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Relieving Post-Stroke Fatigue Using a Group-based Educational Training Approach

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Health Related Sciences with a concentration in Occupational Therapy at Virginia Commonwealth University.

by

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Abstract

RELIEVING POST-STROKE FATIGUE USING A GROUP-BASED EDUCATIONAL TRAINING APPROACH

Catherine Emery (nee Emenheiser), PhD

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2015

Tony Gentry, PhD, Professor Occupational Therapy Department

Post-stroke fatigue is a common problem that may limit participation in everyday activities. Emerging evidence suggests that group-based training in fatigue management may be an efficient means of reducing the effects of post-stroke fatigue. This mixed methods, quasi-experimental study proposed to determine whether a group-based educational program could be successful in relieving post-stroke fatigue and improving participation in daily activities. A convenience sample of stroke survivors (n=20) from retirement communities in southeastern PA were invited to participate in the research. Participants were screened for depression, motor and cognitive recovery, and sleep quality. Fatigue was measured using the Fatigue Severity Scale (FSS) and activity participation was measured using the Physical Self-Maintenance Scale- Instrumental Activities of Daily Living (PSMS-IADL). The measures were administered in a double pre-test, double post-test format over three seven-week phases; a

non-intervention period; a group-based intervention period, and a post-intervention period. Qualitative information was gathered using a self-made Intervention Satisfaction Survey. Data analysis involved measures of central tendency for the demographic information. Tabulations of the survey responses were completed to judge the effectiveness of the group-based program or its' components from the participants' perspectives. Results indicated a statistically significant reduction in reported fatigue post-intervention ($p = .022$), which continued for seven-weeks ($p = .240$). There was a strong effect size for the post-intervention reduction of fatigue ($r = .69$). There was a trend toward improved participation in daily activities. Distribution across groups for presence of social support, age, sex, and level of care was found to be equivalent after one-way chi square analysis. There was no significant influence of these variables on fatigue or participation when used as grouping variables in RM-ANOVA. Participants reported feeling most confident scheduling activity to include rest periods and least confident managing sleep problems. Limitations include small sample size, demographics not being representative of the general stroke population, use of self-report measures with possible ceiling effect of PSMS-IADL, instrumentation effect given multiple administrations, and history effects as groups occurred at different time of the year. Overall, the results indicate that participation in a group-based educational program was effective in reducing post-stroke fatigue in chronic stroke.

Chapter One: Introduction

With this dissertation, I provide evidence that people who have chronic fatigue post-stroke can function more independently and with less fatigue after participating in a group-based fatigue management course. Only two prior studies have been found in the literature that reported on rehabilitation interventions for post-stroke fatigue (Clarke, Barker-Collo, & Feigin, 2012; Zedlitz, Fassoit, & Geurts, 2011) despite the prevalence of fatigue and its impact on participation in daily activities (Stokes, O'Connell, & Murphy, 2011; Ingles, Eskes, & Phillips, 1999; Di Fabio, Soderberg, Choi, Hansen, & Shapiro, 1998).

Cerebrovascular accident (CVA, or stroke) accounts for about one of every 18 deaths in the United States, making it the fourth leading cause of death and a leading cause of serious, long-term disability (American Heart Association (AHA), 2014; National Institute on Neurological Disorders and Stroke (NINDS), 2014). There are approximately 610,000 new cases every year and there are seven million survivors living with the effects of stroke in the United States (AHA, 2014). Globally, stroke is the most commonly occurring neurological disease (NINDS, 2014). The American Stroke Association, a division of the American Heart Association, has set a priority for research to examine the characteristics associated with successful recovery after stroke (AHA, 2014). Post-stroke fatigue is a common experience of stroke survivors, which has been identified as existing separately from post-stroke depressions. While several authors have identified a need for interventions to address this problem, little research has been

conducted into a successful rehabilitation intervention. The prevalence of stroke (AHA, 2014; NINDS, 2014), as well as the high rate of fatigue experienced by survivors (Ingles et al., 1999), seems to justify its inclusion as a research priority by survivors, caregivers and health professionals alike (Pollock, St-George, Fenton, & Firkins, 2014).

The Problem of Post-Stroke Fatigue

Stroke can result in “problems controlling movement, sensory disturbances including pain, problems using or understanding language, problems with thinking or memory; and emotional disturbances” (NINDS, 2014, para 5), although specific levels of disability will differ based on the extent of the stroke and the area of the brain affected. Though we most often identify stroke with obvious physical impairment and communication issues, survivors report that it is the emotional and non-specific symptoms (i.e., fatigue, dizziness, headache, and irritability), sometimes referred to as invisible disabilities, that interfere the most with role reintegration and social participation in the chronic, or post-rehabilitation, condition (Robison et al., 2009; Stone, 2005; Roding, Lindstrom, Malms, & Ohman, 2003).

Fatigue is reported by as many as 75% of stroke survivors (Stokes et al., 2011; Ingles et al., 1999; Di Fabio et al., 1998). Fatigue is generally defined as physical and mental lack of energy; “an overwhelming sense of tiredness, exhaustion, lack of energy or difficulty sustaining routine activities” (Naess, Nyland, Thomassen, Aarseth, & Myhr, 2005, p. 245; Bogousslavsky, 2003; de Groot, Phillips, & Eskes, 2003; Glader, Stegmayr, & Asplund, 2002; Krupp & Pollina, 1996). In a study of 250 stroke survivors, of the 58.3% of patients who reported fatigue, its daily occurrence was “one of the most disabling symptoms after stroke” (van Eijsden, van de Port, Visser-Meily, & Kwakkel, 2012, p. 3). Stroke survivors report that the level of fatigue is

unexpected and that they had not been prepared for its occurrence (Flinn & Stube, 2010). Because fatigue is difficult to adjust to, survivors report it to be very disruptive to resumption of previous roles and routines (Glader et al., 2002), such as social participation, return to work, driving, reading, and daily functional activities (Flinn & Stube, 2010). Incidence of fatigue appears to worsen from three months up to one year post-stroke and then remains steady for up to five years post-event, which negatively affects life satisfaction for stroke survivors (Schepers, Visser-Meily, Ketelaar, & Lindeman, 2006; Astrom, Asplund, & Astrom, 1992).

Fatigue is not uncommon in other neurological disorders (Chaudhuri & Behan, 2004; de Groot et al., 2003; Krupp & Pollina, 1996) including multiple sclerosis (MS), cancer, post poliomyelitis, chronic fatigue syndrome (CFS), Parkinson's disease, and traumatic brain injury (TBI). Fatigue is attributable, in part, to the residual motor impairments such as muscle weakness and muscle fatigability that accompany these disorders (Chaudhuri & Behan, 2004; de Groot et al., 2003; Ingles et al., 1999). But post-stroke fatigue has been described as a primary symptom rather than as an outcome of chronic disease (Chaudhuri & Behan, 2004; de Groot, et al., 2003) and is commonly described as mental exhaustion in the absence of depression (Annoni, Staub, Bogousslavsky, & Brioschi, 2008; Choi-Kwon, Han, Kwon, & Kim, 2005; Michael, 2002; Ingles et al., 1999). Although fatigue is consistently seen after lesions "in pathways associated with arousal and attention, reticular and limbic systems, and basal ganglia" (Levine & Greenwald, 2009, p. 979-980; Michael, 2002), it does not appear to be associated with the type or severity of central nervous system damage or disease (Chaudhuri & Behan, 2004; Ingles et al., 1999). Fatigue is more closely linked to disability after stroke due to the levels of inactivity it causes (Appelros, 2006; Michael, Allen, & Macko, 2006). Monitoring

lifestyle changes is important in the management of fatigue across diagnosis categories and can indicate a role for cognitive-behavioral therapy that addresses fatigue awareness, poor sleep, pain, and physical activity to reduce the impact of fatigue on daily function (Chaudhuri & Behan, 2004).

Post-stroke fatigue has not been researched to the extent that fatigue has in other disorders and little is known about approaches to relieve/reduce its occurrence (Barker-Callo, Feigin & Dudley, 2007; Choi-Kwan et al., 2005; Bogousslavsky & Staub, 2003; de Groot et al., 2003; Ingles et al., 1999). Studies have examined the use of pharmaceutical agents, but these have not been found to be effective in remediating post-stroke fatigue (Briochi et al., 2009; McGeough et al., 2009; Choi-Kwon, Choi, Kwon, Kang & Kim, 2007). Group-based psycho-educational intervention has been used to successfully manage fatigue in MS, cancer, and CFS (Scheurs, Veehof, Passade, & Vollenbroek-Hutten, 2011; Winningham, 2001; Di Fabio et al., 1998) but only recently in post-stroke populations (Clarke et al., 2012; Zedlitz et al., 2011). Based on self-efficacy theory and cognitive behavioral therapy, these group-based intervention approaches focused on an educational course of six to eight weeks in duration that incorporated energy conservation education, exercise routines, sleep hygiene approaches, and modified rest patterns (Matuska, Mathiowetz, & Finlaysen, 2007; Vanage, Gilbertson, & Mathiowetz, 2003; Mathiowetz, Matuska, & Murphy, 2001; Portenoy & Itri, 1999; Di Fabio et al., 1998). Developing and evaluating the efficacy of treatment strategies for post-stroke fatigue is necessary in order to improve stroke recovery and quality of life post-stroke.

Post-stroke fatigue has been shown to disrupt social participation and quality of life for stroke survivors. In a study by van de Port, Kwakkel, Schepers, Heinemans, & Lindeman (2007),

the relationship between fatigue and health-related quality of life (HRQL) was examined in 233 stroke patients. The authors found that fatigue was independently related to HRQL. Flinn & Stube (2010) took a qualitative approach to examining the impact of fatigue and formed focus groups of 19 community-living stroke survivors. The participants reported that they felt a lack of preparation for the fatigue experience and that it had a debilitating effect on daily occupational performance, including social participation. In a qualitative examination of fatigue experienced by patients in chronic conditions, Kralik, Telford, Price, and Koch (2005) reported that fatigue could be overwhelming, that it fluctuated day-to-day and throughout each day and disrupted all aspects of the participants' lives. The most challenging aspect of fatigue was that it was not apparent to others, contributing to the impression by people with stroke that healthcare providers did not consider it important (Kralik et al., 2005; Glader et al., 2002).

Fatigue can cause confusion, frustration, irritability, increased pain perception, decreased immune response and lack of engagement in activity (NINDS, 2014) all of which contribute to reduced quality of life. Fatigue after stroke "is an important cause of long-term morbidity in cerebrovascular diseases" (Chaudhuri & Behan, 2004, p. 978). This could be addressed through increased knowledge concerning interventions that have been shown to increase functional abilities and improve quality of life for stroke survivors (Steultjens, Dekker, Bouter, Leemrijse, & van der Ende, 2005; Michael, 2002). Because post-stroke fatigue impacts functional performance of everyday activities and quality of life, it is critical that rehabilitation professionals develop and evaluate strategies and activities to address this problem and incorporate them into patient education for health management (AOTA, 2014).

Physical Rehabilitation Theory in the Management of Post-Stroke Fatigue

The concept of health has begun to shift from a more exclusive focus on physical aspects of recovery as measures of successful outcome toward a broader view that includes quality of life and well-being in an atmosphere of client-centered treatment (Cott, Wiles, & Devitt, 2007). This shift toward an understanding of health as an integration of body function, activity/participation, and context/environmental factors is codified in the International Classification of Function, Disability and Health (ICF) by the World Health Organization (WHO) (2001). With this shift comes increased attention to the needs of stroke survivors beyond basic activities of daily living (ADL) and an awareness of the chronic nature of stroke recovery. The ICF is the universal framework for disability research (Cott et al., 2007). It provides a systematic conceptualization for understanding the experience of disability. It defines health from the bio-psycho-social perspective involving body components, the individual, and society in terms of activity and participation (van de Port et al., 2007). Outcome is conceptually related to the activities and participation component of the ICF; the individual is seen as the center of the process with quality of life and optimum participation as the ultimate measure of success in adjusting to disability (Cott et al., 2007).

The American Occupational Therapy Association (AOTA, 2014), influenced by the WHO's ICF, published the *Occupational Therapy Practice Framework*, 2nd edition in 2008; which was updated in 2014. The idea of engagement in occupations to support participation is the founding premise of occupational therapy (AOTA, 2014) and this was recognized on a global scale by the WHO's recognition that health is affected by activity and participation. This idea of engagement in occupations to achieve health remains the overarching outcome of occupational

therapy intervention as delineated in the *Occupational Therapy Practice Framework, 3rd ed.* (OTPF), much as optimum participation is seen as the ultimate outcome by the WHO.

Given that the overarching goal of occupational therapy is engagement in occupations and that the guidelines from WHO recommend increased participation to improve health, research is needed to identify interventions for post-stroke fatigue. Also 'recovery' now projects the understanding of the chronic nature of disease and the importance of long-term management of disability and disease to achieve quality of life (WHO, 2001). With this shifted focus to disease management came the understanding that people required education about their conditions. This resulted in the first line of interventions using a psycho-educational model in program development. The idea was to make people aware of the problem (for instance, the existence of fatigue), to provide explanations as to why it occurs and with what frequency, to observe and measure its impact on daily activity, and to suggest methods for its management (Schepers et al., 2006; Michael, 2002).

As theories into health behavior have evolved, so has a growing recognition that education alone does not create behavior changes that manage the problem or reduce the impact on daily activity participation. This has led to the inclusion of Bandura's (1995) concept of self-efficacy: the confidence a person has in the ability to control their life circumstances by completing actions and overcoming barriers to behaviors. Self-efficacy theory involves three interrelated ideas: 1) that people must have knowledge and skills related to the behavior of interest; 2) that they must be confident in their ability to use cognitive and motivational resources; and, 3) that they develop context-specific confidence in completing a desired task or action. Self-efficacy beliefs are predictors of the amount of effort a person will put toward

health-promoting behaviors despite barriers or adverse experiences (Bandura, 1995). While education remains an important first step, current research protocols utilize a cognitive behavioral therapy (CBT) approach in chronic disability management to develop the behavioral change needed to improve the chronic disability condition (Price, Mitchell, Tidy, & Hunot, 2008; Matuska et al., 2007; Gielissen, Verhagen & Bleijenberg, 2007; Prins et al., 2001).

Combining elements of behavioral and cognitive theory, CBT works to change a person's thoughts from 'incapable' to 'capable' of activity engagement through successful experiences (Bruce & Borg, 2002). Activities are used to model success as well as to provide opportunities for participants to experience mastery and build their perceptions of themselves as capable. Group-based intervention is a technique used by occupational therapists, among others, to apply CBT as it provides for active problem-solving generated from people with a shared experience of disability or chronic disease (Schwartzberg, Howe & Barnes, 2008).

Purpose Statement

The purpose of this study was to determine whether participation in a group-based educational program decreased fatigue and improved functional performance for chronic survivors of stroke.

Research Questions

This study was designed to provide evidence in support of the following questions:

1. Does participation in a group-based educational program of fatigue management result in reduced self-report of fatigue among stroke survivors with fatigue as measured by the Fatigue Severity Scale (FSS)?

2. Will participants show carryover of this reduction in the experience of fatigue for up to seven weeks after the program concludes (as measured by the FSS)?
3. Does participation in a group-based educational program of post-stroke fatigue management result in improved self-report of participation in everyday activities (as measured using the Physical Self-Maintenance Scale-Instrumental Activities of Daily Living; PSMS-IADL)?
4. Will stroke survivors report increased participation in everyday activities for up to seven weeks after the program concludes (as measured by the PSMS-IADL)?

Rationale for this Study

Fatigue is acknowledged as a frequent symptom after stroke. It is rated among the most disabling of symptoms that remain in post-stroke reintegration, especially for survivors with less severe physical or cognitive disabilities (Barker-Callo et al., 2007; Ingles et al., 1999) and mild stroke (Carlsson, Moller, & Blomstrand, 2004). Only a limited number of research studies have examined interventions that are successful after stroke (Clarke et al., 2012; Zedlitz et al., 2011). Therapists are in need of evidence-based tools to improve outcomes relative to quality of life for the patients they treat. This study was intended to address that information and resource gap by examining the effects of a group-based educational training approach on post-stroke fatigue.

Summary

As American healthcare evolves to address community-based client-centered intervention, increased attention will be paid to long-term outcomes of the rehabilitation therapy process. Outcomes are increasingly assessed in terms of activity and participation as

recommended by the WHO's ICF. This move coincided with the publication of the OTPF (3rd ed.), which focuses occupational therapy intervention on the ultimate outcome of engagement in occupation. The OTPF provides a mandate for evidence-based intervention that addresses the needs of the clients served by occupational therapists.

Stroke is not only one of the leading causes of chronic disability; it is one of the most frequently treated diagnoses in the field of occupational therapy. As such, it is critical for therapists to examine the needs of stroke survivors for resumption of daily routines. One of the most significant long-term difficulties reported by stroke survivors is fatigue; it is a major limitation to resumption of roles, routines, and quality of life post-stroke. Studies are needed to provide support for community-based intervention strategies in addressing this debilitating symptom of chronic stroke.

This pilot research study tested a group-based educational training program for stroke survivors who were experiencing fatigue that impacted participation in everyday activities. The program was developed from concepts of energy conservation that were successful in treating fatigue in other conditions as well as components specific to the post-stroke condition. Self-report measures of fatigue (FSS) and level of everyday activity (PSMS- IADL) were used at two pre-intervention and two post-intervention points and compared to determine changes in group mean scores across phases of participation. The influence of social support, sex, age, and level of care were examined as they represent potentially confounding variables to the fatigue experience. Participants were surveyed for feedback on the program to contribute to improvement for application in future research and practice.

Chapter Two: Review of the Literature

Introduction

In this chapter, I examine the history of efforts to remediate or manage post-stroke fatigue, the theoretical foundations underlying these efforts, research in the field, and the prospects for future research, with a particular focus on group-based education to address deficits in everyday functional performance related to fatigue post-stroke.

Fatigue is reported by as many as 75% of stroke survivors (Stokes et al., 2011; Ingles et al., 1999; Di Fabio et al., 1998). However, post-stroke fatigue has not been the focus of research into successful methods of rehabilitation intervention as have other conditions for which fatigue is also a concern (Mathiowetz et al., 2001; Winningham, 2001; Whiting et al., 2001). Various group-based educational training approaches have been successfully applied in treating fatigue in other conditions (Schepers et al., 2006; de Groot et al., 2003; Di Fabio et al., 1998); those interventions are presented in this chapter as they provide insight into program components that may be applied to post-stroke fatigue therapies. This group-based approach allows participants to share experiences, develop strategies, increase social participation, and develop a sense of control over common results of disease (Bethoux, 2005), which is considered to be an important element to their success. The limited evidence in support of rehabilitation

interventions for post-stroke fatigue (Clarke et al., 2012; Zedlitz et al., 2011) was reviewed in this chapter.

Pharmacotherapy has been used in hopes of reducing the fatigue experience (Babson, Feldner, & Badour, 2010). Some medications have been used to target depression or the mechanisms of neurological activity (i.e., dopaminergic agents) although effectiveness has not been supported by the limited research results (Clarke et al., 2012). Medications have also been used to target insomnia but “it is believed that fatigue itself is an independent symptom” (Levine & Greenawald, 2009. p. 350) for which these medications do not offer effective treatment. Pharmacological agents also have significant side-effects (tolerance, dependency, impairments in psychomotor and cognitive processing and daytime sedation) which bring into question their overall benefit (Babson et al., 2010; Im, Strader, & Dyken, 2010). The limited evidence to support use of pharmaceutical agents to reduce post-stroke fatigue (Briochi et al., 2009; McGeough et al., 2009) is reviewed here.

Although non-pharmacological interventions for post-stroke fatigue are limited (Zedlitz et al., 2011 & Clarke et al., 2012), the evidence supports use of a combination of cognitive therapy and physical exercise/activity (McGeough et al., 2009). Support for therapeutic interventions in other neurological conditions is strong (Mathiowetz, Matuska, & Murphy, 2001; Krupp & Pollina, 1996) and contributes information on the content of effective non-pharmacologic interventions.

The Evidence for Post-Stroke Fatigue Management Therapies

Research identifying the problem. Fatigue is defined as a perceived “lack of energy, weariness, and aversion to effort” (Krupp & Pollina, 1996, p. 456) that is described as excessive

and problematic and not relieved by rest (Zedlitz et al., 2011; Chaudhuri & Behan, 2004; de Groot et al., 2003). Fatigue is a common, almost universal, complaint of stroke survivors (de Groot et al., 2003) that can cause frustration, irritability, and lack of engagement in activity (NINDS, 2014), all of which contribute to reduced quality of life. Because fatigue is difficult to adjust to, survivors report it to be very disruptive to resumption of previous activity and participation (Glader et al., 2002). Incidence of fatigue appears to worsen from three months up to one year post-stroke and then remains steady for as long as five years post-event; this increased level of fatigue negatively affects life satisfaction for survivors (Schepers et al., 2006; Naess et al., 2005).

Ingles et al. (1999) completed groundbreaking research in the area of post-stroke fatigue. Eighty-eight stroke patients and 56 older persons who volunteered were recruited to complete a modified version of the Fatigue Impact Scale, the Geriatric Depression Scale, and a health and lifestyle questionnaire. The forms were mailed to the participants to be completed independently and returned. Stroke-related medical information was obtained from health records; data included location of the lesion, type of stroke, Stroke Severity Scale score, Barthel Index score, and Oxford Handicap Scale. Results indicated that the number of participants reporting fatigue was greater in the stroke group than in the volunteers (68% as compared to 36%). Forty percent of the stroke group indicated fatigue to be their worst (14 out of 88) or one of their worst (12 out of 88) symptoms with 27% reporting daily experience of fatigue. The researchers also found that the experience of fatigue was similar despite the amount of time post-stroke (i.e., 66% after 3-6 months; 75% after 7-9 months; and, 65% after 10-13 months). Also of significance was that the occurrence of fatigue did not show correlation with either the

number of co-morbid health conditions, age, sex, or scores on the stroke registry measures.

The authors raised the possibility that fatigue was underreported since the questionnaire asked participants to identify if they had problems with fatigue rather than whether they experienced it. Several responses indicated that stroke survivors had fatigue but that, through modified lifestyles, it did not create a problem. The greatest impact of fatigue reported from this study was on physical and psychosocial functioning. Fatigue was found to be independent of the occurrence of depression. The authors concluded that the “recognition and treatment of fatigue are important for maximizing recovery” (p. 173).

Glader et al. (2002) reported on a study of post-stroke fatigue in Sweden. The aim of the study was to improve on previous research by reducing the risk of selection bias and lack of generalizability due to small sample size. Glader et al. (2002) also wanted “to evaluate whether patients with subjective fatigue have a worse outcome two years after the stroke than other stroke patients” (p. 1327). Since most hospitals that provide service to stroke patients in Sweden participate in a national registry called Riks-Stroke, the authors assert that “this study is unique in its coverage of stroke patients in an entire country” (p. 1330) having data available from 70% of all stroke patients in Sweden combined with an 80% response rate of returned surveys. This allowed the authors to examine data from 3805 patients who completed a mailed questionnaire which assessed ADL (Activities of Daily Living) and IADL (Instrumental Activities of Daily Living) performance, self-perceived depression, fatigue, anxiety, and pain. Their results indicated that fatigue was more common among those stroke survivors who required greater assistance with ADL, IADL and who lived in an institutional setting. Self-reported fatigue was also more common among those who were older on average when the stroke occurred and had

a “less advantageous initial condition” (p. 1329) which is defined as not married, dependent on others prior to the stroke, and/or had experienced a second stroke. The authors concluded that “fatigue is frequent and often severe, even late after stroke. It is associated with profound deterioration of several aspects of everyday life... but receives little attention by healthcare professionals” (p. 1327).

A review of the literature was completed by de Groot et al. (2003) to determine current knowledge on occurrence of fatigue in stroke and other neurological conditions as well as to begin work on treatment strategies. They found that few studies that documented the incidence of fatigue in stroke, nor did research address the impact on daily routines and quality of life. This review compared reported characteristics of post-stroke fatigue with fatigue related to other neurological conditions, finding the following similarities: (1) it occurred independently from depression; (2) it was usually chronic and pervasive; (3) it was often reported as one of the worst symptoms; and (4) it did not seem related to age, sex, severity of injury or degree of disability, despite some individual study results which did report relationships among these variables (see above review of Glader et al., 2002). They concluded that, due to these similarities, treatment approaches that have been used with other groups may be effective in post-stroke treatment but that further research was needed.

Naess et al. (2005) studied the impact of fatigue and other factors, including cognition, depression, and emotional reaction on everyday function at long-term follow-up for 192 stroke survivors in Norway who were six years post-stroke on average, as compared to 212 health controls. The researchers found that fatigue was more frequent in stroke survivors than in controls even among those with no reported depressive symptoms. Unlike other studies, these

authors found an association among type of stroke (basilar artery infarction resulted in greater incidence of fatigue), unfavorable outcomes (increased level of stroke severity) and fatigue.

Schepers et al. (2006) used the FSS to measure fatigue one-year post-stroke and to examine potentially predictive characteristics of fatigue. They found that fatigue increased during the first year post-stroke from 50% to 67% of patients while its reported impact on function also increased. Interestingly, patients who had experienced good physical recovery reported the greater negative impact of fatigue on function. The authors did not find a relationship between cognitive disorders and fatigue despite the positive correlation between mental effort and cognitive demand. While noting depression to be an important focus for intervention, they acknowledged the presence of fatigue independent of depression. The authors also examined “health locus of control beliefs” (p. 187), which were explained as beliefs concerning whether healthcare professionals or the person themselves had a greater impact on health states. The authors found that patients who reported a belief in physician control of health also had a higher incidence of fatigue. Those with a higher internal locus of control showed faster physical recovery. Low internal or high external locus of control were paired with more problems caused by fatigue in a variety of patient groups (e.g. chronic fatigue syndrome, chronic anxiety disorder, traumatic brain injury, spinal cord injury, and chronic low back pain). The authors suggested that changing locus of control, which had been successful in chronic pain treatment, might offer an effective, multidisciplinary treatment approach for post-stroke fatigue (Schepers et al., 2006). This finding was used to guide the use of a cognitive-behavioral approach in developing an intervention for post-stroke fatigue. The basic premise of CBT is that individuals must change their mindsets from a negative to positive perspective on

their ability to engage in activities. This is done by providing opportunities to learn about and participate in activities to manage one's own behaviors relative to changing health conditions. In other words, individuals must adopt an internal sense of control over the fatigue experience and thereby reduce its effects on daily life.

In 2007, van de Port et al. looked for correlations between fatigue, ADL, IADL and health-related quality of life (HRQL) in 223 patients assessed at 6, 12, and 36 months post-stroke. Results indicated fatigue to be significantly correlated to IADL and HRQL but not to ADL. This finding supported the authors' "hypothesis that post-stroke fatigue is more strongly related to the more energy-consuming IADLS ...rather than to basic ADLs" (p. 43). Depression skewed the relationship between fatigue and HRQL but fatigue was still independently associated with HRQL (van de Port et al., 2007).

A 2009 literature review (Lerdal et al.) sought to "provide a comprehensive synthesis of knowledge from the literature concerning the description, definition, and measurement [post-stroke] of fatigue and its relationship to socio-demographic and clinical factors" (p. 928). They found no specific theoretical definition but referenced the case definition published by Lynch et al. (2007), which differentiated between community and hospital patients and included the experience of decreased energy and increased need for rest as definitive characteristics. Other findings include: absence of a scale to specifically measure post-stroke fatigue; conflicting results as to the association of age, sex, living conditions, and personality as well as relationships with stroke location and type; number of strokes and neurological findings with post-stroke fatigue, and a possible relationship between pre- and post-stroke fatigue. The

authors concluded that “knowledge on post-stroke fatigue remains limited” (Lerdal et al., 2009, p. 928).

As these studies show, post-stroke fatigue is an important problem that impacts functional activity and quality of life and that is chronic in nature. Stroke survivors reported that lifestyle modifications were necessary to reduce the impact fatigue had on physical and psychosocial function. However, these modifications were made without effective tools to understand and manage the condition due to lack of preparation for, or education on, effective strategies received during the inpatient rehabilitation process. With only limited research into the phenomenon or effective intervention for it, post-stroke fatigue seemed to receive inadequate attention during the rehabilitation process. This lack of attention may have contributed to the poorer outcomes in chronic stroke rehabilitation. Therefore, all authors called for further research examining both the nature of post-stroke fatigue and interventions for managing this condition.

Interventions that Address Post-Stroke Fatigue

A limited number of research studies into effective interventions for post-stroke fatigue were available. These studies have taken two approaches to reducing post-stroke fatigue: pharmacological and rehabilitation therapy. To develop a successful intervention, it was important to review the results found from these previous treatment efforts.

Pharmacological approaches. Choi-Kwon et al. (2007) completed a pharmacological study on the use of the neurotransmission modulating drug fluoxetine to relieve post-stroke fatigue. Fluoxetine was used since studies had suggested possible neurotransmitter changes in the basal ganglia as a source of post-stroke fatigue. The authors enrolled 83 patients who were

split into a placebo group (n=42) and a treatment group (n=40); five patients were not able to complete the three-month protocol. They found no significant difference in the experience of fatigue between the groups using pre- and post- protocol scores on the Visual Analogue Scale and FSS. The study concluded that, since serotonergic dysfunction seems to play a minimal role in post-stroke fatigue, fluoxetine was not an effective treatment (Choi-Kwon et al., 2007).

Brioschi et al. (2009) examined the effect of modafinil in patients with neurological pathologies including stroke (brainstem or diencephalic – BDS; or cortical- CS) and multiple sclerosis (MS). Modafinil is a “wakefulness-promoting molecule supposed to increase excitatory glutamate transmission” (p. 244). Thirty-one patients completed the Fatigue Assessment Inventory on three occasions: at baseline, after three months on the medication, and one month after the medication had been stopped. The results showed a decrease in the severity of fatigue experienced by BDS and MS groups but not for the CS group. The authors concluded that “wakefulness-promoting agents might be effective on subjective primary fatigue” (Brioschi et al., 2009, p. 248) in patients who sustain brainstem or thalamic strokes but were not shown to be effective in relieving post-stroke fatigue after cortical infarctions.

Rehabilitation therapy approaches. A more recent review of the literature was done by McGeough et al. (2009) for the Cochran Database of Systematic Reviews in an effort to identify research supporting treatments that were effective in reducing the occurrence and/or severity of post-stroke fatigue, that had outcomes related to quality of life, disability, functional dependence or mortality, and that were cost-effective. Only a narrative review of available studies was possible due to the diversity of the interventions studied. The authors found only three published and two ongoing studies into post-stroke fatigue. Two of the published studies

reported on pharmacologic treatments and were reviewed previously (Choi-Kwon et al., 2007, Brioschi et al., 2009). The third study included 1140 community-dwelling participants with a variety of chronic diseases including lung disease, heart disease, stroke, and arthritis (Lorig et al., 2001). Participants, including the 129 stroke survivors, were assigned to a chronic disease self- management program (CDSMP) or to a wait-list control group. The intervention group attended seven weekly sessions in community centers and was taught CDSMP by peers. The CDSMP included, in part, education on exercise routines, use of cognitive symptom management, nutrition, fatigue and sleep management, use of community resources, and use of medications. Comparisons were made at baseline and after six months using the Medical Outcomes Study energy/ fatigue scale. This study found no differences in fatigue between the treatment and control groups, although data was not reported separately for each of the chronic diseases represented (Lorig et al., 2001).

Of the two studies in progress at the time, one focused on the use of continuous positive airways pressure (CPAP) for sleep-disordered breathing and used the Fatigue Severity Scale to assess fatigue (McGeough et al., 2009). The second was part of a multi-site, randomized controlled trial of cognitive and graded activity training (COGRAT) for post-stroke fatigue (Zedlitz et al., 2011). The main outcome measure was fatigue. Data was not available for McGeough et al. (2009), who stated “there is no ‘usual care’ arm in this trial, and so it will not be able to test the hypothesis that cognitive treatment is better than usual care” (p. 8). They concluded that more research was needed in the area of post-stroke fatigue. The pilot research referenced was completed prior to the current research, however, and is reviewed next.

Zedlitz et al. (2011) completed a pilot study applying COGRAT to post-stroke fatigue in an outpatient setting in The Netherlands. The authors studied 23 outpatients with stroke in groups of 12 who received cognitive strategy intervention and physical graded activity on consecutive treatment days for 12 consecutive weeks. The cognitive intervention included education on compensation strategies to manage fatigue and cognitive behavioral therapy to change unhelpful thoughts about fatigue. These were two-hour group sessions provided by a neuropsychologist. The physical graded activity involved endurance (walking on a treadmill), strength, and flexibility training (lateral pull down, chest and leg presses, and core muscle exercises). A physiotherapist provided the four hours (two-hour sessions, twice per week) of physical activity. Sixteen people showed significant reduction in fatigue and psychological distress; significant enough to warrant a full scale study (Zedlitz et al., 2011).

Suggestions for future research included a reduction in the size of each group to address participant distraction, “more consistent use of cognitive behavioral techniques and development of a protocol for the graded activity training” (Zedlitz et al., 2011, p. 488). The multicenter randomized controlled trial of outpatients is currently in progress. This work has provided guidance to the current study in several ways. First, it lent support for interventions aimed specifically at fatigue management, addressing education and activity management over non-specific interventions. Second, it supported the use of a cognitive-behavioral approach when teaching compensation strategies to deal with existing fatigue. Lastly, it incorporated elements of activity as a promising factor for reducing fatigue, which was added to the present intervention program due to the results shown here. However, there were important limitations: the participants were still receiving outpatient services where the focus was on

changing physical fitness, the participants all reside in The Netherlands, and cognitive behavioral therapy was not applied consistently during the pilot program (Zedlitz et al., 2011). The authors encourage application to other patient groups, which was the intent of the present research study.

In 2012, Clarke et al. completed a pilot study of a group education program to address the fatigue experienced during acute stroke recovery (3-18 months post event). The authors assigned individuals who were experiencing fatigue post-stroke to a fatigue management group ($n=9$) or to a general stroke education group ($n=7$). Fatigue was measured prior to, at the conclusion of, and three months after the six -week educational groups. Several fatigue scales were used: FSS, Visual Analogue Scale for Fatigue, Checklist Individual Strength, and Short Form-36. An examination of the concurrent validity of these scales indicated that the FSS had the highest validity among the other scales. The group intervention was developed by the authors as there was no formalized program available for post-stroke fatigue. Although not clearly specified, the content development seemed based on intervention research with cancer survivors, MS, and traumatic brain injury. The group sessions were led by a clinical psychologist and covered the following topics: (1) overview of fatigue, (2) fatigue management, (3) sleep/relaxation, (4) exercise and nutrition, (5) mood, and (6) future focus. Although significant differences were not obtained ($p = .086$), fatigue severity was reduced more for the fatigue management group (FSS < 3.9) than for the control group (FSS above the cutoff score of 4). Additionally, social functioning (measured using the SF-36) improved for both groups while depression (measured by the Hospital Anxiety Depression Scale) was reduced for the treatment group but not to the level of significance. The authors suggest that, since both groups showed

improvement, the content of the control group was too similar to the fatigue management group resulting in the lack of statistically significant differences. Limitations include that the groups were composed of people in the acute recovery period, that participants were residents of New Zealand, and that the number of participants was small. The authors suggested that future trials should examine chronic stroke conditions to expand generalizability beyond the acute stage of stroke recovery (Clarke et al., 2012). For the current study, this research supported decisions of session length, intervention frequency and topics covered. Relaxation content was added to address the co-occurrence of anxiety disorders post-stroke as was the contribution of exercise as it is a well-known contributor to fatigue management.

While pharmacological interventions have either not been successful (fluoxetine) or have been shown to have limited effectiveness (modafinil) in relieving post-stroke fatigue, promising preliminary results were reported in studies which have applied psycho-educational interventions that have been shown to be effective for other fatiguing conditions. In order to develop an intervention program for long-term stroke survivors, it was important to consider this evidence.

The Evidence for Psychological Approaches to Fatigue Management in Physical Disability other than Stroke

Fatigue is one of the common sequelae of many neurologic disorders other than stroke. These include MS, CFS, cancer (CA), post-polio syndrome, Parkinson's disease, and TBI (de Groot et al., 2003; Krupp & Pollina, 1996). Researchers have found that characteristics of fatigue are similar among these disorders: fatigue can exist independently of depression and it has not been shown to have a relationship to age, sex, site or severity of brain injury, or degree

of physical impairment (de Groot et al., 2003). Fatigue is often described by patients as one of the worst symptoms and is considered a primary effect rather than a secondary effect of the disease process (Chaudhuri & Behan, 2004; de Groot et al., 2003; Krupp & Pollina, 1996). Since many of the characteristics of post-stroke fatigue are shared in other neurologic disorders, it seemed reasonable that it may respond to interventions used effectively with these other disorders. To date, there is no published research on group-based educational approaches for the treatment of fatigue in post-polio syndrome, Parkinson's disease, or TBI. Therefore, the following review of current research focuses on interventions used for people with MS, CA, and CFS.

Fatigue is one of the most common symptoms reported by MS patients (Matuska et al., 2007). Mathiowetz, Matuska and colleagues have developed an educational program focused on energy conservation strategies to address MS fatigue (Mathiowetz et al., 2001; Vanage et al., 2003; Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005; Matuska et al., 2007; Mathiowetz, Matuska, Finlayson, Luo, & Chen, 2007). As an example of these studies, Mathiowetz, Matuska, and Murphy (2001) conducted a "repeated measures with control and experimental interventions" (p. 449) study. A convenience sample of 54 community-dwelling volunteers who were diagnosed with MS participated in a six-week, two hours per week, energy conservation course. The authors utilized the energy conservation course developed by Packer, Brink, and Sauriol (1995) but focused solely on adults with MS. The program sessions were led by occupational therapists for groups of 8-10 persons. The program covered "the importance of rest throughout the day, positive and effective communication, proper body mechanics, ergonomic principles, modification of the environment, priority setting, activity

analysis and modification, and living a balanced lifestyle” (Mathiowetz et al., 2001, p. 451). The Fatigue Impact Scale, the Self-Efficacy Gauge, and the Short Form 36 were used to measure the self-reported effect of fatigue on functional performance, confidence in the ability to complete activities, and quality of life, respectively. Participants demonstrated less fatigue impact, increased self-efficacy, and improved quality of life after completion of the six week module. The results provided firm evidence for the efficacy of an energy conservation education program to combat fatigue in MS. Other studies in this area have repeated this intervention with larger population samples, and with more time between intervention and outcome measurement (Mathiowetz et al., 2005; Mathiowetz et al., 2007; Matuska et al., 2007). All have reached similar conclusions.

Fatigue that presents a significant obstacle to completion of one’s everyday activity routine is prevalent in patients with CA as well (Cheville, 2009; Winningham, 2001; Portenoy & Itri, 1999). Portenoy and Itri (1999) examined CA-related fatigue and reported on methods to manage it, which were supported by the National Comprehensive Cancer Network (NCCN) (Cheville, 2009). Cheville reported that “a multidimensional approach that includes medications, exercise, psychological intervention, and improved sleep hygiene offers the greatest likelihood of success” (p. 410). Specifically, Portenoy and Itri (1999) described a course of treatment providing education about fatigue, sleep hygiene, regular exercise, stress reduction or cognitive therapies, and dietary intake. This intervention showed application of the concepts of consistent daily energy expenditure, balancing time spent upright/active and in bed/at rest, and nutritional resources important in exercise physiology (Winningham, 2001). These concepts were incorporated into the current research intervention program either as

part of the education on the phenomenon of post-stroke fatigue (nutrition) or as individual sessions (balancing activity with rest, and exercise).

Chronic fatigue syndrome (CFS) is a disorder which has gained recognition by the medical community only recently. It is characterized by physical and mental fatigue although a variety of symptoms may be experienced (Whiting et al., 2001). While a variety of interventions have been used to remediate CFS, debate continues regarding the most effective management. Whiting et al. (2001) completed a systematic review of the literature to assess the effectiveness of intervention for CFS. They examined 44 trials that ranged from 12 to 326 participants and included a range of interventions, such as: behavioral (graded exercise combined with cognitive behavioral therapy), immunological (effect of immunoglobulin), pharmacological, addressed with nutritional supplements, addressed with alternative or complimentary medicine, and combined treatment approaches (cognitive behavioral, social support and/or education). Overall, the results were inconclusive in terms of effectiveness. Only the studies involving behavioral and immunologic approaches yielded data sufficient to meet the validity assessment. While the cognitive behavior and graded exercise therapies showed positive results in relief of fatigue, the immunologic approach was inconclusive (Whiting et al., 2001).

Price et al. (2009) completed a review of the literature on use of cognitive behavioral therapy for CFS. The review included 15 studies involving a total of 1043 participants with CFS. The results indicated that people who received cognitive behavioral therapy (CBT) were more likely to report a reduction in fatigue compared to those who received usual care or were on a waiting list. However, when people who had dropped out of the studies were included; there

was no significant difference between usual care and CBT. The review also examined other intervention techniques and found CBT to be more effective in reducing fatigue; but on “follow-up, the results were inconsistent and the studies did not fit well with each other, making it difficult to draw any conclusions” (Price et al., 2009, p. 2).

The Evidence for Key Components of a Post-Stroke Fatigue Education Program

Although the fatigue experience after neurological injury shares many characteristics, there are some behaviors that appear to have a stronger presence in post-stroke fatigue than with other conditions. Therefore, while the success of previous therapy interventions provided a model for the components of an educational program, any intervention program should address the characteristics which research has shown to have a significant presence post-stroke and which may impact the benefit of a fatigue intervention program. Among those characteristics are the presence of sleep related disorders and pain. Post-stroke pain is another prevalent but invisible disorder with multiple causes (Chari & Tunks, 2010; Harvey, 2010), which are beyond the scope of the current research. Researchers have identified key components of a fatigue management training program, discussed below.

The phenomenon of fatigue. Stroke survivors have reported that they did not feel prepared for the fatigue they experienced after their stroke (Roding et al., 2003). While acknowledging that healthcare professionals may have provided information on the phenomenon, it was not at the right time or under the right circumstances to be useful (Flinn & Stube, 2010). Many survivors had questions related to the presence of fatigue, the lack of control they felt over it, and why it had such an impact on their lives (Flinn & Stube, 2010). Methods of communicating with others presented additional challenges because fatigue is not

visible to others or may not be understood by caregivers, family, or friends. Education on the experience of fatigue and communicating its effects were therefore crucial elements of an educational training intervention program for post-stroke fatigue (Zedlitz et al., 2011; Clarke et al., 2012). Medications to manage chronic conditions often present fatiguing side-effects (Portenoy & Itri, 1999). There were also pharmacologic interventions that may directly address fatigue in chronic neurological conditions (Briochi et al., 2009; Cheville, 2009; Shah, 2009; Whiting et al., 2001). Proper diet has an impact on energy levels and may contribute to the experience of fatigue (Portenoy & Itri, 1999). Because people with chronic illness may not be aware of these factors, educational training interventions should include information about their role as related to increased fatigue. This concept was supported by the research conducted by Clarke et al. (2012) and Zedlitz et al. (2011) in post-stroke fatigue, Mathiowetz et al. (2001) in MS, Cheville (2009) in CA, and Whiting et al. (2001) in CFS.

The role of rest and sleep. Sleep and rest are important factors for maintaining health, performance of daily functions, and well-being (Sterr, Herron, Dijk, & Ellis, 2008). Sleep-related disorders have been shown to be highly correlated with cerebrovascular disease as they are linked with risk factors such as hypertension and heart disease (AHA, 2008; Bassetti, 2005). Sterr et al. (2008) reported that 50% of stroke survivors indicated a change in their sleeping habits after stroke and stated that there was a relationship between physical disability and poor sleep quality unrelated to depression or anxiety. Some of these changes may have been compensatory, such as longer duration of sleep in compensation for poor sleep quality (Campos et al., 2005). It has been surmised that sleep quality may result from lack of resumption of social and occupational daily activities after stroke as return of these activities may contribute

to reorganization of the sleep-wake cycle (Campos et al., 2005). The National Institute on Neurological Disorders and Stroke (2009) reports that medication, degree of physical disability, and anxiety are correlated with sleep-related disorders and need to be considered with therapy interventions after stroke. It has also been noted that people with poor sleep are more aware of pain (NINDS, 2009) or may experience poor sleep due to pain (Colle, Bonan, Gellez-Leman, Bradai, & Yelnick, 2006). Sleep-related disorders are correlated with post-stroke fatigue (Park et al., 2009) and linked with less favorable long-term outcomes (Bassetti, 2005). While obstructive sleep apnea has responded to continuous positive airway pressure (CPAP) (Bassetti, 2005), other sleep-related disorders have been successfully treated using a cognitive-behavioral approach (Knoop, van Kessel & Moss-Morris, 2012; Kwekkeboom et al., 2012; Edinger & Means, 2005). Cognitive-behavioral therapy for sleep-related disorders may integrate concepts of relaxation, stimulus control (a classical conditioning process to address timing and setting for sleep), sleep restriction (a regimen to restrict time in bed to sleeping rather than awake time), and sleep hygiene (healthy sleep habits) (Schwartz & Carney, 2012; Babson et al., 2010; Edinger & Means, 2005). Given the evidence that sleep-related disorders play a role in post-stroke fatigue, it is important to address issues of rest/sleep in therapy interventions for post-stroke fatigue. The use of CBT incorporating various concepts addressing sleep-related disorders is supported in the research protocols of Clarke et al. (2012) and Zedlitz et al. (2011).

Energy conservation. Interventions for fatigue depend on teaching specific strategies to evoke behavioral change and lifestyle modification delivered using methods that compel change rather than just provide information (Matuska et al., 2007; Bethoux, 2006). Energy conservation techniques are commonly used in occupational therapy to help persons with

chronic conditions manage their daily activities (Mathiowetz et al., 2005). Occupational therapy is uniquely qualified for this role due to knowledge about energy conservation principles including time management, efficient body mechanics, environmental modification, and task performance (Mathiowetz et al., 2001). Energy conservation involves the concept of a 'pool of energy' which can be managed in terms of adding to and withdrawing from energy stores (Bethoux, 2006; Packer et al., 1995). Common strategies include: analyzing and modifying daily activities, prioritizing activities to balance work and rest throughout the day, delegating tasks to others, using proper positioning of one's own body and objects for motor efficiency, and conserving energy through the use of adaptive devices. Research suggested that persons who do not feel as if they have the ability to change their fatigue experience (lack a sense of self-efficacy) reported that it has a greater impact on their daily lives (Di Fabio et al., 1998). Interventions taking a psycho-educational approach to increase self-efficacy were supported in the literature (Mathiowetz et al., 2007; Bethoux, 2006; Mathiowetz et al., 2005; DiFabio et al., 1998). Learning these concepts and interacting with other people who experienced fatigue were considered the most important components by participants in the intervention studies (Cheville, 2009; Mathiowetz et al., 2001; Sharpe et al., 1996).

Physical activity. The overall advantage of physical activity in maintaining energy levels has been widely reported (Cheville, 2009). Inactivity results in muscle catabolism, and prolonged rest can exacerbate fatigue. Activity also reduces stress (Dimeo, Rumberger, & Keul, 1998), may result in increased sleep quality, and reduced falls by as much as 30% in those at risk for falls (Physical Activities Guidelines Advisory Committee, 2008). Physical activity promotes feelings of "control, self-esteem, and independence" (Winningham, 2001, p. 992).

After stroke, “nervous system regenerative capability is greater than previously thought and early initiation of tailored programs and perseverance through the first two years is important” (Bassey, 2000, p. 28). Activity should start with what a person is used to and slowly increase in intensity while accounting for individual factors such as mental status, type of activity, intensity, frequency, duration, and progression (Cheville, 2009). Home-based interventions have been shown to be effective (Duncan et al., 1998). The goals for physical activity are to prevent complications from prolonged inactivity, to decrease the recurrence of stroke, and to increase aerobic fitness (Gordon et al., 2004). Studies support incorporating activities to improve aerobic fitness, strength, flexibility, neuromuscular functions of balance, and bimanual coordination (Gordon et al., 2004; Duncan et al., 1998). According to the Physical Activities Guidelines Advisory Committee (2008), 2.5 hours per week of moderately to vigorously intense activity achieves the desired outcomes of aerobic fitness. This translates to 30 minutes per day, five times per week and is supported by research (Cheville, 2009) showing support for repetitive movement (e.g., walking) and aerobic training at 75-80% maximum heart rate for 20-30 minutes, three to five times per week (Cheville, 2009) to address fatigue in chronic conditions.

The focus of graded exercise is not to push to the point of exhaustion but to maintain function by reducing overall debility (Levine & Greenawald, 2009) and counteract impairments that result from chronic disease; e.g., loss of muscle mass, decreased cardiac reserve, and impaired pulmonary ventilation (Winningham, 2001). The research protocols which have incorporated physical activity include: Zedlitz et al. (2011) (post-stroke fatigue) and Dimeo et al. (1998) (CA fatigue). Zedlitz et al. (2011) incorporated graded activity for endurance, muscle strength and flexibility training into their treatment protocol for out-patients experiencing post-

stroke fatigue. The purpose was to enhance physical fitness as well as to change participants thinking about their physical ability. Groups of four received two weekly treatment sessions, each two hours in duration, for 12 weeks using principles for progressively increasing aerobic intensity (increased total treadmill walking time as well as increased incline) and muscle load (weight lifting and core muscle exercises adapted for individual needs). Results from a pilot study by these authors were encouraging in terms of increased heart rate and muscle strength while the multi-center study is still in progress but showing positive preliminary results (Zedlitz et al., 2011).

This section provided research support for the inclusion of education on the phenomenon of fatigue, the role of rest and sleep, energy conservation, and physical activity as components of an educational training program for post-stroke fatigue. The following section examines the theoretical support for such an intervention program.

Theoretical Support for Group-Based Psychosocial Intervention in Managing Disabling

Conditions

The concept of health has undergone significant changes in recent years. Beginning with the WHO's (2001) revision of their disease classification system into ICF, attention has begun to shift from physical aspects of recovery as measures of successful outcome toward quality of life and well-being in an atmosphere of client-centered treatment. This shift adopts a bio-psycho-social model in which health is not seen as solely the absence of disease but also the management of chronic disability in conditions such as stroke (WHO, 2001). Management of disease and disability has been developed using the cognitive behavioral approach in which persons with chronic conditions are provided with skills to take greater control of their state of

health. This approach is based on Bandura's Theory of Self-Efficacy (Bandura, 1995). In order to provide the foundation for development of a group-based educational training program for post-stroke fatigue proposed in this paper, a review of self-efficacy theory, cognitive behavioral therapy, and the role of occupational therapy are presented here.

Self-efficacy theory. The idea that people's health rests, in part, in their own hands has gained acceptance in recent years. Lifestyle habits are seen as having a pivotal role in health maintenance. Perceived self-efficacy refers to "beliefs in one's capabilities to organize and execute the courses of action required to manage prospective situations" (Bandura, 1995, p. 2). Efficacy beliefs affect consideration of changing health habits, perseverance and motivation to begin a course of change, and maintenance of those changes over time. Self-efficacy requires one to build skills to influence motivation and behavior. Effective programs to promote healthier living require participants to monitor the behavior they wish to change, to set individual goals to achieve successes toward broader behavior changes, and to utilize social support in order to sustain the effort (Bandura, 1995).

Bandura (1995) identified four means by which self-efficacy is developed. The first and most effective method was through mastery experiences, which represented successful actions taken by the person wishing to change their behavior. As Bandura stated (1995, p. 3) it "is not a matter of adopting ready-made habits. Rather it involves acquiring the cognitive, behavioral, and self-regulatory tools for creating and executing appropriate courses of action to manage ever-changing life circumstances". Bandura identified four components of intervention effective in providing mastery experiences relative to health behavior: increasing awareness and knowledge of health risks; developing self-regulatory skills for control over health habits;

providing repeated opportunities for practice of new skills; and drawing on social support to maintain changes. The second influence was achieved through vicarious experiences gained by observing the successful actions taken by social models. It was critical that the people observed be seen as similar to the individual; if they were very different, they would not influence behavior changes. Social participation was the third method identified. The idea was that people will make the effort to change behaviors and maintain that change if they are verbally (socially) persuaded that they have what it takes to be successful. This influence to make the attempt then cycles into self-affirmation of the necessary skills through success experiences and perpetuates self-efficacy. The last method, physiological arousal, was identified as a combination of enhanced physical abilities, reduced stress and tendencies toward negative emotions, and more accurate interpretation of bodily states. Self-efficacy beliefs developed as a result of complex cognitive processing and were positively correlated with the intention to engage as well as the actual engagement in health promoting behavior. Once in place, they contributed strongly to the level and quality of human functioning (Bandura, 1995).

The application of self-efficacy theory using a group based approach in chronic disease treatment was supported in the literature. Education-based self-management interventions have been used to benefit persons with osteoarthritis (Allegrante & Marks, 2003), chronic obstructive pulmonary disease (Bourbeau, 2003), CA (Haas, 2000), and chronic pain (Arnstein, Caudill, Mandle, Norris, & Beasley, 1999). As an example, Lorig et al. (2001) assessed health status, healthcare utilization, and self-efficacy outcomes for several chronic diseases (heart disease, lung disease, stroke, and arthritis) using the Chronic Disease Self-Management Program (CDSMP). The CDSMP intervention was a peer-led, community-based program of

seven weekly sessions. Content addressed exercise, cognitive symptom management, nutrition, sleep management, medication use, community resources, managing emotions, communication with health professionals, and health-related problem solving. Data was collected from 831 participants at baseline, at one-year, and at two-year follow-up. Emergency room and outpatient visits were reduced and self-efficacy increased for the CDSMP participants, leading to the conclusion that it provided a low cost means of improving health status in diverse chronic conditions.

Cognitive behavioral therapy (CBT). Cognitive behavioral therapy involves cognitive processing as a fundamental aspect of treatment that attempts to change distorted thinking and unrealistic goals and to develop a knowledge base for problem solving (Bruce & Borg, 2002). CBT developed from the merger of Beck's cognitive theory, Bandura's self-efficacy theory in social psychology, and some tenets of behavioral theorists. The result was an emphasis on the "role of cognitive processes in understanding behavior, developing self-control... and furthering the efficacy of behavioral intervention" (Bruce & Borg, 2002, p. 164).

Bandura's (1995) work most closely supports one of the underlying premises of occupational therapy: that active engagement (doing) results in change (adaptation). In this way, CBT moved away from the reliance on verbal methods of intervention and toward experiences that allowed the person to feel capable of success. Using CBT, the therapist acts as an educator-facilitator who provides structured experiential and self-directed learning opportunities (Bruce & Borg, 2002). Therapy sessions begin with a verbal component during which information and the rationale behind activities is provided. Discussion is encouraged to allow frequent feedback to participants about specific behaviors and thoughts. The session

proceeds with meaningful activities to encourage cognitive and skill development and to allow participants to practice techniques for understanding and to problem solve resources for any difficulties they encounter. Homework is a common aspect of CBT as it provides an opportunity to apply the new skills and resources in context. The homework assignments become the focus of discussion at the subsequent CBT session to reinforce positive behaviors and to offer resources for obstacles encountered. In CBT, it is the sense one has of one's own efficacy that influences goals, problem-solving, and participation as these are related to health maintenance and prevention of functional problems. When cognitive behavioral techniques are used effectively they "foster adaptive behaviors, promote successful management of health-related problems, and increase control and self-efficacy over the consequences of symptoms" (Shevil, 2008, p. 19). Use of cognitive behavioral processes has been recommended in chronic conditions (such as stroke). The techniques of CBT aim to increase one's knowledge and to strengthen that knowledge into skill building through active problem solving. Their benefit comes from the attention to practical problems, provision of information (knowledge and resources) about the problem to promote decision-making, and empowerment of individuals to take control of their health, especially with problems that require daily management (like fatigue) (Bruce & Borg, 2002).

CBT has been researched in people with CA (Gielissen et al., 2007), CFS (Prins et al., 2001), MS (Thomas et al., 2010), arthritis (Lorig, Mazonson, & Holman, 1993), and insomnia (Edinger & Means, 2005; Schwartz & Carney, 2012). As an example, Prins et al. (2001) compared three groups with CFS; one received CBT, another received guided support, and the last was considered the control condition by experiencing only the natural course of the

disease. Measurements were taken of fatigue severity using the Checklist Individual Strength and functional impairment using the Sickness Impact Profile. CBT was found to be significantly more effective for both measures taken than either the control (natural course) or alternate treatment (guided support) conditions (Prins et al., 2001).

The role of occupational therapy. The foundation of occupational therapy (OT) is the provision of activities to increase a person's engagement in occupations (everyday activities) to support participation (AOTA, 2014). The guiding principles of OT, found in the OTPF (3rd ed.) (AOTA, 2014), incorporated concepts from the ICF to reflect current practice since the ICF acknowledged that health was affected by activity and participation (WHO, 2001). The combined use of tasks and activities with practice, feedback, and discussion is at the core of OT intervention. For OT intervention to be successful, clients must be provided with opportunities to practice new strategies and skills allowing change in performance to occur through active engagement (doing). Since stroke is now viewed as a chronic condition, it requires survivors to engage in activities to create behavior and health changes in order to increase quality of life and reintegration (Wolf, Baum, & Connor, 2009).

The theory of occupational adaptation supports group-based intervention as it addresses the person, the occupational environment, and the interaction of the two. The OT group leader uses interactive reasoning and clinical reasoning to provide a supportive environment where experiential learning can occur among group members. This learning develops from the structure of the activity (naturally occurring demands for performance), the immediate skill practice provided in the group format (demonstrated ability to adapt), and the success experienced through adaptations that meet the needs of the person and group

members (Schultz, 2009; Schwartzberg et al., 2008). An occupational therapist as leader grades the activities to provide progressive challenges and success experiences for group members; in the terms of self-efficacy theory, mastery experiences, and physiological arousal. Group intervention also provides a forum for vicarious experiences as individuals learn from the experiences of others with whom they are interacting.

A Theoretical Basis for Group-Based Rehabilitation Therapy

Group-based intervention has been a valued method used in occupational therapy since the origin of the profession (Schwartzberg et al., 2008). Grounded in the moral treatment period, the use and focus of groups has evolved as influenced by socioeconomic and political forces. The functional group model was first developed in mid-1980s “to incorporate the use of purposeful activity and meaningful occupation into the process and dynamics of group work” (Schwartzberg et al., 2008, p. 84). Five areas of research contributed to the development of the functional group model: (1) group dynamics (the interrelationships of group members); (2) effectance (the idea that people are interested in being active and this is self-motivating); (3) needs hierarchy (people have needs arranged in terms of importance and unmet needs are the source of motivation); (4) purposeful activity (a method of meeting needs); and (5) adaptation (engaging in personally meaningful occupations results in learning or overcoming a challenge situation). Benefits of groups are that members act as models of behavior through the active give-and-take process of the social system of a group and that participants gain a sense of self-worth and self-efficacy by actively engaging in the group exercises (Schwartzberg et al., 2008). Assumptions of functional groups, as was used for the current study, include encouragement for each member to take charge of meeting their individual needs, that purposeful activities

presented in groups are effective in improving individual levels of performance, and that active engagement in a group facilitates development and maintenance of occupational skills (i.e., ADL or leisure) (Schwartzberg et al., 2008). Group-based educational training seems to be an ideal forum for promulgating cognitive-behavioral strategies that may reduce post-stroke fatigue and its impact on daily activities.

Group-Based Therapy for Post-Stroke Fatigue

There is a glaring lack of progress into the investigation of interventions for post-stroke fatigue. This is true despite the overwhelming evidence acknowledging post-stroke fatigue as a significant concern itself and as a major source of decreased participation in daily activities. Research on pharmacological interventions for post-stroke fatigue has been inconclusive. Studies examining group-based fatigue management for other neurological disorders, however, suggest a promising approach that may be applicable to the treatment of post-stroke fatigue. Self-efficacy theory provides support for the use of a cognitive-behavioral approach to post-stroke fatigue interventions.

To date, two studies have been published that address post-stroke fatigue using a group-based educational approach. However, as reviewed previously, these studies differed from the current research study in important ways. Zedlitz et al. (2011) did not include community-dwelling stroke survivors, had the group intervention provided by a neuropsychologist complimented by individual physiotherapy sessions, and reported inconsistent application of cognitive behavioral techniques. The study did report successful reduction of fatigue but focused performance outcomes on strength, endurance and walking. The second study by Clarke et al. (2012) included stroke survivors in the acute stage of

recovery, did not include a measure of functional performance to link to fatigue, and the reduced fatigue reported did not reach statistical significance. Intervention was provided by clinical psychologists who are not skilled in addressing limitation in everyday activity performance.

The current study proposed to determine whether a group-based educational training program could be effective as an intervention for post-stroke fatigue. This study included the development and evaluation of a group-based educational training program to increase self-efficacy and problem-solving strategies in stroke survivors with fatigue to address these shortcomings. Chapter Three describes the research plan and its methodology.

Chapter Three: Methodology

Introduction

The purpose of this study was to provide evidence that a group-based educational program could be successful in relieving chronic post-stroke fatigue and improving participation in daily activities. This section provides details about the chosen method including hypotheses, participant selection, intervention, measurement tools, procedures and statistical analysis of the data collected.

Approval

The researcher received approval for this study from the Institutional Review Committee Panel B: Social/Behavioral Research at Virginia Commonwealth University. The approval letter is in Appendix A. A copy of the Informed Consent is also included in that Appendix.

Hypotheses

The study examined the premise that participation in a group-based fatigue management training program for people with chronic fatigue post-stroke would decrease fatigue and increase functional activity. Study hypotheses included:

- H_{A1} = The severity of self-reported fatigue post-stroke would be reduced after participation in the training program as indicated on the Fatigue Severity Scale.

- Ho1= The educational program would have no effect on the severity of fatigue post-stroke as measured by the Fatigue Severity Scale.
- H_A2= The self-reported functional impact of fatigue post-stroke would be reduced after participation in the training program as measured by the Physical Self-Maintenance Scale + Instrumental Activities of Daily Living.
- H_O2= The functional impact of fatigue would not change after participation in the training program, as measured by the Physical Self-Maintenance Scale+ Instrumental Activities of Daily Living.

Design Rationale

The study protocol was modeled on a group-based intervention for fatigue management that had proven to be successful for people with MS (Mathiowetz et al., 2001) adding components to address issues found to impact fatigue in CA (Portenoy & Itri, 1999), CFS (Whiting et al., 2001), and post-stroke fatigue (Clarke et al., 2012). The study design incorporated principles of cognitive-behavioral therapy and self-efficacy theory using a group-based format. The intervention program was intended to foster group interaction and active problem solving on the part of the participants. Specifically, the concepts supported were:

- Group-based intervention provided key elements of self-efficacy theory; namely mastery experiences, vicarious success, and social models;
- Program format incorporated lecture, written materials, practice time, and homework to address multiple learning styles;
- Active problem-solving was encouraged by asking participants to practice learning at home and to share difficulties and successes with others in the group;

- Groups of 8-10 members are optimal for psycho-educational group process (Ettin, Heiman, & Kopel, 1988).

Seven measurement tools were used in this study (refer to Table 1). Since other conditions result in fatigue, some measures served to inform inclusion/exclusion decisions that also involve depression, sleep-related disorders, and motor and cognitive limitations.

Assessments of changes to the experience of fatigue and changes to the impact fatigue had on daily activities were used as the outcome measures. The intent was first to show that post-stroke fatigue and its impact could be reduced and second to provide an occupational therapy intervention for fatigue in chronic stroke.

Table 1

Participation Criteria per Assessment Tool score

| Assessment Tool | Cut-off Score |
|--|--|
| Demographic questionnaire | Not applicable |
| Fatigue Severity Scale | ≥ 4 indicates a high likelihood of fatigue |
| Physical Self-Maintenance- IADL Scale | Not applicable |
| Center for Epidemiologic Studies- Depression | ≥ 16 indicates a high level of depression |
| National Institutes of Health Stroke Scale | ≤ 1 on level of consciousness, motor arm and motor leg questions |
| Pittsburgh Sleep Quality Index | ≥ 8 recommended for clinical populations |
| Intervention Satisfaction Survey | Not applicable |

Study Design

This mixed methods; quasi-experimental study included quantitative and qualitative components. The quantitative design followed an A-B-C design specifically using a repeated measures with double pre-test and double post-test (Shadish, Cook & Campbell, 2002).

Qualitative data was gathered using a satisfaction survey developed by the researcher to assess program contents. Phase A was a seven-week, non-intervention period prior to intervention;

Phase B was the seven-week, intervention period; and, Phase C was the seven-week, post-intervention period. To achieve the 20 participants needed for this pilot study, the research protocol was repeated at three facilities. Group membership varied by site but ranged from 6 – 9 individuals. Table 2 outlines the procedures. The repeated measures design was appropriate to capture change over time during non-intervention, intervention, and post-intervention periods. This design provided the basis for comparison of change on the measures of fatigue and ADL/IADL performance. Threats to validity from maturation, history, and regression are reduced by measuring these variables before and after the intervention (Polit & Beck, 2008, Shadish et al., 2002). Use of a second pre-test provided a measure of any change in function in the absence of intervention as well as a means to examine biases in the determination of observed effects. The use of multiple post-tests contributed to a more sound causal analysis as the “ambiguity about temporal precedence of cause and effect” (Shadish et al., 2002, p. 158) was reduced. This temporal separation of outcome measures allowed analysis of “carry-over” effects of the treatment, which might then be more clearly attributed to the intervention.

In order to preserve integrity of the data, steps were taken to blind the researcher to participant scores at every data collection point. An occupational therapy colleague of the researcher agreed to participate as the Research Assistant. The Research Assistant had earned her Doctorate in Occupational Therapy and specialty certification in Geriatric Care Management. The Research Assistant received instruction on administration and scoring of all research measures. The Research Assistant was present at all recruitment events in order to explain the blinding procedures to potential participants. Upon recruitment, the Research Assistant completed the first visit process and, in collaboration with the researcher, established

Table 2

Study Design and Assessment Timeline

| Timeline by Group | Phase |
|--|--|
| Recruitment Group 1- Wk 1 Group 2- Wk 18 Group 3- Wk 25 | Explained purpose and procedures of the study, distributed the informed consent for consideration, and scheduled a first visit one week later. |
| First visit Group 1- Wk 2 Group 2- Wk 21 Group 3- Wk 25 | Collected informed consent, completed demographic questionnaire, administered first pre-tests (FSS and PSMS-IADL), and administered measures to determine inclusion (NIHSS, PSQI, and CES-D). |
| Phase A Group 1- Wk 2-9 Group 2- Wk 21-28 Group 3- Wk 26-33 | Seven week long, non-intervention period began |
| Phase B Group 1- Wk 10-17 Group 2- Wk 29-36 Group 3- Wk 34-41 | Administered second pre-test (FSS and PSMS-IADL); seven weekly, group intervention sessions began Intervention Satisfaction Survey completed during last group session |
| Phase C Group 1- Wk 18-25 Group 2- Wk 37-45 Group 3- wk 42-49 | Administered first post-test (FSS and PSMS-IADL); seven week, post-intervention period began. Second post-test administered during last week (FSS and PAMS-IADL), conclusion of participation. Gift card winner selected and gift card delivered. |

the data collection timeline for all phases of the research for each group. The Research Assistant administered all assessment measures. Communication occurred at least weekly during the data collection period to assure continued adherence to the procedures. The Research Assistant stored data in a locked filing cabinet in her office until completion of the group's research participation and then turned it over to the researcher for data entry and analysis.

Determination of Variables

The dependent variables of this study were self-ratings of severity of fatigue and its impact on ADL/IADL performance. Fatigue is defined as a subjective experience of lack of energy, physical or mental exhaustion (Lynch et al., 2007). Fatigue was measured using the FSS; a 9-item self-rating scale for which participants rated their agreement with the provided statement. Level of impact of fatigue indicated how much of a problem it was relative to participation in daily activities. Impact was measured using the PSMS-IADL Scale. (See Appendix B through H for all research measures).

The independent variable was the educational training program. The intent of the program was to reduce the experience of chronic fatigue post-stroke by providing educational tools and interactive group experiences in areas that have been shown to have been successful in reducing the fatigue experienced in other conditions (such as energy conservation and activity) and which literature indicated may impact post-stroke fatigue (such as communicating to others and sleep-related disorders).

Co-variables included depression, sleep-related disorders (such as sleep apnea), and physical or cognitive limitations; these factors influenced the experience of post-stroke fatigue. To reduce the possible effects of these variables, pre-assessment tools were used to measure them. In the case of physical or cognitive limitations and presence of sleep-related disorders, scores resulted in volunteer exclusion from the study based on predetermined limits. Presence of social support, sex, age, and level of care (personal care versus independent living) were analyzed to determine their correlation to the dependent variables.

Participant Selection

Convenience sampling was used for this study. Participants were recruited from Personal Care or Independent Living areas of retirement communities in Lancaster and Berks Counties in Pennsylvania (See Appendix I for recruitment flyer sample). In the Personal Care, or Assisted Living level, residents are provided with assistance for activities of daily living, coordination of services from outside health providers, and monitoring of activities for health, safety, and well-being (personal communication Becky Weber, January 2014). Those who reside in Independent Living are responsible for all activities but can be admitted to areas of increased care as needed for changing health conditions.

Inclusion criteria for participation in the research study was: 1) self-reported diagnosis of chronic stroke (at least one-year post event and a minimum hospitalization of one night to exclude survivors of transient ischemic attack), 2) a minimum age of 18 years, 3) significant levels of fatigue on the pre-test administration of the FSS, 4) absence of significant levels of depression as measured on the CES-D, 5) absence of sleep-related disorders as measured on the PSQI, 6) a determination of functional ability to participate in the group sessions as measured by the NIHSS, and 7) completion of an informed consent. Exclusion criteria were: 1) stroke occurrence less than one year ago or diagnosis of transient ischemic attack, 2) under 18 years of age, 3) lack of significant fatigue as measured by the FSS, 4) presence of significant levels of depression, 5) presence of sleep-related disorders for which a physician visit will be recommended, 6) inability to attend the education program due to physical, visual-perceptual, speech, or cognitive limitations to the degree that the measurement tools cannot be completed and active participation in the cognitive-behavior based intervention sessions are not possible,

and 7) incomplete or missing data on the measurement tools. Refer to Table 2 for inclusion/exclusion scores for each measure used. Although the PSMS-IADL scale was used to measure the impact of fatigue on daily function, some studies indicate that the impact of fatigue is often masked by adaptations made to avoid the impact of fatigue by post-stroke survivors who experience fatigue (Robison et al., 2009; Carlsson et al., 2004). Therefore, there was no inclusion/exclusion score for that measurement tool. For all pre-test and post-test procedures, the measurement tools were completed by Research Assistant in order to keep results blind to the researcher for enhanced validity.

To measure depression (a symptom highly correlated with fatigue (Ingles et al., 1999), the Center for Epidemiologic Studies-Depression (CES-D) tool was used. The Pittsburgh Sleep Quality Index (PSQI) was used as a measure of sleep-related disorders. Sleep apnea has been successfully reduced using Continuous Positive Airway Pressure (CPAP); any volunteer showing sleep apnea issues, while excluded from the current study, was recommended to pursue a sleep study. The National Institutes of Health Stroke Scale (NIHSS) was used to assess physical impairments that would make participation in the group untenable (severely limited use of the hemiparetic side, inability to follow directions or maintain attention for the intervention program). A demographic questionnaire was completed in order to describe the study participants. It included questions on age, gender, ethnicity, social support (presence of a caregiver, spouse or family member to assist with self-maintenance or IADLs), and years since stroke occurrence. An Intervention Satisfaction Survey was also used to collect participants' perspectives on methods to improve future iterations of the group-based educational program. All measurement tools are included in Appendix B through H.

Led by the researcher, the educational program was offered three times in order to ensure adequate participation for this pilot study (n= 20), while keeping the group size manageable (8-10). Prior to the program, members of the retirement community were invited to attend the program by placing flyers (Appendix I) in community mailboxes and identifying a facility representative. The researcher and Research Assistant provided community-wide information sessions as scheduled with the facility representative. Interested individuals were encouraged to contact someone on the research team and had questions concerning the study answered. Volunteers for each of the groups were offered the opportunity to participate in a raffle drawing for \$25 gift cards and three were awarded after completion of the study.

Description of the Setting

Participants for this research study were recruited from two continuing care retirement communities in south-central Pennsylvania: Garden Spot Village and Phoebe-Devitt Homes. Garden Spot Village is a non-profit, moderately sized continuing-care community in New Holland, PA. It offers seniors independent living options as well as personal and skilled care residency. It is a values-based community with a mission to enhance the lives of older adults. Phoebe-Devitt Homes is not-for-profit organization of Phoebe Ministries, providing retirement living facilities in 14 locations. The mission of Phoebe Ministries is to serve the needs and enhance the lives of elders. Two sites were approached and agreed to participate in this research study: Phoebe–Berks, and Phoebe-Allentown.

Residents of the Independent Living and Personal Care living areas were invited to participate as they represented the population of chronic stroke survivors of interest to this study. At both communities, a private dining room in the Village Center was used to provide the

educational sessions. The Center was where all residents collect mail and attend community events and was centrally located within the community. The room was large enough to allow practice activities as indicated in the program. Chairs were arranged in an open circle for the presentation of the topic. During activity stations sessions, participants moved around as indicated by the activity for practice and returned to the seated area for wrap-up. Restrooms were available outside the private dining room for ready access.

The groups were held at a time that was convenient for the residents and avoided alternate programming to the extent possible as coordinated with the facility staff. The groups were held weekly between 9am and 1pm, which was considered ideal timing to not disrupt sleep routines.

Measures

The objective of the research study was to determine if a group-based educational training approach can be successful in decreasing the severity of fatigue and its impact on participation in daily activities as measured by the FSS and the PSMS-IADL. The CES-D, PSQI, and NIHSS were used to exclude participants who had scores indicating presence of co-variables that may limit full participation in the educational program. Refer to Table 2 for scoring criteria to determine participation.

Information about the participants was gathered using a demographic questionnaire in order to describe the participants and make comparisons to the general stroke population as indicated and to assure group equivalency. The measurement tools used in this research study, of which some are self-report scales, are valid and reliable measures of the dependent variables (fatigue severity and impact on ADL and IADL performance) and the co-variables (depression,

sleep-related disorders, and physical and cognitive impairment levels). (Refer to Appendix B through H for copies of each assessment tool). Potential confounding variables of the presence of social support, sex, age, and level of care (Personal Care versus Independent Living) were analyzed for correlations to the fatigue experience. Self-report scales are advantageous to use when assessing subjective experiences like fatigue that may be difficult to describe to others but have the limitation of not being verifiable by observable behavior (Polit & Beck, 2008).

The FSS (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989) is the most frequently used measure of fatigue in the literature (Bethoux, 2006, Clarke et al., 2012). It is a nine-item self-report questionnaire scale. Each item is graded one (strong disagreement) through seven (strong agreement); the final score is the total of the items. The FSS has an internal consistency, Cronbach's alpha, of .93 and correlation to the Visual Analogue Scale of .69. Test-retest reliability is .84. (Krupp et al., 1989).

The PSMS-IADL was developed in 1969 (Lawton & Brody, 1969) and is freely accessible for use. It contains 30 items in the categories of toileting, feeding, dressing, grooming, physical ambulation and bathing (the physical self-maintenance scale). Each item provides five selections from independent to dependent but is scored dichotomously; 1= independent; 0= all other choices. The IADL portion contains eight categories: ability to use the telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medications, and ability to handle finances. Each category provides three to five choices differing in degree of independence with the activity with multiple levels resulting in a score of one. Individual item scores are tallied for an overall sum. Results of reliability testing show reproducibility coefficient of .95 and correlation coefficient (Pearson's r) of .87 for the PSMS

and an inter-rater reliability of .85 for the IADL scale (Lawton & Brody, 1969). Validity was tested via Pearson correlations which were in the moderate range of .31 to .74 supporting validity of the measures compared to other functional measures (Lawton & Brody, 1969).

The CES-D (Radloff, 1977) is a self-administered, 20-item self-report measure of depression, which asks participants to indicate the number of occurrences of feelings or behaviors over the past week. Respondents indicate the frequency of feelings by circling a number between zero (rarely) and three (most or all of the time) and the final score is the sum of these ratings. The CES-D has a Cronbach's alpha of .91 and test-retest of .67. In comparison to the Raskin Depression Scales, concurrent validity of the CES-D is .8 (Locke & Putnam, 2010). Because of the strong correlation between fatigue and depression, volunteers who had a high score on the CES-D (>16) were excluded from participation.

The NIHSS is a 15-item measure of level of consciousness, eye movement, visual field deficit, and motor and sensory involvement and has been shown to be predictive of both short and long term outcomes for people with stroke. Items are scored by degree of severity using weighted scores (Lyden et al., 1999). It is commonly used as a deficit classification tool in clinical assessment and stroke research (D'Olhaberriague, Litvan, Mitsias, & Mansbach, 1996). It was used in this study as measure of physical limitation to inclusion. Content validity was attained by item selection based on expert opinion and literature review. Interclass correlation coefficients were rated as .95 among neurologists; .94 between neurologists and nurses (Dewey et al., 1999).

The PSQI is a self-rated questionnaire about sleep quality and disturbances over the past month. Nineteen items are combined into seven component scores of subjective sleep quality,

time to fall asleep, duration of sleep, sleep efficiency, disturbances, use of medications for sleep, and daytime functional impairment (Buysse, Reynolds, Monk, Berman & Kupfer, 1989). Although developed for the psychiatric population, it has become a tool commonly used with various diagnostic groups as well as normal participants to determine quality of sleep. Carpenter and Andrykowski (1998) suggest a higher cut-off score than recommended by the authors of the PSQI since the mean score for populations with sleep problems was 8.0 rather than 5.0. Measures of reliability and validity resulted in an internal consistency of .83, test-retest reliability of .85, sensitivity of 89.6% and specificity of 86.5% in differentiating good from poor sleepers (Buysse et al., 1989). In this study, the PSQI was used to exclude participants with possible sleep apnea. Anyone who tested positive for sleep apnea was referred to their doctor for further assessment; no one required this referral during the study.

As this was a pilot study of the group-based intervention program, an Intervention Satisfaction Survey tool developed by the researcher was used to gather data from participants at the conclusion of the intervention in order to improve future iterations of the program. Participants were asked to indicate overall satisfaction with the components of the sessions, their expectations for future use of the strategies, attendance, and what additional information they would have liked to have been included.

Materials

The group-based intervention was intended to achieve the following goals: to increase participants' knowledge related to post-stroke fatigue; to increase the participants' self-efficacy in managing post-stroke fatigue; and to provide participants with strategies to reduce the effects of post-stroke fatigue on activity participation (refer to Table 3).

Table 3

Program Goals and Objectives

| Program Goals | Objectives |
|---|---|
| 1. Increase knowledge related to post-stroke fatigue. | <ul style="list-style-type: none"> ✓ Identify symptoms ✓ Identify the impact of fatigue on activity participation |
| 2. Increase self-efficacy in managing post-stroke fatigue. | <ul style="list-style-type: none"> ✓ Report increased levels of control |
| 3. Provide strategies to reduce effects of post-stroke fatigue for improved activity participation. | <ul style="list-style-type: none"> ✓ Name problems related to the fatigue experience ✓ Use strategies to generate solutions to identified problems ✓ Communicate the impact of fatigue to others, such as caregivers, family, friends, or healthcare professionals |

While the educational training program incorporated some concepts from the energy conservation course developed by Packer et al. (1995) that were successful in addressing fatigue in other conditions (Matuska et al., 2007; Mathiowetz et al., 2005; Mathiowetz et al., 2001), components that address characteristics of post-stroke fatigue have also been developed. Using the cognitive-behavioral approach, each session included information on the specific topic, activities to practice the concepts, and assignment of homework for real-life application. Each session began with a discussion of successes and failures with those application attempts. Review of homework at the start of each subsequent session provided for active problem-solving among the group members as well as mastery and vicarious success experiences. Each participant was provided with handouts for each program session to highlight key items of the presentation and to reduce the need for note taking, which may have

distracted the participants from full attention during the lecture presentation. Homework assignments were provided via handouts and explained during the session. Participant notes from their homework were used by the participants to track the strategies employed and enhance recall of problem-solving attempts for group discussion.

Procedures

The education program was composed of seven weekly sessions, each lasting 60 minutes and led by an OT. The group format utilized a cognitive behavioral approach based on self-efficacy theory and occupational adaptation theory. The purpose was to provide participants with problem-solving strategies that could be applied to novel situations that arose in daily living by providing mastery experiences, vicarious success, and social models to guide learning (Bandura, 1995). The program presented information about post-stroke fatigue, sleep-related disorders, managing energy using energy conservation concepts, and being active according to the following session outline:

1. Understanding and communicating about post-stroke fatigue
2. Building energy: Pacing and reducing stress
3. Sleep-related disorders and their management
4. Building energy: Being active and modifying activities
5. Budgeting energy: Prioritizing and planning
6. Activity scheduling
7. Course review and goal setting

Each session began with a review of the homework from the previous session, moved to presentation of that session's topic including practice exercises, and concluded with a review of the information, a clarification of the homework for the next session, and a reminder of the date of the next session. This format allowed participants to apply the concepts presented

during the education sessions in their daily routine and bring concerns or issues back to the group for assistance and problem solving. Homework was assigned as well to ensure practice of the information and served as the basis for the problem-solving discussions (refer to Table 4 for details on each session topic).

Initial assessment. The research study was explained during open forum sessions sponsored by the facility. Volunteers, or interested individuals, were provided more detailed information as requested during more private sessions. These volunteers were then provided time (one week after recruitment) to fully consider participation. The Research Assistant met with each individual in their home to complete the first visit after that week. This included collection of the signed informed consent, completion of the demographic questionnaire, FSS, PSMS-IADL Scale, CES-D, NIHSS, and PSQI (Refer to Table 1 for the timetable of assessment). A numerical identifier was used on all forms in the event that data needed to be removed. These procedures were followed for all 20 participants at all locations. All assessments were stored in a portable, locked file box between meetings and will be stored for the duration of the study in a locked file cabinet at the researcher's home.

Non-intervention phase. To provide a comparison condition, participants received no intervention for a period of seven weeks following acceptance into the study. At the end of this time period, the Research Assistant scheduled a meeting to re-administer the FSS and PSMS-IADL measures. Scores were tallied to be compared to the initial scores to determine if there was a change in fatigue levels or its impact on daily activities.

Group-based educational intervention phase. The educational sessions began in a lecture/discussion format led by the researcher. Each group session followed this format:

Table 4

Intervention Program by Session.

| Session | Activity | Homework |
|---------|--|---|
| 1 | Discussed purpose, goals and format of the program Discussed terminology and current concepts about fatigue (invisible disabilities and attitudes of others) Developed strategies to communicate effectively | Explain fatigue to a friend and ask for help to complete an activity Keep notes on difficulties and successes with the homework and questions or lingering issues. |
| 2 | Reviewed Homework 1 Discussed the importance of pacing and reducing stress Practiced relaxation and elements of a rest schedule | Create a rest schedule including activities that are required and preferred Continue note taking of difficulties and successes |
| 3 | Reviewed Homework 2 Presented terminology and concepts (relaxation, stimulus control, sleep restriction, and sleep hygiene considerations) Generated group ideas on activities to make you tired and ready for sleep | List activities that were effective in making you tired Develop three strategies to improve sleep experience. Continue note taking of difficulties and successes and lingering issues or questions. |
| 4 | Reviewed Homework 3 Presented terminology and concepts on being active, body mechanics/ergonomics, and arranging work areas Generated ideas on modification strategies | Complete the work area modification activity Continue note taking of difficulties and successes with modifications and any lingering issues or questions |
| 5 | Reviewed Homework 4 Presented concept of building energy by prioritizing and planning Completed activity analysis form | Complete Activity Modification activity Continue note taking of difficulties and successes with modifications and any lingering issues or questions |
| 6 | Reviewed Homework 5 Presented concepts of balancing rest and activity Completed daily analysis worksheet | Complete weekly schedule Continue note taking of difficulties and successes with modifications and any lingering issues or questions |
| 7 | Reviewed Homework 6 Established short- and long-term goals Wrap-up: Discussed lingering concerns or questions | In session: Complete Intervention Satisfaction survey |

1) discussion among participants focused on review of previous homework (15 minutes); 2) a teaching session (15 minutes); 3) practice activity and homework (20 minutes); and 4) a summary (review of the session, clarification of the homework, and reminder of the next session date) (10 minutes). The first session began with an overview of the program and introduction of members. Participants were provided with handouts as appropriate to reinforce the topic of the day and to facilitate carry-over of the concepts in their home environments. Handouts contained the information provided in the teaching portion of the session for easy reference by participants. Participants were asked to take notes to record their successes and challenges in completing the homework assignments; these notes formed the basis of the group discussion that started each session. At the conclusion of the seven-week program, participants again completed the fatigue and activity participation measures (FSS and PSMS-IADL, respectively) with the Research Assistant.

Post-intervention phase. Seven weeks after the conclusion of the group-based educational program, participants were contacted to complete the fatigue and activity participation measures (FSS and PSMS-IADL) to allow analysis of the long-term carryover of the information presented during the intervention.

Statistical Analysis

Demographics of the groups were summarized using measures of central tendency and variance. Scores on the CES-D, the NIHSS, and the PSQI determined inclusion or exclusion and were measured only at the first, pre-intervention data collection point. Scores on the measures of the dependent variables of fatigue and level of activity participation (i.e., FSS and PSMS-IADL, respectively) were compared across data collection points in order to test the hypotheses that

both the severity of fatigue and the impact of fatigue on participation in daily activities would decrease after participation in the group-based educational training program. The statistical software package SPSS version 22 and Excel tools were used to calculate the mean of the scores from the double pre-intervention and post-intervention data collection points. A repeated-measures analysis of variance (RM-ANOVA) was used to determine if change occurred (significance $p < .05$). Since the same participants represent the different conditions of measures; there was a relationship between scores. In order for the statistical analysis to be valid, the variances of the differences between conditions must be equal. This is known as the 'assumption of sphericity' and was calculated using Mauchly's test in SPSS (Field, 2009). If there is a violation of sphericity, Mauchly's test will provide a corrected F -statistic.

To analyze whether presence of social support, sex, age, or level of care influenced fatigue or activity participation scores, these potential confounding variables were entered as grouping variables in the RM-ANOVA. The categorical variables of age and sex were analyzed using Chi-square (χ^2) to check for any relationship. Survey review was conducted on the results of the Intervention Survey. Since this was a pilot study of the group-based educational program, feedback gained from the survey results will be used to modify the intervention program to better meet participants' needs in future iterations.

Summary

Post-stroke fatigue is a common problem that may limit participation in everyday functional routines. Emerging evidence suggests that group-based training in fatigue management may be an efficient means of reducing the effects of post-stroke fatigue.

Evaluating intervention approaches for this pervasive symptom of stroke is important in order

for occupational therapists to address the participation goals of patients whom they treat. This pilot study used a quasi-experimental, mixed methods design to assess the effectiveness of a group-based educational training program in relieving fatigue severity and its impact on activity participation experienced post-stroke. A convenience sample of stroke survivors (n=30) was invited to participate in the research, which included a seven-week long, group-based intervention. The group sessions provided content related to relief of post-stroke fatigue and to foster active problem solving and lifestyle redesign recommendations among group members. The FSS and PSMS-IADL measures were used to determine pre- and post- intervention fatigue severity and impact on activity performance and an Intervention Satisfaction Survey (qualitative format) was used to assess the effects of the educational training program. Data analysis (using SPSS version 22) involved measures of central tendency for the demographic information (i.e., age, sex, and time since stroke). A RM-ANOVA was done to examine the differences between the pre- and post-intervention FSS and PSMS-IADL measurements using the categories of presence of social support, sex, age, race, and level of care as grouping variables. Age and sex were analyzed using chi-square analysis to determine relationship. Tabulations of the Intervention Satisfaction Survey responses were completed to judge the effectiveness of the group-based program or its' components from the participants' perspectives. It was hoped that the study would contribute (1) a standard intervention program to use during rehabilitation to address post-stroke fatigue, and (2) support to the program's effectiveness for relieving post-stroke fatigue and the limitation to daily activity participation it causes. The results of the statistical analysis are presented in the next chapter.

Chapter Four: Results

Introduction

The aims of this research study were to: 1) evaluate the effectiveness of a group-based educational program in reducing post-stroke fatigue; 2) determine if that reduced fatigue improved participation in daily activities; 3) show that these improvements could be sustained in the long term; and, 4) provide support for content of a group-based educational program. These outcomes were evaluated using a RM-ANOVA design across four data collection points using the FSS and PSMS-IADL measures. In addition, the potential influence of the presence of social support, sex, age, and level of care were analyzed. As part of this mixed methods study, a qualitative tool- the Intervention Satisfaction Survey- was also administered. Content analysis on the participants' responses was completed.

Nineteen volunteer participants completed all phases of the study. Descriptive information on all participants and the statistical analysis of the measures are described in the following sections. The results are presented in terms of the aims of this research study.

Characteristics of the Participants

There were 30 volunteers recruited to participate in this research study. At the first visit (the time participants are asked to consider the informed consent), five volunteers declined participation; two had moved from the facility (one to home, one to acute care); and, one was going to be out-of-town for the duration of the intervention and declined participation. Upon

completion of the informed consent and eligibility measures, one person was excluded due to NIHSS motor leg score of >1; this resident was not able to participate in any group session either due to a schedule conflict. One resident withdrew three weeks into the group-based intervention phase; follow-up interview indicated no concerns about the content, just lack of comfort with the group-based discussions. Data from these 10 volunteers was excluded from data analysis. Twenty participants completed Phase A (non-intervention) and Phase B (group-based intervention); 19 completed Phase C (post-intervention) as one person transferred to another facility at the conclusion of Phase B. Data from these 19 participants was used for RM-ANOVA, while data from all 20 was used in other analyses.

Table 5 shows the distribution of the sample in terms of demographic information, including age, sex, race, time since stroke (in years), and presence of a caregiver as divided by level of care (Personal Care versus Independent Living) and overall. Age ranged in years from 74 – 100, with an overall average of 87.1 years ($SD = 6.58$). This range is the upper end of stroke incidence statistics, which indicate 55-75 years to show higher incidence of stroke (AHA, 2014). The ages of Personal Care residents averaged 90.45 years ($SD = 5.92$); while Independent Living residents averaged 82.89 years ($SD = 5.37$). Females accounted for 65% of the participants overall; 82% of Personal Care and 44% of Independent Living residents. This reflects the longer average life expectancy for women. All participants were White; the absence of any participants of color was not representative of stroke survivors nationally. Time since the stroke occurred ranged from 14 months to 20 years. The average time since stroke was 5.99 years overall ($SD = 5.58$); 4.04 years ($SD = 2.36$) in Personal Care residents; and, 8.38 years ($SD = 7.70$) for the Independent Living residents. Overall, 45% of participants lived with a family member who

Table 5

Descriptive Statistics of Demographic Information

| Variable | Overall | | Personal Care Residents | | Independent Living Residents | |
|-----------------------------------|----------|-------------------------------------|-------------------------|-------------------------------------|------------------------------|-------------------------------------|
| | <i>n</i> | % or <i>M</i> | <i>n</i> | % or <i>M</i> | <i>n</i> | % or <i>M</i> |
| Age | 20 | <i>M</i> = 87.1 | 11 | <i>M</i> =90.45 | 9 | <i>M</i> = 82.89 |
| <75 years | 1 | <i>SD</i> = 6.58 | 0 | <i>SD</i> = 5.92 | 1 | <i>SD</i> = 5.37 |
| 75-85 years | 7 | | 3 | | 4 | |
| 86-95 years | 9 | | 5 | | 4 | |
| >95 years | 3 | | 3 | | 0 | |
| Sex | | | | | | |
| Male | 7 | 35% | 2 | 18% | 5 | 56% |
| Female | 13 | 65% | 9 | 82% | 4 | 44% |
| Race | | | | | | |
| White | 20 | 100% | 11 | 100% | 9 | 100% |
| Time since stroke (years) | 20 | <i>M</i> = 5.99 <i>SD</i> = 5.58 | 11 | <i>M</i> = 4.04 <i>SD</i> = 2.36 | 9 | <i>M</i> = 8.38 <i>SD</i> = 7.70 |
| Presence of social support | | | | | | |
| Yes | 9 | 45% | 4 | 36% | 5 | 56% |
| No | 11 | 55% | 7 | 64% | 4 | 44% |

provided social support; this represents 36% of Personal Care residents and 56% of Independent Living residents with social support. The implications of the participants' demographic characteristics on generalizability of the results of the current study will be explored in Chapter Five.

Effect of Rehabilitation Approaches on Post-Stroke Fatigue

The first hypothesis of this research study was that participation in a group-based educational program would reduce the experience of post-stroke fatigue. This was tested by measuring levels of fatigue using the FSS. This measure was administered four times; at the

beginning and the end of a 7-week non-intervention phase; at the conclusion of a 7-week group-based educational program; and, 7-weeks after that program had ended. Table 6 shows the mean FSS scores and standard deviations at each date collection point. Figure 1 is a representation of this data in graph form.

Table 6 shows that, after an initial rise in mean FSS scores during the non-intervention phase ($M = 35.95$ to $M = 40.47$), fatigue declined after the intervention phase ($M = 30.31$) and continued that decline during the post-intervention phase ($M = 26.58$). The RM-ANOVA analysis (shown in Table 7) indicated the decrease in mean FSS scores was statistically significant ($p < .05$) only after the intervention phase, however. Since the same participants were tested in each phase, the assumption of sphericity (i.e., that scores in different conditions are independent of one another) cannot be assumed. Therefore, Mauchly's test was used to assess the variances of the differences between phases. In this case, Mauchly's test was not significant and the scores could be analyzed without correction. This allowed rejection of the null hypothesis and indicated that the group-based educational program was successful in relieving the experience of fatigue in chronic stroke. Since the change in FSS mean scores was significant, the effect size r was calculated for Phase B (post-intervention). This resulted in an effect size $r = .64$, which indicates a large effect.

Effect of Post-Stroke Fatigue on Participation in Daily Activities

The second hypothesis of this research study was that participation in daily activities would improve if post-stroke fatigue were reduced. This was tested using the PSMS-IADL measure, which was administered at the same four date collection points as had been done with the FSS. Table 6 also shows the mean PSMS-IADL scores and standard deviations.

Table 6

Means and Standard Deviations for FSS and PSMS-IADL scores (n=19)

| Measure | M | SD |
|--|-------|-------|
| <u>Fatigue Severity Scale (FSS)</u> | | |
| Non-intervention pre-test (pre-test 1) | 35.95 | 10.54 |
| Non-intervention post-test (post-test 1) | 40.47 | 11.56 |
| Group intervention post-test (pre-test 2) | 30.31 | 8.81 |
| Post-intervention post-test (post-test 2) | 26.58 | 10.31 |
| <u>Physical Self-Maintenance-Instrumental Activities of Daily Living- (PSMS-IADL)</u> | | |
| Non-intervention pre-test (pre-test 1) | 6.32 | 4.33 |
| Non-intervention post-test (post-test 1) | 7.31 | 4.68 |
| Group intervention post-test (pre-test 2) | 7.52 | 4.39 |
| Post-intervention post-test (post-test 2) | 7.36 | 4.72 |

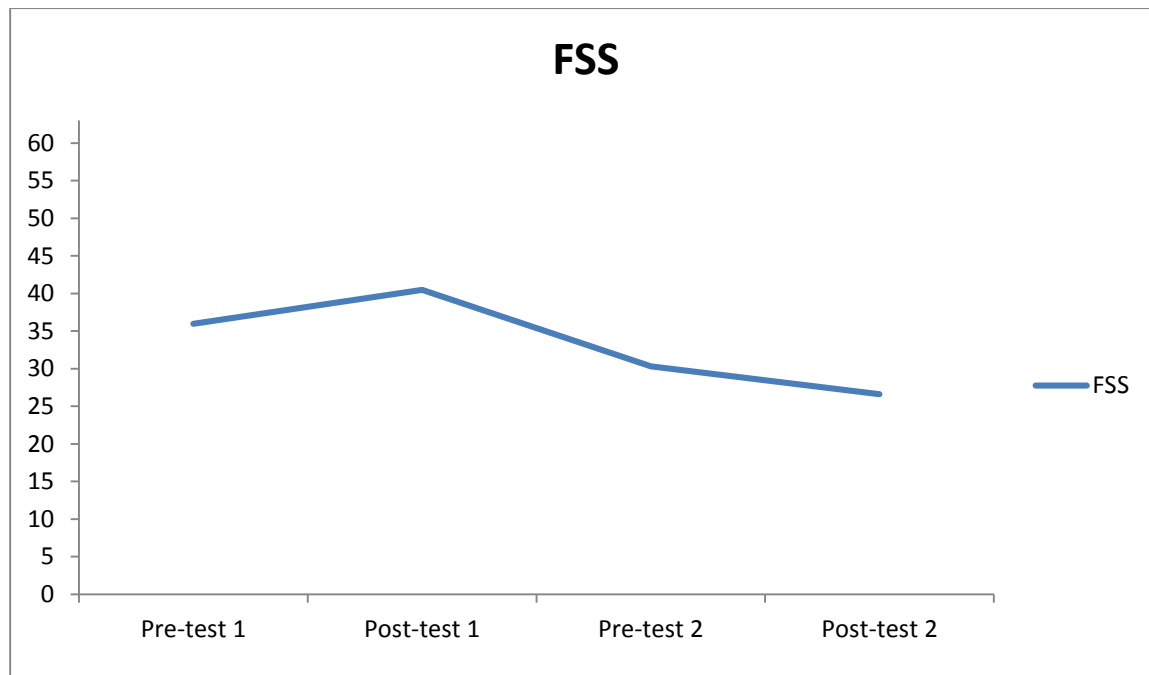


Figure 1. Mean scores on the FSS at the four data collection points.

Table 6 shows that participation in daily activity showed a trend toward increased participation during the non-intervention ($M = 6.32$ to 7.31) and intervention phases ($M = 7.36$), but this trend declined slightly in the post-intervention phase ($M = 7.36$). Figure 2 shows this data in graph form. The RM-ANOVA (shown in Table 7) indicated that none of these changes reached statistical significance. As previously explained, Mauchly's test of sphericity was used to assure equal variance in the difference in mean scores. For the PSMS-IADL, this value was significant, which meant that a corrected value was applied. This correction did not change the lack of statistical significance of the mean PSMS-IADL scores. This result caused acceptance of

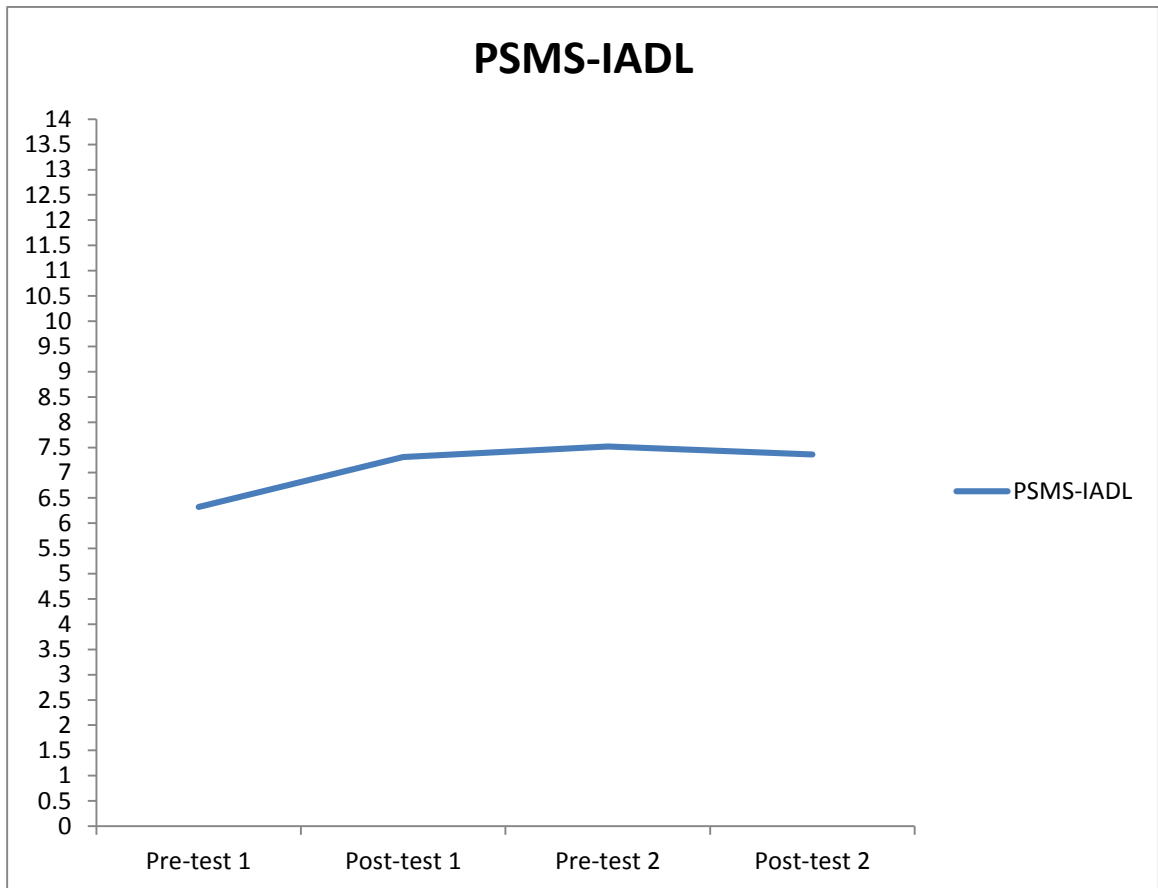


Figure 2. Mean scores on the PSMS-IADL at the four data collection points.

Table 7

Results of RM-ANOVA for FSS and PSMS-IADL Mean Scores across Phases (n=19)

| Measure | Sum of Squares | df | Mean Square | F | Significance |
|---------------------|----------------|----|-------------|--------|--------------|
| FSS: Phase A | 389.26 | 1 | 389.26 | 1.496 | .237 |
| Phase B | 1960.47 | 1 | 1960.47 | 12.423 | .022 |
| Phase C | 265.32 | 1 | 265.32 | 1.474 | .240 |
| PSMS-IADL | | | | | |
| Phase A | 19.00 | 1 | 19.00 | 3.054 | .098 |
| Phase B | .842 | 1 | .842 | .153 | .700 |
| Phase C | .474 | 1 | .474 | .024 | .878 |

the null hypothesis, which stated that participation in daily activities would not change due to reduced post-stroke fatigue.

Possible Influence of Demographic Characteristics

The variations in presence of social support (i.e., living with a person who provided care routinely), age, sex, and/or level of care (i.e., Personal Care or Independent Living) were anticipated as potential influences on fatigue (FSS scores) and/or participation in daily activities (PSMS-IADL scores). Therefore, these characteristics were used as grouping variables to test their influence on the results. For purposes of analysis, participants were placed in age groups. Table 5 provided these characteristics by participant.

The number of characteristics and the categories within each precluded use of chi-square analysis using contingency tables. A log-linear analysis would be indicated; however, the assumptions required for log-linear analysis (i.e., expected cell count >1 and <20% of the cells have under five cases) were not met. Therefore, one-sample chi-square analysis for presence of social support, age, sex, and level of care was completed. The obtained values for presence of social support ($X^2 = .2$), sex ($X^2 = 1.8$), and level of care ($X^2 = .2$) were less than the critical value

($df = 1$; $p < .05$; critical value = 3.84), indicating that the distribution of participants across groups was not significantly different. The distribution across age groups ($X^2 = 8$) exceeded the critical value of 7.82; indicating unequal distribution. Only one participant was less than 75 years old; when that potential outlier was removed from the calculation, the assumption of equal distribution was achieved ($X^2 = 2.85$; $df = 2$, $p < .05$, critical value = 5.99). The distribution of ages was generally reflective of stroke incidence statistics. Implications of these characteristics will be discussed in greater detail in Chapter Five.

To assess whether these potentially confounding variables influenced the scores on the measures of fatigue or participation in activities, a RM-ANOVA was completed with presence of social support, sex and level of care. This data is presented in Table 8; no values were found to be statistically significant ($p < .05$).

Feedback on Post-Stroke Fatigue Program Effectiveness

The final aim of this research study was to provide support for the content of the group-based educational program on post-stroke fatigue. In order to gather information on effectiveness, participants were asked by the researcher to complete an Intervention Satisfaction Survey as part of the last group session. This qualitative survey asked participants to indicate how confident they felt in applying the post-stroke fatigue principles covered during the group sessions and to provide suggestions for improvement in terms of additional topics or areas of concern. A total of seven participants completed the survey tool individually. The others chose to use it as a guide to an open group discussion about the program and the research process. These comments were noted by the researcher and will be presented here.

Table 8

Results of RM-ANOVA for FSS and PSMS-IADL Grouped by Sex and by Setting (n=19)

| Variable | Measure by data collection point | df | Mean Square | F | Significance |
|----------------------------|----------------------------------|-----|-------------|-------|--------------|
| Presence of social support | FSS | | | | |
| | Non-intervention | 1 | 118.948 | .443 | .515 |
| | Group intervention | 1 | 182.737 | 1.169 | .295 |
| | Post intervention | 1 | 79.195 | .426 | .523 |
| | PSMS-IADL | | | | |
| | Non-intervention | 1 | 1.900 | .293 | .595 |
| | Group intervention | 1 | 1.769 | .309 | .586 |
| | Post intervention | 1 | 22.926 | 1.175 | .293 |
| | Sex | FSS | | | |
| Non-intervention | | 1 | 106.356 | .395 | .538 |
| Group intervention | | 1 | 14.860 | .089 | .769 |
| Post intervention | | 1 | 33.434 | .171 | .679 |
| PSMS-IADL | | | | | |
| Phase A | | 1 | 2.036 | .315 | .582 |
| Phase B | | 1 | 2.729 | .481 | .497 |
| Phase C | | 1 | 1.003 | .048 | .829 |
| Level of care | | FSS | | | |
| | Non-intervention | 1 | 403.135 | 1.601 | .223 |
| | Group intervention | 1 | 143.015 | .901 | .356 |
| | Post intervention | 1 | 559.264 | 3.547 | .077 |
| | PSMS-IADL | | | | |
| | Non-intervention | 1 | 5.398 | .861 | .367 |
| | Group intervention | 1 | 2.931 | .518 | .482 |
| | Post intervention | 1 | 11.390 | .564 | .463 |

Survey Question 1 asked participants to indicate the number of group sessions they attended. Most participants deferred to the Researcher for this information and did not fill it in on their own. Seven individuals attended all seven group sessions; five individuals attended six sessions; two individuals attended five sessions; four individuals attended four sessions; and, two individuals attended three sessions. Average attendance was 5.5 sessions. The spouses of three participants also attended the group sessions. The failure to attend a session was due to

health condition changes for two participants; three participants reported previously scheduled activities. Participants were provided with materials from their missed sessions and given time to ask questions about it at the close of the next group session.

Question 2 on the survey asked participants to rank their confidence in applying the post-stroke fatigue principles covered in the group-based educational program. A Likert-scale was used for indicating level of confidence with a range from 'not confident at all' (1) to 'totally confident' (10). No descriptive terms were provided between the end points on the Likert-scale (see Appendix H for the instrument). Participants' responses indicated that they felt most confident applying information on scheduling activities to include rest periods ($M= 8.5$). The areas with the lowest range of scores included: understanding and communication needs related to fatigue ($M =7$, range = 3-9); managing sleep problems ($M = 6.43$, range 3-9); and, keeping fatigue from interfering with activities ($M = 7.79$, range 3-9). Managing sleep problems was the item for which lowest average levels of confidence were reported. Table 9 presents the range and average of the responses for each of the items. The group means for those who attended four or fewer sessions did not appear to differ significantly from those who attended five or more sessions on either the FSS or the PSMS-IADL, however.

A majority of the participants who completed the survey were part of a group held at a site with a robust wellness program. Although the implications of this will be developed further in Chapter 5, it would appear that there may have been a carryover effect of the level of involvement. That is, participants were very active and had confidence in their ability to balance activity with rest because they did it as a daily routine before the intervention.

Table 9

Intervention Satisfaction Survey Results

| Question | Response (average) | Range of responses |
|--|--------------------|--------------------|
| A. Understand and communicate needs related to fatigue? (n= 7) | 7 | 3-9 |
| B. Pace activities and use relaxation techniques? (n= 7) | 6.86 | 6-9 |
| C. Manage sleep problems? (n= 7) | 6.43 | 3-9 |
| D. Incorporate activity throughout schedule? (n= 6) | 8.33 | 7-9 |
| E. Prioritize and plan your daily routine? (n= 7) | 8 | 4-9 |
| F. Schedule activities and include rest periods? (n= 6) | 8.5 | 8-9 |
| G. Apply the strategies to future activities? (n= 7) | 7.79 | 6-9 |
| H. Keep fatigue from interfering with activities? (n= 7) | 7.29 | 3-9.5 |

Question 3 on the survey asked for input on what additional information should be covered during the group-based intervention program. Only two individuals provided written comments: one added “see people earlier after their stroke perhaps in hospital or rehab”; the other wrote that the program “was informational”. Every group discussion included a recommendation that this information be given earlier in the stroke recovery process (suggestions as to when this would be more useful included during acute care hospitalization or inpatient rehabilitation). Most participants indicated that they had already adjusted their daily routine and activity level to the fatigue occurrence and that getting the information earlier may have increased the efficiency of those adaptations. The participants reported that knowing about this issue, as well as being provided with strategies to reduce the impact of fatigue, would have reduced their frustration and facilitated problem-solving.

Participants discussed that it was helpful to meet other people with similar concerns/issues rather than thinking one was alone in experiencing them. This is supported from the researcher’s note on the generalized relief expressed by participants of the first

session when fatigue was explained to be related to having had a stroke and not a personal character flaw (i.e., lazy or 'milking the stroke'). This related to decreased self-criticism for feeling tired and needing to take rests.

Participants were also thankful that attention was finally being paid to the issue by medical professionals, who they saw as not taking their concerns seriously. Some participants took the opportunity to air the difficulties they experienced with their primary care physician during this discussion. Relative to the issue of fatigue was the concern about overuse of medications to address problems and the dosing of medication that failed to account for daily routines or sleep schedules.

This input lent support to the content of the group-based educational program and to the inclusion of a rehabilitation professional as group leader/facilitator. Recommendations for the timing of post-stroke fatigue education, as noted above, are discussed in Chapter Five.

Summary

This chapter reported the results of the quasi-experimental mixed methods research study designed to assess the effectiveness of a seven-session weekly group-based educational training program in relieving fatigue severity and its impact on participation in daily activities among chronic stroke survivors. A total of 19 participants were included in the repeated measures analysis. Demographic information and the scores on the fatigue severity (FSS) and level of activity participation (PSMA-IADL) were presented. Results from the RM-ANOVA indicated a significant decrease in fatigue levels after the intervention phase that continued post-intervention. The trend toward increased participation in daily activities did not reach statistical significance and a potential ceiling effect is explored in Chapter Five. Grouping by

presence of social support, sex, age, or level of care (Personal Care versus Independent Living) did not show a significant difference in scores for fatigue or level of activity participation. Although sample size precluded use of log-linear analysis, one-sample chi-square analysis did not show significant differences in distribution of the sample in terms of presence of social support, sex, age or level of care. This supports the conclusion that the group-based educational program was the source of the reduced fatigue. Intervention Satisfaction Survey results revealed greatest reported benefit for scheduling activities and including rest; the least confidence was reported for managing sleep problems. The next chapter will further discuss the meaning of these results as well as the limitations of the current research and recommendations for future research.

Chapter Five: Discussion

Introduction

The intent of this research study was to determine whether post-stroke fatigue and its impact on completion of daily activities could be reduced after participation in a group-based educational program. The research study was also completed to provide support for the content of a post-stroke fatigue program. The results indicate that the intervention significantly reduces post-stroke fatigue and that the gains made are maintained for seven weeks after group participation. There was a trend toward increased participation in daily activities that did not reach statistical significance- a possible ceiling effect of the measure is explored here. Participants indicated support for education on the topic and showed strongest confidence in their ability to schedule activity and rest in their daily routines following the intervention.

In light of these results, this chapter will consider implications of the results presented in Chapter Four. This begins with a consideration of possible explanations for the statistical findings and their relationships to previous literature. Next, the clinical, theoretical, and research implications of the study will be presented. Finally, a review of the limitations of the study and suggestions for future research will be provided.

Rehabilitation Therapies Can Reduce Post-Stroke Fatigue

The results of this study show that post-stroke fatigue can be reduced through participation in a group-based educational program and that the effect was large (effect size $r=$

64). This result extends the success seen for the pilot study by Zedlitz et al. (2011) who reported reduced fatigue in 16 out of 23 stroke survivors during out-patient rehabilitation. The intervention used in that study combined an individualized exercise regimen developed by a physiotherapist with group-based cognitive behavioral sessions led by a neuropsychologist. The results of the current study also verified the reduced fatigue Clarke et al. (2012) reported in their pilot study of 19 stroke survivors. Clarke et al. (2012) had seen reduced fatigue after participation in a psycho-educational group but the reduction did not reach statistical significance. That research included a cognitive-behavioral group led by a psychologist for long-term stroke survivors.

The current study is the first to offer a group-based educational program whose content was developed specifically from successful fatigue management programs for other neurological conditions, including MS (Mathiowetz et al., 2001), CA (Portenoy & Itri, 1999), and CFS (Price, 2009). This supports the idea, presented in Chapter Three, which shared characteristics of fatigue in neurological disorders makes the use of content from those successful programs reasonable for application to post-stroke fatigue. Specifically, previous research has suggested a role for education on: 1) the phenomenon of fatigue (Roding et al., 2003; Flinn & Stube, 2010), 2) the role of rest and sleep (Sterr et al., 2008; Park et al., 2009), 3) managing energy (Mathiowetz et al., 2001; Bethoux, 2006; Sharpe et al., 1996), and 4) physical activity (Cheville, 2009 and Winningham, 2001). All of these were included as components of the group-based educational program offered in the current study. Their effectiveness is supported by the results, which show a reduction in post-stroke fatigue. Further discussion of the program components will be included later in this chapter.

The application of the principles of cognitive-behavioral therapy to chronic conditions such as stroke had been suggested in the literature (Lorig et al., 1993; de Groot et al., 2003; Shevil, 2008, Zedlitz et al., 2011, & Clarke et al., 2012); and is supported by the results of the current study. The CBT principles applied in the group-based education program used in the current study include providing progressive challenges (physiologic arousal) leading to successful outcomes whether developed individually (mastery) or learned from the experience of other participants (vicarious) (Bandura, 1995, Bruce & Borg, 2002). Zedlitz et al. (2011) had identified the inconsistent application of CBT as a potential limitation to their study, which was corrected in the current study and supported by the successful reduction of fatigue.

Another unique feature of the current study is the involvement of an occupational therapist in providing the group-based educational program. Occupational therapists are skilled in the use of groups (Schwartzberg, 2008) and their unique skills in adaptation and occupation-based activity allows for the natural application of cognitive-behavioral techniques (AOTA, 2014; Schwartzberg, 2008; Bruce & Borg, 2003). The occupational therapist uses interactive and clinical reasoning skills to foster a sense of confidence in group participants' abilities to control their health outcomes, or self-efficacy (AOTA, 2014). The results of the current study lend support to a role for occupational therapy in using group-based educational programs as part of stroke rehabilitation.

This study supports findings from research in other neurological conditions in which fatigue reduction is achieved and maintained over time (Mathiowetz et al., 2007; Lorig et al., 2001). Studies have shown that fatigue persists in chronic stroke (Cott et al., 2007; Naess et al., 2005; Carlsson et al., 2004; Glader et al., 2002). However, previous research into post-stroke

fatigue (Zedlitz et al., 2011; Clarke et al., 2012) did not examine the long-term effects of fatigue reduction, making this study the first of its kind to do so.

Participation in Daily Activities Was Not Changed

The results of this study show a trend of increased activity participation over time that did not reach statistical significance. And that trend toward increased participation fell in the post-intervention period, although not back to pre-intervention levels. This trend supports the linked hypotheses of this research study that fatigue has an inverse impact on participation in daily activities. That is, it was anticipated that if post-stroke fatigue was reduced, there would be an increase in participation in daily activities. While it did not reach statistical significance, it is important in that it supports that anticipated connection of fatigue and participation in daily activity completion.

The results supported previous research linking fatigue to levels of activity participation (Glader et al., 2002; van de Port et al., 2007). The lack of statistically significant changes supports the suggestion by Ingles et al. (1999) that, in chronic stroke; adjustments have already been made to activity participation to accommodate the fatigue experienced. These habits may not be quickly changed despite the decreased levels of fatigue.

Participants in the current research were recruited from the Independent Living or Personal Care areas of retirement communities and, as such, were more functionally independent prior to intervention. Although the analysis of level of care and participation in daily activity did not indicate that level of care was a significant variable, it seems reasonable to suspect that level of care may have created a ceiling effect. The highest score obtainable on the PSMS-IADL is 14, while the average initial score for all participants (n=20) was 6.32. At this level,

a person is completing all self-care and mobility independently as well as some higher level tasks (for example, meal preparation, laundry and/or financial management). Given the physical environment of Independent Living or Personal Care, access to a broader community is not needed and therefore, limits are placed on how much improvement could be made in functional performance.

Demographic Characteristics Influence Interpretation of Results

Potentially confounding variables did not appear to have a measurable effect as there were no significant changes noted when the data was grouped by presence of social support, sex, or level of care (i.e., Personal Care versus Independent Living). The ages of the participants (refer to Table 5 in Chapter Four) reflected the age range common in stroke (AHA, 2014), although there was a higher percentage of participants among the 'old-old' rather than more equally distributed between ages 55 and older (age group with highest prevalence of stroke; AHA, 2014). The higher percentage of women participants again supports national data on stroke occurrence, which indicates that an older average age of stroke onset for women ($X= 75$ years compared to 71 years for men) to have stroke (AHA, 2014).

The absence of any participants of color is not representative of stroke survivors in general; African-Americans have almost twice the risk of a first time stroke than Whites (AHA, 2014). Data was not available on comparisons of level of care within the national statistics, but it seems reasonable that the fact that fewer of the oldest participants lived independently is reflective of the known decrease in physical strength factors with increasing age.

Participants Felt Confident in Applying Techniques to Relieve Fatigue

For the participants who completed the Intervention Satisfaction Survey, averaged ratings indicated a sense of confidence in their learning after participation in the group-based educational program. It is of interest to note that the group of participants who provided individual responses was among the most active of all participants. As mentioned in Chapter Four, one particular site had a robust wellness program and a Wellness Coordinator who monitored residence performance. This monitoring included computer-based check-ins of exercise and activity participation; if there was a reduction in frequency or performance, a contact was made by that Coordinator to assess potential status changes. This built an expectation for scheduling activities and likely contributed to that area receiving the highest average score for confidence in application. This result is supported in the literature, which suggests a role for activity throughout the lifespan and in chronic stroke (Mead, Bernhardt, & Kwakkel, 2012; Michael et al., 2006; Gordon et al., 2004).

The confidence reported in applying principles of sleep and rest complements previous research supporting the use of a cognitive-behavioral approach for sleep problems (Knoop et al., 2012; Kwekkeboom et al., 2012; Edinger & Means, 2005). Previous research has shown that this is a critical area for maintaining health and performance of daily functions (Sterr et al., 2008) and that they are highly correlated to cardiovascular disease (AHA, 2014; Bassetti, 2005). During the recruitment process, many residents had concerns related to sleep. As a relatively new area of concern in rehabilitation (AOTA, 2014), these concerns may not have been addressed to the extent that other consequences of stroke had been. That lack of information seemed reflected in the finding that this area had the lowest confidence rating.

Participants did not always complete the homework (i.e., opportunities to practice skills between group sessions and report on successes or problems), which may have contributed to the less than total confidence reported. Perhaps group participation made them aware of the strategy but without practice they were not as confident in independent application. However, one person wrote that her lack of confidence in communicating with others was based on the techniques provided not working when attempted. No other statement indicated that the information was ineffective.

In discussion, the groups all reported that the information on fatigue would have been more useful earlier in the recovery process. One participant proposed that it should occur in the acute hospital or during in-patient rehabilitation. This verifies the finding by Flinn and Stube (2010) that information is not provided at the right time or circumstances to be useful to stroke survivors. It further supports a role for a group-based educational program on post-stroke fatigue as an important part of stroke rehabilitation.

One of the aims of this research study was to support the program's effectiveness for relieving post-stroke fatigue; overall results of the satisfaction survey indicate that the topics seemed relevant for the participants. This is significant in terms of providing tools for use in OT practice, but the small number of responses limits the conclusion of effectiveness. This is an area in need of further investigation.

Implications for Occupational Therapy Practice

To the best knowledge of the researcher, this is the first research study applying principles of fatigue management in a group-based educational program led by an occupational therapist for the post-stroke population. Previous research into interventions for post-stroke

fatigue provided intervention by physiotherapists during the out-patient phase of rehabilitation rather than in the chronic condition (> one year post event) used in the current research (Zedlitz et al., 2011). The inclusion of an occupational therapist allowed physical activity to be promoted beyond walking on a treadmill to improve gait. Another adjustment made in the current research was to address fatigue in chronic stroke (i.e., more than one year post-event). This is important in terms of providing interventions that are effective throughout the recovery process.

The only other studies of post-stroke fatigue did not seek participants in the post-rehabilitation, or chronic, stage of stroke (Zedlitz et al., 2011 & Clarke et al., 2012), and did not include program components reflective of energy management, which were common in the successful approaches used for other neurological conditions in the literature. There was no assessment of the effectiveness of the program by the participants. Both of these elements, which were considered to be limitations of the Clarke et al. (2012) study, were included in the current research study.

Results from this research study indicated that post-stroke fatigue can be reduced through rehabilitation therapies that incorporate CBT principles in a group-based educational program, such as the one introduced here. In an environment of evidence-based intervention, this provides a tool for rehabilitation professionals to address this consequence of stroke. This is particularly important since management and prevention of post-stroke fatigue was recently identified as a top ten research priority for stroke survivors, caregivers and health professionals alike (Pollack et al., 2014). It is critical that the success of a post-stroke fatigue intervention

program get disseminated to OT professionals, stroke survivors, and caregivers in order to address the stated need for this specific information among those very groups.

The lack of change in self-reported functional performance is of concern, however. From a therapy viewpoint, intervention for fatigue alone in the absence of functional performance changes would likely not be eligible for insurance coverage. Whether this lack of improvement in functional performance is a result of the already high level of independence among the participants or a reflection of the assessment tool, it would have an impact on OT intervention. Future researchers may wish to include participants with lower functional performance scores, in order to examine whether the intervention may have an impact on everyday activities or use an ADL/IADL assessment tool that is more sensitive to change.

Considerations regarding assessments. When considering implementation of group-based education for post-stroke fatigue, it is important to determine the best tools to measure outcomes. In this regard, the self-report nature of both the FSS and the PSMS-IADL might be a limitation. In addition, the PSMS-IADL is sensitive to small and even temporary changes. As a bimodal rating measure, scores can change from independent (as score of 1) to needing assistance (a score of 0) as a result of needing to use an ambulatory device (whether or not that device is used independently) or an episode of incontinence (even if managed through use of incontinence products). A measure that requires observation of performance may be more robust in assessing the impact of decreased fatigue on functional performance.

Having participants who were already relatively independent within the level of care suggests a potential ceiling effect of ADL and IADL performance, which was presented previously in this paper. Given the high level of independent function, it may not have been

possible to measure any improvement as those changes may have been more qualitative than quantitative in nature. This has implications for the selection of participants as well as the selection of an assessment tool.

Considerations regarding intervention. Although the group-based educational program introduced in this research was effective in reducing fatigue post-stroke and participants reported confidence in their learning, the components have not been individually assessed. It would be an important next step to further evaluate the program components. Use of information from the successful interventions used for other neurological disorders worked in this study, but may not represent the most effective means of addressing post-stroke fatigue.

As noted by the participants, timing of the intervention was not ideal for their needs. Inclusion in the early stages of stroke recovery may be indicated. There is support for post-stroke fatigue management to be a standard part of the stroke rehabilitation protocol, but the timing of that intervention requires more research.

And, although participation in the group-based intervention did result in a reduction of self-reported fatigue, it did not eliminate it. Average scores remained moderately high indicating a role for chronic fatigue management.

Considerations of multiple impairments post-stroke. The participants in this research study were screened to reduce the impact of co-occurring conditions or impairments (i.e., depression, motor ability for physical activity, sleep-related disorders, and cognitive limitations). As these conditions or complications are common post-stroke, it would be important to recognize that this intervention may not be as effective with a general stroke

population. It may be necessary to make adaptations to the program in order to assure benefit for the stroke survivors with more physical and/or cognitive involvement.

Considerations regarding caregiver support. It is important to include caregivers in any post-stroke educational program. In the current study, three spouses of stroke survivors regularly attended the group sessions. One was critical for communication with an aphasic participant; others were able to verify or critique participation statements or concerns related to the session topic. Education on physical activity as an important component of building energy and reducing fatigue is important as clients and their caregivers must become adept at balancing activity with rest. Understanding the skills and abilities of stroke survivors as well as understanding the need for rest is a key to the successful reduction of the impact of fatigue. Managing participation expectations on the part of the caregiver(s) is another key component to assuring best outcomes for the client and for the caregivers. Learning about the incidence of post-stroke fatigue and the need to incorporate rest because of it may make the delegation of daily task completion less frustrating.

Theoretical and Research Implications

The issue of self-efficacy. Cognitive-behavioral technique is showing increased evidence of effectiveness in addressing methods to change health behaviors and improve health outcomes. The current study asked for clients to rate their confidence in applying the content of the educational program. While this is a component of self-efficacy, it does not capture the entire construct and greater attention to development of self-efficacy may increase program effectiveness. Measures of self-efficacy may be more robust in terms of demonstrating intervention effectiveness, particularly for the 'invisible' conditions such as fatigue for which

finding an objective, observable measure is difficult. If post-stroke fatigue management programs improve self-efficacy, there may be a stronger correlation to participation in daily activities as well as overall improvement in quality of life.

Ecological validity. This study examined reduction of fatigue and improved participation in daily activity with community-dwelling stroke survivors. This allowed the researcher to focus on everyday activities, the unique feature of occupational therapy intervention, in context of 'normal' living rather than the constraints of institutional intervention. Group dynamics resulted in topics receiving different emphasis between the three groups. While this improves ecological validity, broad application of the results must be done with caution.

Considerations for the future. The hope of this researcher is that this study will lay the foundation for future research on effective strategies to prevent post-stroke fatigue. Numerous studies have indicated the prevalence of the problem (Stokes et al., 2011; Ingles et al., 1999; Di Fabio et al., 1998) while also suggesting research to support an intervention program or tool. The current environment in healthcare of the chronic nature of recovery (WHO, 2001), the importance of participation as an outcome of intervention (Cott et al., 2007; AOTA, 2014), and the demand for evidence-based interventions (Pollack et al., 2014; McGeough et al., 2009) all call for research into this important phenomenon of stroke.

Suggestions for future research are to analyze the program contents for effectiveness and the timing of delivery for efficacy in order to develop a standard intervention protocol. As previously mentioned, the contents were based on the literature but may not be the only topics that are important for this population. Exploration of the timing for implementation of post-stroke fatigue intervention also needs to be completed as the current research suggested that it

may be less effective in the non-acute stages of stroke recovery. A time-series study might allow determination of best timing for implementation during post-stroke recovery.

Lastly, the addition of a more robust qualitative aspect of the study is recommended. Analyzing the discussions that occur during the group-based educational program sessions might give better information as to the contents of most relevance to stroke survivors in managing their fatigue. Increased use of homework notes or a fatigue journal would also contribute to a better understanding of the application issues (successes as well as difficulties) encountered by participants.

Limitations of the Research

This study reports significant results that impact stroke rehabilitation. However, there are limitations that need to be considered. First, the sampled population is a very small and is not representative of the general stroke population. Participants were volunteers who were approached by staff members after receiving a general invitation from the research team; as such they may differ in important ways from the stroke population as a whole. As noted in Chapter Four, the ethnic/race and age distribution of participants does not match the AHA stroke statistics (2014). The AHA (2014) reported that women have a higher lifetime risk for stroke (one in five for women; one in six for men) and are slightly older on average at onset of stroke (75 years versus 71 years for men). The “overall age- and sex-adjusted black/white incidence rate ratio was 1.51” (AHA, 2014, e79). This lack of representativeness limits the comparability of results to the larger population of stroke survivors.

Participants who did not experience co-occurring depression, severe cognitive or physical impairment, sleep-related disorders or low sleep quality were deliberately chosen for

this study but this selectivity limits the generalizability of the results to the greater population of stroke survivors. The sample was selected from retirement community residents in a discrete geographical area in south-central PA, which also limits the application of results to all stroke survivors. Considering that a majority of stroke survivors return home, it would be important to explore the impact of a group-based educational program on post-stroke fatigue in the open community as well. A randomized, controlled trial with a larger sample size is warranted.

The two measures used in this study (FSS and PAMS-IADL) rely on self-report, the accuracy of which relies on full understanding of the questions and honesty in responses. There was no objective measure used concurrently to assess the accuracy of responses. The Researcher was blinded to the scores, however; through the utilization of the Research Assistant for data collection. Participants were also aware that the Researcher was completing this research in partial completion of a doctoral degree. It is possible that participants adjusted responses, based on the Hawthorne effect, to improve that outcome.

Lastly, there are limitations related to the study procedures. One facility dropped out of the research just after IRB approval and the search to find another interested site took some time. This resulted in groups occurring at different time points; the first group completed participation from February to June while the second and third groups ran from August through December/January. It is possible that the groups could have differed in significant but unknowable ways. There may have been a learning effect on the part of the research team; experience running the first group may have influenced topic coverage in future intervention programs for the Researcher; while the Research Assistant may have become more familiar with the measures in subsequent administrations. Topics received different emphasis based on

the group dynamics, which enhances ecological validity but introduces caution for broad application of the intervention.

Summary and Conclusion

With this dissertation, I have provided evidence that a seven-week group-based training program can reduce the fatigue of stroke survivors, and that this reduction lasts for at least seven weeks. Based on the data analysis, participation in a group-based educational training program did result in a significant reduction in fatigue as measured by the FSS and a trend toward increased participation in everyday activities that was not statistically significant. Participants reported feeling most confident in their ability to schedule activity and rest throughout their daily routine and least confident in managing sleep issues based on the feedback on the group-based intervention. There was no significant change in participation in everyday activity over the same time periods, although participation did show a trend toward improvement. These results may not be generalized to the general stroke population due to the small sample size and non-representativeness of the participants in terms of color/ethnicity/race, and over-representation of the 'old-old' among the participants, who were from retirement facilities in one geographical area of the country. It is recommended that this study be replicated using a larger and more representative sample of the post-stroke population.

The field of occupational therapy can benefit from these results as they provided evidence in support of an intervention program that addresses an area of interest that has been under-investigated in post-stroke recovery. Post-stroke fatigue needs more attention in research as well as in practice and this project has provided a resource to clinicians to address that need.

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Appendix A

IRB Approval
Proposed Informed consent

IRB HM20000082 Relieving Post-Stroke Fatigue Using a Group-Based Educational Training Approach

On 11/18/2013, this study involving the research use of human subjects was **approved** according to 45 CFR 46.108(b) by VCU IRB Panel A .

• [If study is approved for the inclusion of Children, insert the following text: This study involves **children**, and is approved under children's category

There are no items to display

• [If study is approved for the inclusion of Prisoners, insert the following text: This study involves **prisoners**, and is approved under prisoner category

There are no items to display

• [If study is approved for the inclusion of Pregnant Women, Fetuses, Neonates of Uncertain Viability, Non-Viable Neonates, and/or Post-Delivery Materials, insert the following text: This study includes **[insert the text from the applicable response in Question 1 of the Pregnant Women, Fetuses, Neonates and Post-Deliver Material smartform page]**, and is approved under category

There are no items to display

The information found in the electronic version of this study's smart form and uploaded documents now represents the currently approved study, documents, informed consent process, and HIPAA pathway (if applicable). You may access this information by clicking the Study Number above.

[IRB Coordinator/Administrator: If study is approved for the inclusion of Children, insert the following bulleted language, as applicable, in reference to parental signature requirements. If not applicable to study, remove bulleted language:

- Note: For children involved in this study, the IRB finds that **[insert the permission and signature of one parent is required or the permission and signature of both parents is required (unless one is deceased, unknown, incompetent, or not reasonably available, or when only one parent has legal responsibility for the care and custody of the child)]**.

This approval expires on 10/31/2014. Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review notices will be sent to you prior to the scheduled review.

If you have any questions, please contact the Office of Research Subjects Protection (ORSP) or the IRB reviewer(s) assigned to this study.

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: Relieving Post-Stroke Fatigue Using a Group-Based Educational Training Approach

VCU IRB NO.:HM20000082

If any information contained in this consent form is not clear, please ask the study staff to explain any information that you do not fully understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY

The purpose of this research study is to find out if participation in a group-based educational program led by an occupational therapist results in decreased fatigue and improved functional performance for people who have had a stroke.

You are being asked to participate in this study because you have had a stroke which has caused you to experience fatigue and interferes with your ability to participate in daily activities.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

Upon approval of the Institutional Review Board at Virginia Commonwealth University and if you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

In this study, you will be asked to provide your contact information (telephone number and/or email address) so that you can be contacted so schedule a meeting for completion of the tools being used in assessment and to send reminders about the group meeting dates. You will be asked to complete several assessments to determine your baseline level of fatigue, functional performance, depression, physical limitations after your stroke, and the quality of your sleep. After a seven-week period, you will be asked to complete the assessments of fatigue and functional performance; these will tell us whether there was any natural improvement in your level of fatigue or functional performance. You will also be asked to begin the educational program by attending seven weekly group sessions. Each session will last approximately one hour. In each session, you will be in a group with other stroke survivors. In each session, you will be provided with information about fatigue, given a chance to practice methods to help reduce the impact on daily activities, and given homework to apply these methods at home. At the start of each session (after the first one), you will be asked to share your experience at home to help or get help from other group members on ways to make the methods successful at home. You will be asked to keep a journal about your experiences in order to share this information with the group. In the first session, you will learn about the impact of fatigue and develop strategies to talk about it with other people. In the second session, you will learn about scheduling activities throughout your day and methods to reduce stress and anxiety. In the third session, you will learn methods to improve your sleep experience. In the fourth session, you will learn how to modify activities to use less energy but allow you to remain as active as possible. In the fifth session, you will learn to rate the importance of activities and to plan ahead to reduce the impact of fatigue. In the sixth session, you will learn the concepts of balancing rest and activity

and complete a weekly schedule. In the seventh session (the last one), you will be asked to set goals and complete the assessments of fatigue and functional performance to show whether the group-based program reduced your fatigue and/or improved your functional performance of daily activities. You will also be asked to complete an Intervention Satisfaction survey about your experience in the group-based program. This is to help evaluate the content of the sessions. Seven weeks after the program is over, you will be contacted to complete the assessments of fatigue and functional performance. This is to see if the methods taught to relieve fatigue resulted in long-term improvements.

Significant new findings developed during the course of the research which may relate to your willingness to continue participation will be provided to you.

RISKS AND DISCOMFORTS

Information will be collected from you specifically for research purposes. All research information will be maintained and secured in locked file cabinets or password protected flash drive. It will not be possible to identify you from the reports or publications that may result from this study as it will be summary information about the group. Your name, address, telephone number, email address will be maintained in a separate file and only used for reminders for the assessments and group program dates. You may withdraw from this study at any time.

BENEFITS TO YOU AND OTHERS

You may not directly benefit from this study. However, you will be able to keep the materials presented during the educational sessions. And the information we learn from people in this study may help us design better programs for people who have fatigue after a stroke.

COSTS

There are no costs for participating in this study other than the time you will spend in the groups and filling out assessments.

PAYMENT FOR PARTICIPATION

Every volunteer will also be entered in a drawing to receive one of two \$25 gift cards. The winner will be notified at the completion of the study.

ALTERNATIVES

The only alternative to participation is if you choose not to participate.

CONFIDENTIALITY

Potentially identifiable information about you will consist of information you provide about yourself on the demographic survey and the assessments. Data is being collected only for research purposes. There will be a chart with your name, contact information and a consecutive identification number. Only the Research Assistant will have access to this file. This will be stored separately from the program attendance information and will be kept in password protected thumb drive and will be deleted when the research study ends.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes or by Virginia Commonwealth University. Personal information about you might be shared with or copied by authorized officials of the Department of Health and Human Services (if applicable).

What we find from this study may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers.

We will not tell anyone the answers you give us. But, if you tell us that someone is hurting you, or that you might hurt yourself or someone else, the law says that we have to let people in authority know so they can protect you. Depending on the circumstances, the report may need to be made to the police or adult protective services.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study. Your decision to withdraw will involve no penalty and you will still be eligible in the \$25 gift card drawing

Your participation in this study may be stopped at any time by the study staff/ without your consent. The reasons might include:

- the study staff thinks it necessary for your health or safety;
- you have not followed study instructions;
- the sponsor has stopped the study; or
- administrative reasons require your withdrawal.
-

QUESTIONS

If you have any questions, complaints, or concerns about your participation in this research, contact:

Catherine Emery, MS, OTR/L; Doctoral student and Student Investigator

Telephone: 717-203-2553

email: emeryc@mymail.vcu.edu

and/or

Tony Gentry, PhD, OTR/L, Dissertation Chair; Primary Investigator

Telephone: 804-828-3397

email: logentry@vcu.edu

If you have any general questions about your rights as a participant in this or any other research, you may contact:

Office of Research

Virginia Commonwealth University

800 East Leigh Street, Suite 3000
P.O. Box 980568
Richmond, VA 23298
Telephone: (804) 827-2157

Contact this number for general questions, concerns or complaints about research. You may also call this number if you cannot reach the research team or if you wish to talk with someone else. General information about participation in research studies can also be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

Participant name printed

Participant signature

Date

Name of Person Conducting Informed Consent

Discussion / Witness ³

(Printed)

Signature of Person Conducting Informed Consent

Date

Discussion / Witness

Principal Investigator Signature (if different from above)

Date ⁴

Appendix B

Fatigue Severity Scale (FSS)

Fatigue Severity Scale (FSS- English version*)

| | <i>strongly agree</i> | <i>strongly agree</i> |
|---|---------------------------|---------------------------|
| | ←-----→ | |
| 1. My motivation is lower when I am fatigued. | 1 2 3 4 5 6 7 | |
| 2. Exercise brings on my fatigue. | 1 2 3 4 5 6 7 | |
| 3. I am easily fatigued. | 1 2 3 4 5 6 7 | |
| 4. Fatigue interferes with my physical functioning. | 1 2 3 4 5 6 7 | |
| 5. Fatigue causes frequent problems for me. | 1 2 3 4 5 6 7 | |
| 6. My fatigue prevents sustained physical function. | 1 2 3 4 5 6 7 | |
| 7. Fatigue interferes with carrying out certain duties and responsibilities. | 1 2 3 4 5 6 7 | |
| 8. Fatigue is among my three most disabling symptoms. | 1 2 3 4 5 6 7 | |
| 9. Fatigue interferes with my work, family, or social life. | 1 2 3 4 5 6 7 | |

**Patients are instructed to choose a number from 1 to 7 that indicates their degree of agreement with each statement where 1 indicates strongly disagree and 7, strongly agree. [Krupp et al. Arch Neurol 1989]*

Appendix C

Physical Self-Maintenance Scale- Instrumental Activities of Daily Living

PHYSICAL SELF-MAINTENANCE SCALE (ACTIVITIES OF DAILY LIVING, OR ADLS)

In each category, circle the item that most closely describes the person's highest level of functioning and record the score assigned to that level (either 1 or 0) in the blank at the beginning of the category.

| | | |
|---|--|---|
| A. Toilet | | |
| 1. | Care for self at toilet completely; no incontinence | 1 |
| 2. | Needs to be reminded, or needs help in cleaning self, or has rare (weekly at most) accidents | 0 |
| 3. | Soiling or wetting while asleep more than once a week | 0 |
| 4. | Soiling or wetting while awake more than once a week | 0 |
| 5. | No control of bowels or bladder | 0 |
| B. Feeding | | — |
| 1. | Eats without assistance | 1 |
| 2. | Eats with minor assistance at meal times and/or with special preparation of food, or help in cleaning up after meals | 0 |
| 3. | Feed self with moderate assistance and is untidy | 0 |
| 4. | Requires extensive assistance for all meals | 0 |
| 5. | Does not feed self at all and resists efforts of others to feed him or her | 0 |
| C. Dressing | | — |
| 1. | Dresses, undresses, and selects clothes from own wardrobe | 1 |
| 2. | Dresses and undresses self, with minor assistance | 0 |
| 3. | Needs moderate assistance in dressing and selection of clothes | 0 |
| 4. | Needs major assistance in dressing, but cooperates with efforts of others to help | 0 |
| 5. | Completely unable to dress self and resists efforts of others to help | 0 |
| D. Grooming (neatness, hair, nails, hands, face, clothing) | | — |
| 1. | Always neatly dressed, well-groomed, without assistance | 1 |
| 2. | Grooms self adequately with occasional minor assistance, ex, with shaving | 0 |
| 3. | Needs moderate and regular assistance or supervision with grooming | 0 |
| 4. | Needs total grooming care, but can remain well-groomed after help with others | 0 |
| 5. | Actively negates all efforts of others to maintain grooming | 0 |
| E. Physical Ambulation | | — |
| 1. | Goes about grounds or city | 1 |
| 2. | Ambulates within residence on or about one block distance | 0 |
| 3. | Ambulates with assistance of (check one below) | 0 |
| | A () another person, b () railing, c () cane, d () walker, e () wheelchair | |
| 4. | Sits unsupported in chair or wheelchair, but cannot propel self without help | 0 |
| | 1. ___ Gets in and out without help. 2. ___ Needs help getting in and out. | |
| 5. | Bedridden more than half the time | 0 |
| F. Bathing | | — |
| 1. | Bathes self (tub, shower, sponge bath) without help | 1 |
| 2. | Bathes self with help getting in and out of tub | 0 |
| 3. | Washes face and hands only, but cannot bathe rest of body | 0 |
| 4. | Does not wash self, but is cooperative with those who bathe him or her | 0 |
| 5. | Does not try to wash self and resists efforts to keep him or her clean | 0 |
| For scoring interpretation and source, see note following the next instrument | | |

INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADLs)

In each category, circle the item that most closely describes the person's highest level of functioning and record the score assigned to that level (either 1 or 0) in the blank at the beginning of the category.

| | | |
|--|---|---|
| A. Ability to use telephone | | — |
| 1. | Operates telephone on own initiative; looks up and dials numbers | 1 |
| 2. | Dials a few well-known numbers | 1 |
| 3. | Answers telephone, but does not call | 1 |
| 4. | Does not use telephone at all | 0 |
| B. Shopping | | — |
| 1. | Takes care of all shopping needs independently | 1 |
| 2. | Shops independently for small purchases | 0 |
| 3. | Needs to be accompanied on any shopping trip | 0 |
| 4. | Completely unable to shop | 0 |
| C. Food Preparation | | — |
| 1. | Plans, prepares, and serves adequate meals independently | 1 |
| 2. | Prepares adequate meals if supplied with ingredients | 0 |
| 3. | Heat and serves prepared meals or prepares meals, but does not maintain adequate diet | 0 |
| 4. | Needs to have meals prepared and served | 0 |
| D. Housekeeping | | — |
| 1. | Maintains house alone or with occasional assistance (ex, domestic help for heavy work) | 1 |
| 2. | Performs light daily tasks such as dishwashing, bedmaking | 1 |
| 3. | Performs light daily tasks, but cannot maintain acceptable level of cleanliness | 1 |
| 4. | Needs help with all home maintenance tasks | 1 |
| 5. | Does not participate in any housekeeping tasks | 0 |
| E. Laundry | | — |
| 1. | Does personal laundry completely | 1 |
| 2. | Launders small items; rinses socks, stockings, etc. | 1 |
| 3. | All laundry must be done by others | 0 |
| F. Mode of Transportation | | — |
| 1. | Travels independently on public transportation or drives own car | 1 |
| 2. | Arranges own travel via taxi, but does not otherwise use public transportation | 1 |
| 3. | Travels on public transportation when assisted or accompanied by another | 1 |
| 4. | Travel limited to taxi or automobile with assistance of another | 0 |
| 5. | Does not travel at all | 0 |
| G. Responsibility for Own Medications | | — |
| 1. | Is responsible for taking medication in correct dosages at correct time | 1 |
| 2. | Takes responsibility if medication is prepared in advance in separate dosages | 0 |
| 3. | Is not capable of dispensing own medication | 0 |
| H. Ability to Handle Finances | | — |
| 1. | Manages financial matters independently (budgets, writes checks, pays rent and bills, goes to bank); collects and keeps track of income | 1 |
| 2. | Manages day-to-day purchases, but needs help with banking, major purchases, etc. | 1 |
| 3. | Incapable of handling money | 0 |

Scoring Interpretation: For ADLs, the total score ranges from 0-6, and for IADLs, from 0-8. In some categories, only the highest level of function receives a 1; in others two or more levels have scores of 1 because each describes competence that represents some minimal level of function. These screens are useful for indicating specifically how a person is performing at the present time. When they are also used over time, they serve as documentation of a person's functional improvement or deterioration.

Source: Lawton, M. P. & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist*, 9, 179-186.

Appendix D

Center for Epidemiologic studies Depression Scale (CES-D)

Center for Epidemiologic Studies Depression Scale (CES-D)

Directions: Do not score if missing more than 4 responses. 1) For each item, look up your response and corresponding score (0-3). 2) Fill in the score for each item under the last column labeled "Score". 3) Calculate your Total Score by adding up all 20 scores.

| During the past week... | Rarely or none of the time (less than 1 day) | Some or a little of the time (1-2 days) | Occasionally or a moderate amount of time (3-4 days) | All of the time (5-7 days) | Score |
|---|--|---|--|----------------------------|-------|
| 1. I was bothered by things that usually don't bother me. | 0 | 1 | 2 | 3 | |
| 2. I did not feel like eating; my appetite was poor. | 0 | 1 | 2 | 3 | |
| 3. I felt that I could not shake off the blues even with help from my family. | 0 | 1 | 2 | 3 | |
| 4. I felt that I was just as good as other people. | 3 | 2 | 1 | 0 | |
| 5. I had trouble keeping my mind on what I was doing. | 0 | 1 | 2 | 3 | |
| 6. I felt depressed. | 0 | 1 | 2 | 3 | |
| 7. I felt that everything I did was an effort. | 0 | 1 | 2 | 3 | |
| 8. I felt hopeful about the future. | 3 | 2 | 1 | 0 | |
| 9. I thought my life had been a failure. | 0 | 1 | 2 | 3 | |
| 10. I felt fearful. | 0 | 1 | 2 | 3 | |
| 11. My sleep was restless. | 0 | 1 | 2 | 3 | |
| 12. I was happy. | 3 | 2 | 1 | 0 | |
| 13. I talked less than usual. | 0 | 1 | 2 | 3 | |
| 14. I felt lonely. | 0 | 1 | 2 | 3 | |
| 15. People were unfriendly. | 0 | 1 | 2 | 3 | |
| 16. I enjoyed life. | 3 | 2 | 1 | 0 | |
| 17. I had crying spells. | 0 | 1 | 2 | 3 | |
| 18. I felt sad. | 0 | 1 | 2 | 3 | |
| 19. I felt that people disliked me. | 0 | 1 | 2 | 3 | |
| 20. I could not "get going". | 0 | 1 | 2 | 3 | |
| Total Score: | | | | | |

Scoring Results: Total Score of 16 or higher is considered depressed.

Appendix E

National Institutes of Health Stroke Scale (NIH-SS)

N I H STROKE SCALE

Patient Identification _____

Pt. Date of Birth ____/____/____

Hospital _____ (____-____)

Date of Exam ____/____/____

Interval: Baseline 2 hours post treatment 24 hours post onset of symptoms ±20 minutes 7-10 days
 3 months Other _____ (____)

Time: ____:____:____ am pm

Person Administering Scale _____

Administer stroke scale items in the order listed. Record performance in each category after each subscale exam. Do not go back and change scores. Follow directions provided for each exam technique. Scores should reflect what the patient does, not what the clinician thinks the patient can do. The clinician should record answers while administering the exam and work quickly. Except where indicated, the patient should not be coached (i.e., repeated requests to patient to make a special effort).

| Instructions | Scale Definition | Score |
|--|--|-------|
| <p>1a. Level of Consciousness: The investigator must choose a response if a full evaluation is prevented by such obstacles as an endotracheal tube, language barrier, orotracheal trauma/bandages. A 3 is scored only if the patient makes no movement (other than reflexive posturing) in response to noxious stimulation.</p> | <p>0 = Alert; keenly responsive. 1 = Not alert; but arousable by minor stimulation to obey, answer, or respond. 2 = Not alert; requires repeated stimulation to attend, or is obtunded and requires strong or painful stimulation to make movements (not stereotyped). 3 = Responds only with reflex motor or autonomic effects or totally unresponsive, flaccid, and areflexic.</p> | _____ |
| <p>1b. LOC Questions: The patient is asked the month and his/her age. The answer must be correct - there is no partial credit for being close. Aphasic and stuporous patients who do not comprehend the questions will score 2. Patients unable to speak because of endotracheal intubation, orotracheal trauma, severe dysarthria from any cause, language barrier, or any other problem not secondary to aphasia are given a 1. It is important that only the initial answer be graded and that the examiner not "help" the patient with verbal or non-verbal cues.</p> | <p>0 = Answers both questions correctly. 1 = Answers one question correctly. 2 = Answers neither question correctly.</p> | _____ |
| <p>1c. LOC Commands: The patient is asked to open and close the eyes and then to grip and release the non-paretic hand. Substitute another one step command if the hands cannot be used. Credit is given if an unequivocal attempt is made but not completed due to weakness. If the patient does not respond to command, the task should be demonstrated to him or her (pantomime), and the result scored (i.e., follows none, one or two commands). Patients with trauma, amputation, or other physical impediments should be given suitable one-step commands. Only the first attempt is scored.</p> | <p>0 = Performs both tasks correctly. 1 = Performs one task correctly. 2 = Performs neither task correctly.</p> | _____ |
| <p>2. Best Gaze: Only horizontal eye movements will be tested. Voluntary or reflexive (oculocephalic) eye movements will be scored, but caloric testing is not done. If the patient has a conjugate deviation of the eyes that can be overcome by voluntary or reflexive activity, the score will be 1. If a patient has an isolated peripheral nerve paresis (CN III, IV or VI), score a 1. Gaze is testable in all aphasic patients. Patients with ocular trauma, bandages, pre-existing blindness, or other disorder of visual acuity or fields should be tested with reflexive movements, and a choice made by the investigator. Establishing eye contact and then moving about the patient from side to side will occasionally clarify the presence of a partial gaze palsy.</p> | <p>0 = Normal. 1 = Partial gaze palsy; gaze is abnormal in one or both eyes, but forced deviation or total gaze paresis is not present. 2 = Forced deviation, or total gaze paresis not overcome by the oculocephalic maneuver.</p> | _____ |

Rev 10/1/2003

N I H STROKE SCALE

Patient Identification. _____

Pt. Date of Birth ____/____/____

Hospital _____

Date of Exam ____/____/____

Interval: Baseline 2 hours post treatment 24 hours post onset of symptoms \pm 20 minutes 7-10 days
 3 months Other _____ (_____)

| | | |
|---|---|-----------------------------------|
| <p>3. Visual: Visual fields (upper and lower quadrants) are tested by confrontation, using finger counting or visual threat, as appropriate. Patients may be encouraged, but if they look at the side of the moving fingers appropriately, this can be scored as normal. If there is unilateral blindness or enucleation, visual fields in the remaining eye are scored. Score 1 only if a clear-cut asymmetry, including quadrantanopia, is found. If patient is blind from any cause, score 3. Double simultaneous stimulation is performed at this point. If there is extinction, patient receives a 1, and the results are used to respond to item 11.</p> | <p>0 = No visual loss. 1 = Partial hemianopia. 2 = Complete hemianopia. 3 = Bilateral hemianopia (blind including cortical blindness).</p> | <p>_____</p> |
| <p>4. Facial Palsy: Ask – or use pantomime to encourage – the patient to show teeth or raise eyebrows and close eyes. Score symmetry of grimace in response to noxious stimuli in the poorly responsive or non-comprehending patient. If facial trauma/bandages, orotracheal tube, tape or other physical barriers obscure the face, these should be removed to the extent possible.</p> | <p>0 = Normal symmetrical movements. 1 = Minor paralysis (flattened nasolabial fold, asymmetry on smiling). 2 = Partial paralysis (total or near-total paralysis of lower face). 3 = Complete paralysis of one or both sides (absence of facial movement in the upper and lower face).</p> | <p>_____</p> |
| <p>5. Motor Arm: The limb is placed in the appropriate position: extend the arms (palms down) 90 degrees (if sitting) or 45 degrees (if supine). Drift is scored if the arm falls before 10 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic arm. Only in the case of amputation or joint fusion at the shoulder, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice.</p> | <p>0 = No drift; limb holds 90 (or 45) degrees for full 10 seconds. 1 = Drift; limb holds 90 (or 45) degrees, but drifts down before full 10 seconds; does not hit bed or other support. 2 = Some effort against gravity; limb cannot get to or maintain (if cued) 90 (or 45) degrees, drifts down to bed, but has some effort against gravity. 3 = No effort against gravity; limb falls. 4 = No movement. UN = Amputation or joint fusion, explain: _____</p> <p>5a. Left Arm</p> <p>5b. Right Arm</p> | <p>_____ _____</p> |
| <p>6. Motor Leg: The limb is placed in the appropriate position: hold the leg at 30 degrees (always tested supine). Drift is scored if the leg falls before 5 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic leg. Only in the case of amputation or joint fusion at the hip, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice.</p> | <p>0 = No drift; leg holds 30-degree position for full 5 seconds. 1 = Drift; leg falls by the end of the 5-second period but does not hit bed. 2 = Some effort against gravity; leg falls to bed by 5 seconds, but has some effort against gravity. 3 = No effort against gravity; leg falls to bed immediately. 4 = No movement. UN = Amputation or joint fusion, explain: _____</p> <p>6a. Left Leg</p> <p>6b. Right Leg</p> | <p>_____</p> |

Rev 10/1/2003

N I H STROKE SCALE

Patient Identification. _____

Pt. Date of Birth ____/____/____

Hospital _____ (____-____)

Date of Exam ____/____/____

Interval: Baseline 2 hours post treatment 24 hours post onset of symptoms ±20 minutes 7-10 days
 3 months Other _____ (____)

| | | |
|--|--|--------------|
| <p>7. Limb Ataxia: This item is aimed at finding evidence of a unilateral cerebellar lesion. Test with eyes open. In case of visual defect, ensure testing is done in intact visual field. The finger-nose-finger and heel-shin tests are performed on both sides, and ataxia is scored only if present out of proportion to weakness. Ataxia is absent in the patient who cannot understand or is paralyzed. Only in the case of amputation or joint fusion, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice. In case of blindness, test by having the patient touch nose from extended arm position.</p> | <p>0 = Absent. 1 = Present in one limb. 2 = Present in two limbs. UN = Amputation or joint fusion, explain: _____</p> | <p>_____</p> |
| <p>8. Sensory: Sensation or grimace to pinprick when tested, or withdrawal from noxious stimulus in the obtunded or aphasic patient. Only sensory loss attributed to stroke is scored as abnormal and the examiner should test as many body areas (arms [not hands], legs, trunk, face) as needed to accurately check for hemisensory loss. A score of 2, "severe or total sensory loss," should only be given when a severe or total loss of sensation can be clearly demonstrated. Stuporous and aphasic patients will, therefore, probably score 1 or 0. The patient with brainstem stroke who has bilateral loss of sensation is scored 2. If the patient does not respond and is quadriplegic, score 2. Patients in a coma (item 1a=3) are automatically given a 2 on this item.</p> | <p>0 = Normal; no sensory loss. 1 = Mild-to-moderate sensory loss; patient feels pinprick is less sharp or is dull on the affected side; or there is a loss of superficial pain with pinprick, but patient is aware of being touched. 2 = Severe to total sensory loss; patient is not aware of being touched in the face, arm, and leg.</p> | <p>_____</p> |
| <p>9. Best Language: A great deal of information about comprehension will be obtained during the preceding sections of the examination. For this scale item, the patient is asked to describe what is happening in the attached picture, to name the items on the attached naming sheet and to read from the attached list of sentences. Comprehension is judged from responses here, as well as to all of the commands in the preceding general neurological exam. If visual loss interferes with the tests, ask the patient to identify objects placed in the hand, repeat, and produce speech. The intubated patient should be asked to write. The patient in a coma (item 1a=3) will automatically score 3 on this item. The examiner must choose a score for the patient with stupor or limited cooperation, but a score of 3 should be used only if the patient is mute and follows no one-step commands.</p> | <p>0 = No aphasia; normal. 1 = Mild-to-moderate aphasia; some obvious loss of fluency or facility of comprehension, without significant limitation on ideas expressed or form of expression. Reduction of speech and/or comprehension, however, makes conversation about provided materials difficult or impossible. For example, in conversation about provided materials, examiner can identify picture or naming card content from patient's response. 2 = Severe aphasia; all communication is through fragmentary expression; great need for inference, questioning, and guessing by the listener. Range of information that can be exchanged is limited; listener carries burden of communication. Examiner cannot identify materials provided from patient response. 3 = Mute, global aphasia; no usable speech or auditory comprehension.</p> | <p>_____</p> |
| <p>10. Dysarthria: If patient is thought to be normal, an adequate sample of speech must be obtained by asking patient to read or repeat words from the attached list. If the patient has severe aphasia, the clarity of articulation of spontaneous speech can be rated. Only if the patient is intubated or has other physical barriers to producing speech, the examiner should record the score as untestable (UN), and clearly write an explanation for this choice. Do not tell the patient why he or she is being tested.</p> | <p>0 = Normal. 1 = Mild-to-moderate dysarthria; patient slurs at least some words and, at worst, can be understood with some difficulty. 2 = Severe dysarthria; patient's speech is so slurred as to be unintelligible in the absence of or out of proportion to any dysphasia, or is mute/anarthric. UN = Intubated or other physical barrier, explain: _____</p> | <p>_____</p> |

Rev 10/1/2003

N I H STROKE SCALE

Patient Identification. _____

Pt. Date of Birth ____/____/____

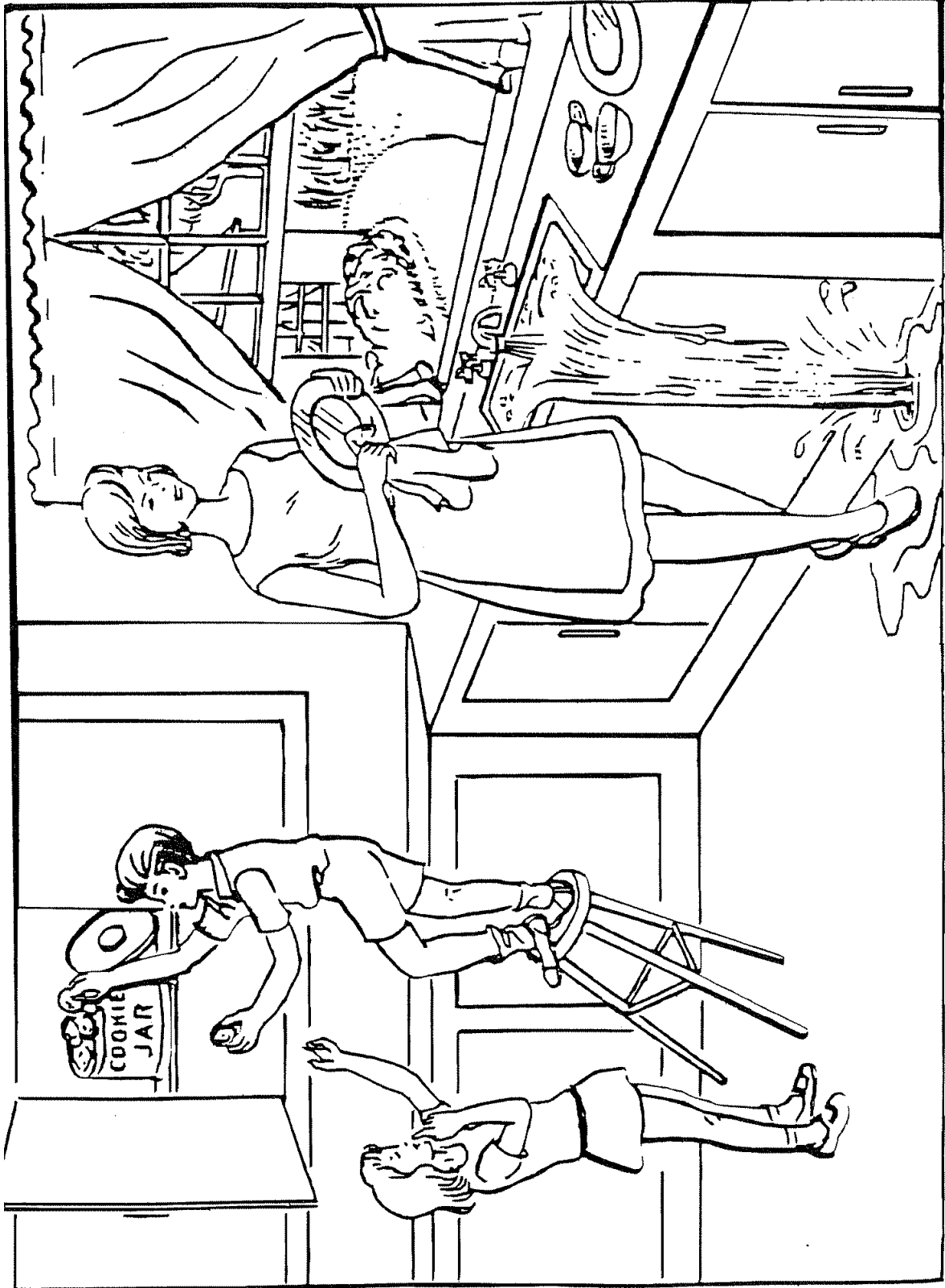
Hospital _____ (____-____-____)

Date of Exam ____/____/____

Interval: Baseline 2 hours post treatment 24 hours post onset of symptoms \pm 20 minutes 7-10 days
 3 months Other _____ (_____)

| | | |
|---|---|---------------------------|
| <p>11. Extinction and Inattention (formerly Neglect): Sufficient information to identify neglect may be obtained during the prior testing. If the patient has a severe visual loss preventing visual double simultaneous stimulation, and the cutaneous stimuli are normal, the score is normal. If the patient has aphasia but does appear to attend to both sides, the score is normal. The presence of visual spatial neglect or anosagnosia may also be taken as evidence of abnormality. Since the abnormality is scored only if present, the item is never untestable.</p> | <p>0 = No abnormality.</p> <p>1 = Visual, tactile, auditory, spatial, or personal inattention or extinction to bilateral simultaneous stimulation in one of the sensory modalities.</p> <p>2 = Profound hemi-inattention or extinction to more than one modality; does not recognize own hand or orients to only one side of space.</p> | <p>_____</p> <p>_____</p> |
|---|---|---------------------------|

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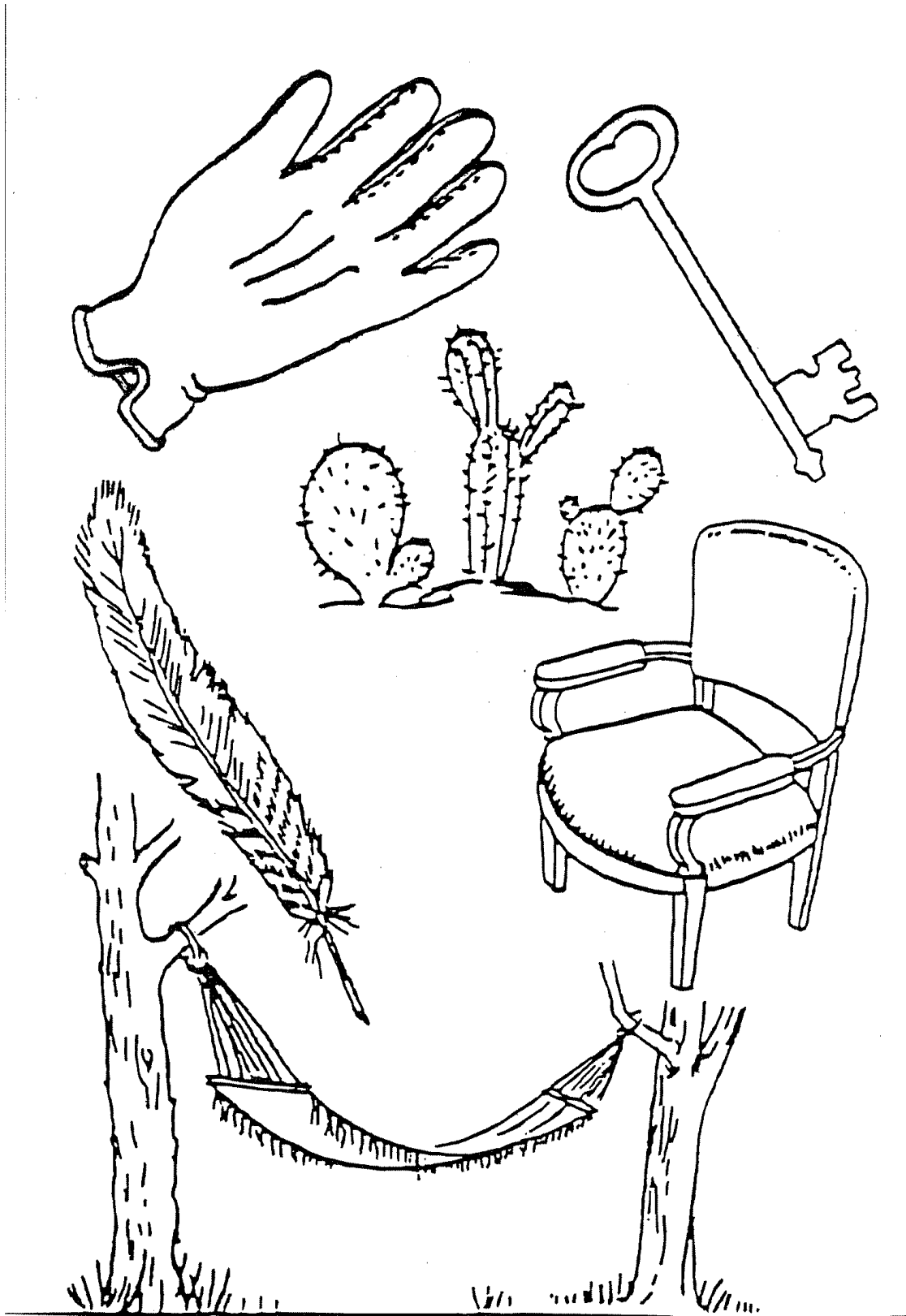
You know how.

Down to earth.

I got home from work.

**Near the table in the dining
room.**

**They heard him speak on the
radio last night.**



MAMA
TIP – TOP
FIFTY – FIFTY
THANKS
HUCKLEBERRY
BASEBALL PLAYER

Appendix F

Pittsburgh Sleep Quality Index (PSQI)

Subject's Initials _____ ID# _____ Date _____ Time _____ AM
 _____ PM

PITTSBURGH SLEEP QUALITY INDEX

INSTRUCTIONS:

The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

1. During the past month, what time have you usually gone to bed at night?
 BED TIME _____
2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night?
 NUMBER OF MINUTES _____
3. During the past month, what time have you usually gotten up in the morning?
 GETTING UP TIME _____
4. During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spent in bed.)
 HOURS OF SLEEP PER NIGHT _____

For each of the remaining questions, check the one best response. Please answer all questions.

5. During the past month, how often have you had trouble sleeping because you . . .
 - a) Cannot get to sleep within 30 minutes

| | | | |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the past month _____ | Less than once a week _____ | Once or twice a week _____ | Three or more times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
 - b) Wake up in the middle of the night or early morning

| | | | |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the past month _____ | Less than once a week _____ | Once or twice a week _____ | Three or more times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
 - c) Have to get up to use the bathroom

| | | | |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the past month _____ | Less than once a week _____ | Once or twice a week _____ | Three or more times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|

- d) Cannot breathe comfortably
- | | | | |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the past month _____ | Less than once a week _____ | Once or twice a week _____ | Three or more times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
- e) Cough or snore loudly
- | | | | |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the past month _____ | Less than once a week _____ | Once or twice a week _____ | Three or more times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
- f) Feel too cold
- | | | | |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the past month _____ | Less than once a week _____ | Once or twice a week _____ | Three or more times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
- g) Feel too hot
- | | | | |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the past month _____ | Less than once a week _____ | Once or twice a week _____ | Three or more times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
- h) Had bad dreams
- | | | | |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the past month _____ | Less than once a week _____ | Once or twice a week _____ | Three or more times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
- i) Have pain
- | | | | |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the past month _____ | Less than once a week _____ | Once or twice a week _____ | Three or more times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
- j) Other reason(s), please describe _____
-

How often during the past month have you had trouble sleeping because of this?

| | | | |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|
| Not during the past month _____ | Less than once a week _____ | Once or twice a week _____ | Three or more times a week _____ |
|------------------------------------|--------------------------------|-------------------------------|-------------------------------------|

6. During the past month, how would you rate your sleep quality overall?

Very good _____

Fairly good _____

Fairly bad _____

Very bad _____

7. During the past month, how often have you taken medicine to help you sleep (prescribed or "over the counter")?

Not during the past month _____ Less than once a week _____ Once or twice a week _____ Three or more times a week _____

8. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?

Not during the past month _____ Less than once a week _____ Once or twice a week _____ Three or more times a week _____

9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?

No problem at all _____
 Only a very slight problem _____
 Somewhat of a problem _____
 A very big problem _____

10. Do you have a bed partner or room mate?

No bed partner or room mate _____
 Partner/room mate in other room _____
 Partner in same room, but not same bed _____
 Partner in same bed _____

If you have a room mate or bed partner, ask him/her how often in the past month you have had . . .

a) Loud snoring

Not during the past month _____ Less than once a week _____ Once or twice a week _____ Three or more times a week _____

b) Long pauses between breaths while asleep

Not during the past month _____ Less than once a week _____ Once or twice a week _____ Three or more times a week _____

c) Legs twitching or jerking while you sleep

Not during the past month _____ Less than once a week _____ Once or twice a week _____ Three or more times a week _____

d) Episodes of disorientation or confusion during sleep

Not during the past month _____ Less than once a week _____ Once or twice a week _____ Three or more times a week _____

e) Other restlessness while you sleep; please describe _____

Not during the past month _____ Less than once a week _____ Once or twice a week _____ Three or more times a week _____

Buyse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ: Psychiatry Research, 28:193-213, 1989.

lmw:F5.PSQ (4/2002)

Appendix G

Demographic Questionnaire

Demographic Questionnaire

Name:

Phone:

Sex: M F

Age/DOB:

Diagnosis:

Months since stroke:

Other medical conditions, if any:

Current medications:

Presence of a friend or family member as caregiver: Y N

For what activities do you receive assistance?

How often is this assistance provided?

Appendix H

Intervention Satisfaction Survey

Intervention Satisfaction Survey

1. How many program sessions did you attend?

2. After participating in this educational program, how confident are you that you can :

| | |
|---|--|
| A. Understand and communicate your needs to others related to PSF? | Not at all ----- Totally confident 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 confident |
| B. Pace your activities and use relaxation techniques? | Not at all ----- Totally confident 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 confident |
| C. Manage sleep problems? | Not at all ----- Totally confident 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 confident |
| D. Incorporate activity through your schedule? | Not at all ----- Totally confident 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 confident |
| E. Prioritize and plan your daily routine? | Not at all ----- Totally confident 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 confident |
| F. Schedule activities and include rest periods? | Not at all ----- Totally confident 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 confident |
| G. Apply the strategies learned to future activities? | Not at all ----- Totally confident 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 confident |
| H. Keep the fatigue you feel from interfering with the activities you do? | Not at all ----- Totally confident 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 confident |

3. What additional information would you like to have had covered during the program?

Appendix I

Recruitment flyer

Did you have a stroke at least one year ago?

Did you fatigue (a lack of energy or sense of exhaustion) cause you to reduce or change your daily activities?

Are you interested in learning ways to reduce the effects of fatigue?

Would you be willing to join a group to help other stroke survivors avoid the effects of fatigue also?

Be a part of a research study to examine the effectiveness of a group-based program to reduce fatigue and the effects it has on daily function. You will benefit by learning strategies from others in your situation. You will help other stroke survivors by sharing your experiences. And you will be helping me complete my dissertation research.

Please consider joining our group to help stroke survivors *Live Life to Its Fullest*©

To learn more:

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Vita

Catherine Elizabeth Emery (nee Emenheiser) was born on November 29, 1961, in York County, Pennsylvania. She graduated from Red Lion Area Senior High School, Red Lion, Pennsylvania in 1979. She received her Bachelor of Science in PsychoBiology from Albright College in 1983 and provided cognitive retraining therapy to traumatically brain injured adults at Reading Rehabilitation Hospital until 1986. Catherine received a Masters of Science in Occupational Therapy from Boston University in January 1989, where she completed a specialization in traumatic brain injury rehabilitation. Upon returning to Pennsylvania, she worked in Mechanicburg before returning to the neurotrauma unit of Reading Rehabilitation Hospital. She taught for Penn State- Berks Campus 1993-4. She served on the Pennsylvania Occupational Therapy Association Board of Directors from 1993- 1996 and received the President's Service Award in 1995. That same year, she began work in long-term care facilities in the Lancaster and Berks County areas of Pennsylvania through 1999. She achieved Specialty Certification in Neurorehabilitation through the American Occupational Therapy Association 1998-2006. Catherine joined the full-time teaching faculty at Alvernia University in 1999, where she continues to teach in the Occupational Therapy Department, currently serving as MSOT Program Coordinator. She also continues to work in home health care as a per diem occupational therapist in Pennsylvania.