested using a Chi Square test to assess correlations between exercise adherence and reports of fatigue, depression, decline in mobility status, and physical inactivity. Difficulty with fatigue was reported by 39 (70.9%) of the participants. Twenty-one (38.2%) reported issues with depression and 22 (40%) reported not being physically active. Mobility decline since discharge from physical therapy was reported by 21 (38.2%) of the sample. Results of the Chi Square tests are shown in Table 3. There were no statistical significant correlations found. Power calculations yielded a power of 0.3526 with a sample size of 50.[69] Power at 0.3526 indicates that correlations found due to true relationships instead chance were low. Results of the Chi Square tests failed to reject null hypotheses 3-6.

Table 3. - Correlation with Exercise Adherence

Variable	*P*	X^2
Fatigue	0.682	0.168
Depression	0.697	0.152
Mobility decline	0.408	0.686
Physical inactivity	0.062	3.494

Alpha = 0.05

Chapter Five: Discussion

Patient report of HEP adherence and reasons for non-adherence were collected and analyzed in this study to help physical therapists understand factors that influence post-discharge activities of patients in the chronic stage post-stroke. These data were collected and gathered due to the importance of appropriate ongoing exercise and physical activity after discharge from rehabilitation for patients in the chronic stage post-stroke. There were some limitations to this study including the study design and the validity of the survey. The design of the study was a cross sectional survey study using a convenience sample of people that have had a stroke and have been discharged from physical therapy. Because the participants were recruited from stroke support groups, they may not be representative of the stroke population. There were inclusion criteria to participate. The participants had to have had a stroke and been discharged from physical therapy in the previous 1-6 months. The sample did, however, have some confounding factors that could influence the homogeneity of the sample such as age, time since stroke, and location of rehabilitation post-stroke. These data were all collected on the survey. The survey was developed for this study for which there was not a gold standard tool to use for criterion validity. Recall bias can be a limiting factor with a survey study. The small sample size and low power of this study were also limitations to drawing inferences from the results.

Sixty-five percent of the participants reported adhering to the HEP provided at discharge from rehabilitation. This adherence rate is higher than the results of Shaughnessy and Resnick with physician recommended exercises.[11] Adherence rates calculated in this study may reflect an inherent difference in exercise recommendations made by a physical therapist compared to recommendations made by a physician. The therapeutic relationship a physical therapist has with a patient involves ongoing directed exercise as part of skilled therapy. A HEP given to a patient at the time of discharge from physical therapy includes specific exercises that have been practiced under the direction of a physical therapist. Teaching patients to perform exercises is part of routine care provided to patients in physical therapy. It is significant that some patients report being adherent with HEP from physical therapy. Physical therapists need to be vigilant in providing a HEP at discharge and instructing patients about continuing to be active after discharge. Physical therapists should be concerned about increasing the adherence with HEP after discharge with patients that have had a stroke. The adherence rate in this study was higher than previously documented but still below the 80% target identified in null hypothesis 1. Increasing the adherence rate is a significant concern due to the positive impact ongoing exercise can have for individuals post-stroke.

Exercise programs that have demonstrated improvements in both function and impairments are programs ranging from 60-90 minutes of exercise 3-4 times per week.[3,6,15,18,19,28,30] This intensity was not representative of the responses provided by participants in this study making frequency and duration of exercise important parameters for physical therapists to instruct patients about at discharge. Repetition and intensity of exercise has been shown to influence plasticity in the chronic stage post-stroke.[10,36,37,41,48,52,53] The content of HEP as well as frequency and duration become important issues for physical therapists in light of this connection between intensity and plasticity. Physical therapists need to be providing HEP that reflect an intensity level that is consistent with programs documented to facilitate improvements in the sub-acute and chronic stages post-stroke. More data are needed on frequency and duration as well as specific exercises being performed to assess appropriateness of exercise activities. The frequency and duration data in this study did not allow for any specific conclusions.

The data on reasons for non-adherence indicated that individuals have been performing an exercise routine that is different than the one prescribed by the physical therapist (9 responses). Reasons for performing different exercises were not reported, but may be helpful for physical therapists to know. Other frequently indicated reasons for non-adherence (3 or more) were pain, boring, and fear of falling. Both pain and fear of falling are problems that are within the scope of practice of physical therapists. A well designed HEP that is not adhered to does not have value. Physical therapists may be able to educate their patients more effectively if they know about willingness to exercise and resources in terms of equipment and space to adhere with the HEP prescribed. Consistent with other aspects of clinical care, including patients by soliciting patient input when selecting exercises may be helpful with improving adherence with physical therapy HEP prescription. Patient involvement with HEP development may be able to impact deviation to different exercises in the time immediately following discharge from physical therapy. Physical therapists may also benefit from asking patients to perform the HEP at home independently before discharge to assess for safety or pain limitations of the HEP in the patient's home environment. Additionally, structured follow-up to assess exercise behavior and educate patients on modifications as appropriate may improve exercise adherence as well as improve benefit to patients by promoting appropriate exercises to address both functional limitations and neuroplasticity potential.

Participants in this study attended a stroke support group meeting. This deviates from the sample in the study by Shaughnessy and Resnick where the participants were all on a contact list for a stroke support group but not necessarily in attendance at a meeting.[11] There may be a difference in motivation and life style between people that actively attend a stroke support group meeting and people that do not attend. Stroke support groups may provide both support and accountability for participants. Stroke support groups may also provide an avenue for education and connection to individuals that have had a stroke after discharge from therapy.

The results of this study found no statistically significant correlations between adherence and depression, fatigue, mobility decline, or physical inactivity. However, there were a high number of individuals reporting non-adherence with PT HEP that reported doing other exercises instead. Correlations may be present between exercise in general and depression, fatigue, mobility decline, and physical inactivity in individuals that have had a stroke.

Exercise behavior by individuals that have had a stroke seems to be less than optimal. Participation in appropriate exercises at adequate intensities is important for individuals post-stroke. It is important to maintain functional gains as well as to facilitate ongoing improvement. Failure to exercise can have a negative impact on individuals post-stroke. Physical therapists share responsibility with patients and other clinicians in determining appropriate HEP prescription as well as providing ongoing support for long term adherence with exercise after discharge from physical therapy. Ultimately, the goal is good disability management long-term to promote active life participation and continued progress after structured rehabilitation has been discharged.

Chapter Six: Conclusion

Exercise is important for individuals post-stroke. Physical therapists have an opportunity to influence this behavior with HEP prescription at the time of discharge. The results of this study suggest that 65.3% of patients are adherent with HEP recommendations made by physical therapists in the time immediately following discharge. Frequency and duration of exercise reported by participants in this study were lower than what has been shown to facilitate ongoing functional and impairment improvements after discharge from physical therapy.[3,6,15,18,19,28,30] This suggests that frequency and duration of exercise may not be high enough to promote maximal benefit from exercise activity. Specific content of exercise programs and continuing adherence with exercise programs over time are both unknown. Correlations were not significant between HEP adherence and depression, fatigue, mobility decline or physical inactivity in this study. Correlations between these variables and exercise activity in general were not assessed in this study and may be relevant. The results of this study suggest several additional research questions.

Additional research is needed on exercise behavior of individuals post-stroke with a lager sample size to increase power. Specific information on HEP as well as specific exercises actually being performed including both frequency and duration are needed. Longitudinal data on exercise activity over time in individuals post-stroke is relevant. Greater understanding of barriers such as pain and fear of falling are needed to direct physical therapists in education and interventions to minimize these barriers. Finally clinical programming aimed at improving exercise adherence in the immediate time post discharge and on an ongoing basis needs to be implemented and tested in the stroke population.

Appendix-Survey

Age ________ Gender ________
Who is answering the survey? Self Other (please circle the appropriate response)
Date of stroke (month & year) ________________
Date of last physical therapy visit including home care and outpatient (month& year) ___________________
Where did you receive physical therapy? (name of facility or agency)___________________

Exercise is defined as any physical activity to address physical fitness. Exercise instructions are any directions provided verbally, in writing, on video tape or DVD, or by demonstration. Performing any part of the exercises you were instructed to do with or without modifications is considered doing the exercises you were instructed to do.

	Question	Circle your answer	
1.	Do you think exercise is important for someone who has had a stroke?	YES	NO
2.	Did you exercise before you had a stroke?	YES	NO
3.	Does fatigue influence your daily activities?	YES	NO
4.	Do you consider yourself to be depressed?	YES	NO
5.	Do you consider yourself to be physically active?	YES	NO
6.	Has it gotten harder for you to move around since stopping physical therapy?	YES	NO
7.	Did you receive instructions from your physical therapist to continue exercising at home after physical therapy treatments ended?	YES	NO
8.	Did you understand the exercise instructions the physical therapist gave to you?	YES	NO
9.	Do you do the exercises the physical therapist gave you to do?	YES	NO

If you do the exercises the physical therapist gave you to do, answer the next 3 questions.

Do you know how to modify the exercises the physical therapist gave you to make them easier or harder?

1. Yes
2. No

In a typical week, how often do you do the exercises that the physical therapist gave you?

1. Less than 1 time per week

2. 1-2 times per week
3. 3-4 times per week
4. 5-6 times per week
5. 7 times per week

In a typical exercise session, how long do you exercise?
1. Less than 15 minutes
2. 15-30 minutes
3. 31-45 minutes
4. greater than 45 minutes

If you do not do the exercises the physical therapist gave you to do, answer the next 2 questions.

What are the reasons you do not do the exercises the physical therapist gave you? (circle all that apply)
1. Not enough time
2. Do not know what exercises to do
3. No one to exercise with me
4. No place to exercise
5. Exercise is too hard
6. Exercises are not helpful to me
7. Exercise causes pain
8. Exercise is boring
9. Afraid of falling while exercising
10. Concerned about getting hurt while exercising
11. I do exercises, but not the ones the physical therapist gave me
12. Other ________________________

Would a follow up phone call from the therapy clinic encourage you to exercise?
1. Yes
2. No

Everyone respond to the last question.

Tell us what you think the role, if any, exercise has had in your recovery and daily functioning since having a stroke.
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Curriculum Vitae
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Education

May 1989	B.S. Physical Therapy; Indiana University
August 2008	M.S. Therapeutic Outcomes Research; Indiana University

Employment

05/2005 – current	Saint John's Health System; Anderson, IN Physical Therapist; Erskine Rehab & Regional Balance Center
05/2000 – 05/2005	Easter Seals Crossroads Rehabilitation Center; Indianapolis, IN Physical Therapist; Adult Services Program
05/1992 – 05/2000	Rehabilitation Hospital of Indiana; Indianapolis, IN Sr. Physical Therapist; Brain Injury, Neuromuscular & Amputee Program
05/1989 – 05/1992	Saint John's Health System; Anderson, IN Physical Therapist; Bennett Rehabilitation Center

Professional Activities

Federation of State Boards of Physical Therapy
- Exam Development Committee 2008-2010
- Item Writer 2006

Indiana University
- Guest Instructor DPT Program 2006-current
- Assistant Instructor Neurological PT Skills Lab 1997-2003

American Stroke Association
- Speakers Bureau 2002-current

University of Indianapolis
- Guest Lecturer 1996 & 2001-2004

Professional Presentations
- Stroke Awareness (Women's Health Day) 2008
- Exercise Post-Stroke (Central Indiana Stroke Support Groups) 2007-2008
- Stroke Symptoms & Risk Factors 2004 & 2005
- Stroke Survivor and Caregiver Symposium 2003
- Physical Therapy Management of the TBI Patient 1999
- Indiana Brain Injury Association Conference 1997

Certifications
- NDT – Adult Hemiplegia
- APTA Credentialed CI

Professional Organizations

American Physical Therapy Association
- Neurology & Research Sections

American Society of Neurological Rehabilitation