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# A Pilot Study: Examining the Effectiveness of Managing Fatigue Post-Stroke via Telehealth

Nicole Gronhovd  
*University of North Dakota*

Hannah Muehlberg  
*University of North Dakota*

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A PILOT STUDY: EXAMINING THE EFFECTIVENESS OF MANAGING FATIGUE  
POST-STROKE VIA TELEHEALTH

by

Nicole Gronhovd, MOTS and Hannah Muehlberg, MOTS

Master of Occupational Therapy, University of North Dakota, 2013

Advisor: Dr. Jan Stube, Ph.D., OTR/L, FAOTA

An Independent Study

Submitted to the Occupational Therapy Department

of the

University of North Dakota

In partial fulfillment of the requirements

for the degree of

Master of Occupational Therapy

Grand Forks, North Dakota  
May 17, 2014

This Independent Study Paper, submitted by Nicole Gronhovd, MOTS and Hannah Muehlberg, MOTS in partial fulfillment of the requirement for the Degree of Master of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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Faculty Advisor

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Department   Occupational Therapy

Degree       Master of Occupational Therapy

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## ABSTRACT

There is currently a lack of research on the effectiveness of energy conservation techniques to treat the fatigue experienced by individuals following a stroke. Because of this, the purpose of this research study was to explore the effects of *Managing Fatigue: A Six Week Course for Energy Conservation*, developed by occupational therapists, Packer, Brink, and Sauriol (1995), on the level of fatigue individuals experience following a stroke. As telehealth is an emerging area in occupational therapy service delivery, the present study also aimed to determine the effectiveness of occupational therapy services delivered via teleconference.

A pilot study using a pretest-posttest single subject design was implemented to obtain and analyze data from one participant. UND and Altru IRB approval were received and the participant gave informed consent. The participant completed the *Managing Fatigue* course over five consecutive sessions via teleconference with the principal investigators and their advisor. A self-developed demographic questionnaire and the Patient-Reported Outcomes Measurement Information System (PROMIS) Fatigue Short Form 7a were completed by the subject prior to completion of the *Managing Fatigue* course. Additionally, the Fatigue Impact Scale (FIS) and the Canadian Occupational Performance Measure (COPM) were utilized prior to and following participation in the *Managing Fatigue* course to analyze potential changes in fatigue

severity and subject-perceived occupational performance. All assessments and delivery of the *Managing Fatigue* course were completed via teleconference.

The subject participating in this research was a 70 year old male who experienced a left-side ischemic stroke five years prior to the study. Following completion of the *Managing Fatigue* course, fatigue severity noted from the FIS decreased from 47 to 13 out of a possible 160 on the Fatigue Impact Scale (FIS), evidencing improved fatigue severity. Decreases in fatigue were noted in physical, cognitive, and social categories. The subject's average perceived occupational performance score improved from 4.8 to 5.2 out of a possible 10 following participation in the *Managing Fatigue* course. Furthermore, his average satisfaction score increased from 4.2 to 5.0 out of a possible 10 in prioritized areas of occupation through the use of the COPM. This evidences increased subject-perceived occupational performance and satisfaction in areas of occupation of importance to the subject.

Although performance and satisfaction in occupational performance increased and fatigue severity decreased following participation in the *Managing Fatigue* course, it cannot be inferred that participation in the course was the cause of the change.

Limitations of the research, including that it was a pilot study and utilized a single-subject sample size, result in a lack of generalization to a larger population and warrant future research with a larger sample to study the effectiveness of the *Managing Fatigue* course on post-stroke fatigue. Furthermore, the decrease in fatigue evidences a possible benefit of the use of teleconference service delivery. However, as changes in data from pretest to posttest were evident, future research is warranted to study the influence of telehealth with the post-stroke fatigue population.

# **CHAPTER I**

## **INTRODUCTION**

### **Rationale**

This study stemmed from the work of Jan Stube, Ph.D., OTR/L, FAOTA, the advisor of the principal investigators, who has completed previous research on the area of post-stroke fatigue. Combined with Dr. Jan Stube's knowledge and the principal investigators' interest in the population of individuals who have had strokes, the three teamed up to complete this pilot study. Furthermore, with telehealth being an emerging area in the scope of occupational therapy practice, additional research for future occupational therapy practice in this area is warranted.

It is reported that approximately 50% of individuals experience fatigue following a stroke, evidencing high prevalence of this symptom in individuals post-stroke (Annoni, Staub, Bogousslavsky, & Brioschi 2008; Appelros, 2006; Ingles, Eskes, & Phillips, 1999; van der Werf, van den Broek, Anten, & Bleijenberg, 2001). Moreover, this fatigue experienced is reported to be among the worst or of the more severe symptoms post-stroke (Ingles et al., 1999). Different than normal "tiredness", post-stroke fatigue is described as being a chronic mental and physical fatigue that does not lessen with rest (de Groot, Phillips, & Eskes, 2003; Kirkevold, Christensen, Anderson, Johnsen, & Harder, 2012). The severity of this fatigue may significantly impair one's ability to participate in areas of occupation and the post-stroke recovery process.

One possible way to address post-stroke fatigue is through a *Managing Fatigue* course. *Managing Fatigue: A Six-Week Course for Energy Conservation*, developed by occupational therapists Tanya Packer, Nicky Brink, and Adele Sauriol (1995), is an energy conservation course that lasts six weeks. During this course, individuals gain education on the importance of rest, communication of needs, effective body mechanics, organizing the environment, setting priorities, and having a balanced lifestyle (Packer, Brink, & Sauriol, 1995). Though this course has yet to be trialed with the post-stroke population, it has proven to be effective with fatigue experienced by individuals with other neurological conditions, such as multiple sclerosis (Ghahari, Packer, & Passmore, 2010; Holberg & Finlayson, 2007; Matuska, Mathiowetz, & Finlayson, 2007). Considering past effectiveness of energy conservation programs among persons with neurological disorders, the *Managing Fatigue* course is likely to assist in decreasing fatigue experienced by individuals post-stroke.

As previously stated, telehealth is an emerging area in the scope of occupational therapy practice. It is defined by the American Telemedicine Association as “the delivery of rehabilitation services via information and communication technologies” (Brennan et al., 2011, p. 663). According to the American Occupational Therapy Association (AOTA) (2013), telehealth is a feasible method for occupational therapists, and other healthcare professionals, to participate in alternative methods of service delivery. Through telehealth, occupational therapists may assist clients to acquire various skills, suggest environmental modifications, and educate on assistive technology/adaptive techniques. Due to the amount of services that can be delivered via telehealth, the use of

this technology may drastically change occupational therapy practice on a regional, national, and global level.

Approximately 20% of individuals in the United States live in rural areas (Laditka, Laditka, & Probst, 2009). According to the United States Census Bureau, 40.1% of North Dakotans live in rural settings in 2010 (United States Census Bureau, 2010). In comparison to other states, North Dakota has the eighth highest percentage of individuals living in rural settings; Maine is ranked first with 61.34% of its population living in a rural setting (United States Census Bureau, 2010). Concerns regarding rural populations include underfunded healthcare systems, low numbers of healthcare professionals, larger caseloads, poorer quality of care (secondary to the aforementioned issues), and increased travel time for healthcare professionals (Johnson, Johnson, Zurawski, & Siegel, 2003; Ladika et al., 2009; Wielandt & Taylor, 2010). Taking these concerns and limitations into consideration, the use of telehealth would allow occupational therapists, along with other healthcare professionals, to provide more appropriate client care, improve productivity, and decrease travel time for clients and healthcare professionals. Use of this technology may prove to be a beneficial tool for occupational therapists to treat post-stroke fatigue, and other diagnoses and symptoms, on a regional level by providing an alternative method of service delivery (AOTA, 2005).

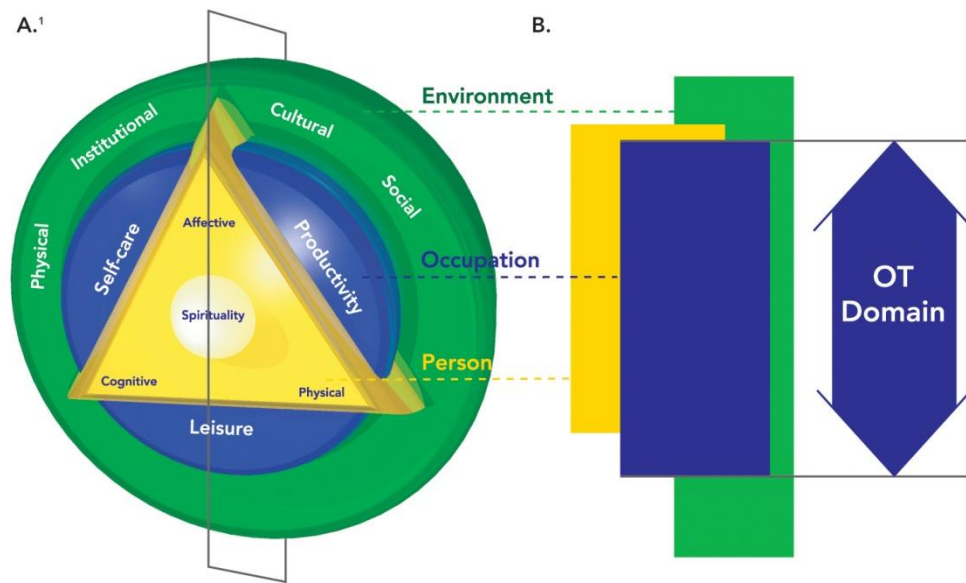
In addition to a regional level, telehealth technology may change occupational therapy practice on national and global levels as well. A systematic review conducted by Hailey, Roine, Ohinmaa, and Dennett (2011) found practitioners using telehealth technology contacted their clients more frequently and provided clients with more information and/or interventions. Use of telehealth allows occupational therapists to

distribute their services to a larger variety of clients by taking away the traveling time and allowing clients to receive occupational therapy services regardless of distance. Overall, the use of telehealth technology to provide occupational therapy services will likely provide positive outcomes for individuals on a regional, national, and global level. Because of these benefits of telehealth coupled with the practical concern of people with post-stroke fatigue and travel time, telehealth was selected as a viable method of service delivery for this independent study research.

### **Theoretical Framework**

The Canadian Model of Occupational Performance and Engagement (CMOP-E) is the theoretical framework integrated into the principal investigators' independent study. Previously referred to as the Canadian Model of Occupational Performance (CMOP), this model was expanded to include the aspect of occupational engagement in order to place greater emphasis on participation in occupations (Polatajko et al., 2007). According to this model, occupational performance occurs through the interaction of the variables that comprise the *person* (affective, cognitive, and physical aspects), *occupation* (self-care, productivity, or leisure), and the *environment* (physical, institutional, cultural, and social aspects) (Polatajko et al., 2007). This interaction is displayed in Figure 1 below. If any aspect of the model is disrupted, one's occupational performance declines (Clarke, 2003). What is significant and unique about the CMOP-E model is that it views spirituality as the core of an individual, expressed through other aspects of the person, occupations, and the environment (Clarke, 2003). It is important to note that spirituality is referred to as being different from religion (Udell & Chandler, 2000). Although spirituality may include religious beliefs, spirituality is defined as one's search for





A.<sup>1</sup> Referred to as the CMOP in *Enabling Occupation* (1997a, 2002) and CMOP-E as of this edition  
 B. Trans-sectional view

*Figure 1. From Enabling Occupation II: Advancing an Occupational Therapy Vision of Health, Well-being, and Justice through Occupation* (p. 23), by E.A. Townsend and H.J. Polatajko, 2007, Ottawa, ON: CAOT Publications ACE. Copyright [2007] by the Canadian Association of Occupational Therapists. Reprinted with permission.

purpose and meaning in one's life (Law, Polatajko, Baptiste, & Townsend, 1997; Udell & Chandler, 2000). By educating participating subjects on the information presented in this independent study, spirituality will be addressed by allowing subjects to experience a sense of meaning obtained through increased participation in meaningful occupations. Overall, placing spirituality as the core of the individual and using a holistic approach makes this a client-centered model align well with the use of *Managing Fatigue* and this study as a whole.

The CMOP was identified as being the theoretical foundation of Packer, Brink, and Sauriol's *Managing Fatigue* course (1995). Overall, this course is designed to improve the person's ability to perform in various areas of meaningful occupation while

in his/her environment. Environment (whether physical, institutional, cultural, or social) has a large influence on an individual's occupational performance, and may either facilitate or impede participation in various occupations (Law et al., 1997). During participation in the course, education on how to interact with one's environment and/or potential modification of one's environment will be provided. This environmental education will likely enable individuals to have improved participation in various self-identified, meaningful occupations. According to Law, Polatajko, Baptiste, and Townsend (1997), "occupation is a basic human need" (p. 34). Through participation in the *Managing Fatigue* course, individuals will potentially be better able to participate in various occupations as adaptations to various tasks and activities will be suggested throughout the course. Combined, the core aspects of the CMOP-E will be addressed throughout this study to assist in the rehabilitation process post-stroke and to help individuals improve their occupational performance.

Cognitive behavior therapy (CBT) is another theoretical foundation that will be integrated into this study. According to Cole and Tufano (2008), cognition influences behavior and occupational performance in all of the areas of occupation. Because of this, major cognitive focuses of CBT, such as self-efficacy and self-awareness, will be integrated into this study in hopes of improving participants' outcomes and overall occupational performance.

Self-efficacy, which refers to one's perceived competence to successfully interact within one's environment (Cole & Tufano, 2008), is a main focus in this study. Packer, Brink, and Sauriol (1995) conceptualize the fatigue cycle in their manual (found on overhead 1.4) as being: fatigue → decreased activity → feelings of inadequacy → stress,

before repeating the cycle. According to McCraith (2011), integrating information, trialing techniques, and achieving insights are characteristics of CBT occupational therapy intervention approaches. By implementing and trialing energy conservation techniques learned throughout the *Managing Fatigue* course, the individuals participating in the study are hypothesized to decrease fatigue, and in turn, gain a better sense of adequacy and self-efficacy as they will gain insights and be more competent in their environment and able to interact within the environment more effectively.

Another focus of CBT is self-awareness (Cole & Tufano, 2008). Self-awareness is increased throughout the *Managing Fatigue* course through a variety of activities, including answering questions relating to their current fatigue and rest, rearranging their environment to better reflect proper body mechanics, analyzing and prioritizing activities they need to complete, and sharing experiences with group members to further each other's insight (Packer et al., 1995). Complimenting self-awareness, self-monitoring is a common CBT intervention strategy that involves "paying deliberate attention to some aspect of one's behavior" (McCraith, 2011, p. 273). As one implements information learned during participation in the *Managing Fatigue* course, he/she will likely assess its effectiveness and/or impact on his/her fatigue levels through the use of self-monitoring. Furthermore, by participating in this study, individuals are expected to gain insight into their strengths and limitations to further assist them in utilizing techniques taught in this course and promote occupational performance, which also improves self-awareness and self-monitoring.

Although the use of CBT with the post-stroke population is not well researched, CBT has proven to be an effective method for other neurological diagnoses, such as

chronic fatigue syndrome. Deale, Chalder, Marks, and Wessely (1997) found that 70% of individuals with chronic fatigue syndrome had improved functioning after receiving treatment based on CBT. Based on the work of Deale et al., van Kessel et al. (2008) also had good outcomes when using CBT with individuals experiencing fatigue related to multiple sclerosis. Similar to the Packer, Brink, and Sauriol's (1995) *Managing Fatigue* course, van Kessel et al. (2008) utilized CBT by creating a manual focused on scheduling activities and rest, improving sleep, understanding symptoms of multiple sclerosis, changing thought patterns, utilizing social support, and coping with stress. While utilizing this CBT manual, van Kessel et al. (2008) found that participants experienced improvement in their fatigue. Based on the research completed on individuals with fatigue related to other neurological diagnoses, it is likely that incorporating CBT aspects into this study will have a positive effect on the post-stroke population as well. Overall, integrating CBT aspects into this study is intended to promote a better sense of self and allow individuals to utilize aspects taught in the course more effectively.

### **Statement of the Problem**

Individuals post-stroke experience difficulty participating in meaningful activities and occupations due to symptoms of post-stroke fatigue. Since post-stroke fatigue impacts up to 50% of individuals, developing a program (or utilizing an existing program) to address this issue would benefit the lives of many individuals (Annoni et al., 2008; Appelros, 2006; van der Werf et al., 2001). Also, finding an effective and feasible delivery method to use with individuals in rural areas with limited accessibility to occupational therapy services would improve client care and improve the scope of occupational therapy practice.

## **Hypothesis**

The principal investigators hypothesize that the *Managing Fatigue* course administered via teleconference will decrease the levels of fatigue that participants are experiencing and increase their engagement in meaningful occupations. The potential changes in fatigue level will be assessed via the FIS scores obtained both prior to and after each participant completes the *Managing Fatigue* course. Furthermore, potential changes in performance and satisfaction in meaningful occupations will be assessed by obtaining COPM scores at baseline and following completion of the *Managing Fatigue* course.

The principal investigators also hypothesize that teleconference will be an effective delivery method for occupational therapy services. The possible differences in scores of the FIS and COPM from baseline to following participation in the course will also be reflective of the effectiveness of telehealth in both the treatment of post-stroke fatigue and the administration of the *Managing Fatigue* course.

## **Assumption**

As the baby boomer generation (those individuals born between the years of 1946 and 1964) ages, it is assumed that there will be an increase in the number of individuals who experience a stroke. Thus, the prevalence of post-stroke fatigue as a more common symptom experienced may increase over time. Additionally, telehealth services are increasing in popularity as a means of providing cost-effective services in the healthcare world. Therefore, as the American Occupational Therapy Association (AOTA) identifies telehealth is an emerging area and a feasible method for delivering occupational therapy services, it is assumed that using this technology as a means of delivering occupational

therapy services will increase with time. Lastly, it is assumed that by having individuals participate in this course via a group format, group members will gain insight and learn from each other's experiences.

### **Scope and Delimitation**

This study is aimed at identifying the potential benefits of completion of an energy conservation course, *Managing Fatigue*, to treat post-stroke fatigue via telehealth. Completion of this course is aimed at educating subjects on the areas of importance of rest, communication of needs, effective body mechanics, organizing the environment, setting priorities, and having a balanced lifestyle as a means of improving independence and performance in all areas of occupation (Packer et al., 1995). By incorporating an education component, allowing subjects to share experiences with each other, and assigning homework in each session, subjects will gain greater insight to their own strengths, limitations, and how to increase their occupational performance in areas of occupation. Additionally, education on the wide array of aforementioned topics will give subjects a comprehensive, thorough understanding of how to use the techniques to potentially decrease fatigue experienced and increase occupational performance.

Another aspect of investigation during this study is the potential benefits of using telehealth as a form of occupational therapy service delivery. In order to incorporate telehealth into this research study, *Managing Fatigue* will be provided via teleconference. Providing this course via teleconference will allow participating individuals to partake in this study in a location of convenience to them. Additionally, as post-stroke fatigue is such a debilitating symptom that may influence an individual's ability to travel to and from a certain location, the method of teleconference may allow the individuals to

participate in the course when their fatigue is more severe. In terms of the principal investigators, all research was conducted on the University of North Dakota campus to ensure subject confidentiality.

Potential participants were recruited from Altru Rehabilitation Center and underwent a screening process in January, 2014. Beginning in February, 2014, participants meeting inclusion criteria completed an initial telephone interview, lasting approximately one hour, to complete demographic information, the Canadian Occupational Performance Measure (COPM) to assess each subject's perception of his/her own occupational performance, and the Fatigue Impact Scale (FIS) to assess subjects' baseline fatigue. After the initial interviews, the energy conservation course took place once per week from February to March, 2014 for approximately one hour for six consecutive weeks via teleconference. Upon completion of the six week course, participants completed a second telephone interview, lasting approximately one hour, to complete the FIS and COPM a second time to assess possible changes in levels of fatigue and perception of occupational performance. After completion of data collection, data analysis and written reports were completed between the months of March and April, 2014.

### **Importance of the Study**

As previously discussed, past researchers have shown the prevalence and severity of fatigue experienced following a stroke, and how this fatigue impairs occupational functioning. Although this is such a debilitating symptom, little research has been completed regarding how to treat this symptom in occupational therapy practice. Since energy conservation programs have shown to be effective with fatigue associated with

other neurological diagnoses such as multiple sclerosis and chronic fatigue syndrome, it is likely that an energy conservation program will prove to be a beneficial treatment method for fatigue experienced following a stroke. Completing research on the effectiveness of an energy conservation program for post-stroke fatigue will contribute to the field of knowledge to determine best practice for this symptom, as well as for this population of individuals in general. If the energy conservation course, *Managing Fatigue* by Packer, Brink, and Sauriol (1995), is shown to be effective this may drastically change occupational therapy practice in relation to individuals experiencing post-stroke fatigue. More specifically, the use of *Managing Fatigue* will provide us with information on the possible benefit of educating individuals experiencing post-stroke fatigue on the importance of rest, communication of needs, effective body mechanics, organizing the environment, setting priorities, and having a balanced lifestyle as a means of improving independence and performance in all areas of occupation. Overall, research completed on occupational therapy intervention for this symptom will advance client care and therefore improve client outcomes and occupational functioning.

Additionally, due to its recent emergence in the area of occupational therapy, additional research needs to be completed on the use of telehealth technology with the post-stroke population. Past research using telehealth technology with the post-stroke population has proven telehealth to be an effective means of service (Johansson and Wild, 2011). However, due to the fact that it is an emerging area in occupational therapy, additional research examining its effects will assist in supporting its use in future occupational therapy practice, specifically for the post-stroke population. Overall, completion of the *Managing Fatigue* course via telehealth to assess its effects on post-



stroke fatigue will be beneficial information for healthcare professionals and future research.

In terms of theoretical foundation, there is a lack of research on the use of CBT with the post-stroke population. Furthermore, although there is a lack of research regarding the use of CBT for fatigue related to neurological diagnoses, the research that has been conducted has shown that CBT is an effective method to treat the fatigue associated with chronic fatigue syndrome and multiple sclerosis (Deale et al., 1997; van Kessel et al., 2008). Due to this past research, it is likely that incorporating aspects of CBT into treatment for fatigue management for the post-stroke fatigue population will be effective in significantly reducing the impact fatigue has on occupational functioning.

Overall, this study will provide additional research on the post-stroke population, the effect post-stroke fatigue has on occupational functioning, the effectiveness of an energy conservation program for treatment of post-stroke fatigue. Furthermore, this study will explore the benefits of using telehealth technology and advantages to using a CBT approach when working with those experiencing fatigue secondary to a stroke. Altogether, this study will provide foundational research on a variety of topics related to post-stroke fatigue.

## **Definition of Terms**

**Canadian Model of Occupational Performance (CMOP):** Theory emphasizing that occupational performance is influenced by the interaction between factors composing the person, occupation, and environment. This theory is considered to be a client-centered approach due to its emphasis on spirituality.

**Canadian Occupational Performance Measure (COPM):** An occupational therapy assessment delivered via interview with the individual to identify any occupational performance limitations. Individuals completing the assessment are asked to choose their five most important problems and rank these five items with their importance, current performance, and current satisfaction.

**Cognitive Behavioral Therapy (CBT):** A frame of reference which analyzes cognitive processes and the course of how an individual's thoughts influence his/her behaviors.

**Fatigue Impact Scale (FIS):** A 40 question self-report questionnaire composed of questions related to the effect fatigue has on cognitive, physical, and psychological functioning.

**Post-stroke fatigue:** A common, chronic symptom people experience following a stroke that does not lessen with rest.

**PROMIS Fatigue Short Form 7a:** An assessment consisting of seven questions used to provide an objective measure for fatigue. Possible scores range from seven to thirty-five.

**Teleconference:** A common form of telehealth in which services are delivered through the use of a telephone.

**Telehealth:** The delivery of healthcare services through the use of various forms of technology, including email, teleconference, videoconference, etc.

## **CHAPTER II**

### **LITERATURE & STUDIES REVIEW**

#### **Post-Stroke Fatigue Definition**

Fatigue is an issue that affects people of all ages, genders, and nationalities. Depending on its severity fatigue can be debilitating for individuals who have neurological diagnoses of multiple sclerosis, traumatic brain injury, Parkinson's disease, post-polio syndrome, and chronic fatigue syndrome (de Groot, Phillips, & Eskes, 2003; Park et al., 2009). Similarly, fatigue following a stroke hinders the rehabilitation process which could lead to impaired ability for clients to regain functions that were affected due to stroke (Park et al., 2009). Post-stroke fatigue negatively impacts the lives of individuals in multiple areas of life. It is known to impact the quality of life by limiting the recovery which reduces the opportunities to return to work and leisure activities; it also contributes to increase in mortality, depression, and sleeping problems (Kutlubaev, Duncarn & Mead, 2012; Park, et al., 2009). This fatigue experienced is an area that needs to be addressed in healthcare and future research (Lerdal, & Kottorp, 2011).

Post-stroke fatigue is a frequent impairment for individuals who have experienced a stroke. Although there is not a concrete definition for post-stroke fatigue, several researchers describe it as a severe mental and/or physical tiredness experienced after a stroke that is exacerbated by increased stress and physical activity (Annoni, Staub, Bogousslaysky, & Brioschi, 2008; Kirkevold, Christensen, Andersen, Johnsen, & Harder, 2012; Zedlitz, Rietveld, Geurts, & Fasotti, 2012; Zedlitz, van Eijk, Kessels, Geurts, &

Fasotti, 2012). Post-stroke fatigue is different from normal tiredness because post-stroke fatigue is more chronic and cannot be lessened with rest (de Groot et al., 2003, Kirkevold et al., 2012).

### **Prevalence and Etiology**

Fatigue is experienced by approximately 50% of individuals following a stroke and is still a prevalent issue even two years post-stroke (Annoni et al., 2008; Appelros, 2006; van der Werf, van den Broek, Anten, & Bleijenberg, 2001). After interviewing 15 individuals who were experiencing post-stroke fatigue, Barbour and Mead (2012) found that 80% believed the fatigue came as a direct result from the stroke and/or recovery. Post-stroke fatigue is common with an occurrence rate of 36-70% within the initial first two years post incident (Ingles, Eskes, & Phillips, 1999). Additionally, fatigue was reported by 40% of participants in a study to be their worst or among their most severe symptoms post-stroke (Ingles et al., 1999).

The relationship between post-stroke fatigue and location of the lesion is still uncertain and the results of studies depict varying results. Tang et al. (2010), in a prospective cohort study, found that a basal ganglia infarct was an independent predictor of post-stroke fatigue. The severity of the fatigue may also vary depending on the type of the stroke experienced. Several studies have concluded that the prevalence of post-stroke fatigue is higher after a stroke following a transient ischemic attack (Kutlubaev et al., 2012; Winward, Sacklye, Metha, & Rothwell, 2009). Chestnut (2011) investigated individuals who experienced either a small-vessel ischemic stroke or a large-vessel ischemic stroke. His results showed that all participants with a large-vessel ischemic stroke experienced post-stroke fatigue, and that 77.8% of participants with a small-vessel

ischemic stroke experienced post-stroke fatigue. However, despite the difference in types of stroke, both resulted in post-stroke fatigue experienced by the majority of the population (Chestnut, 2011).

There are several other diagnoses and confounders that can exacerbate or cause symptoms of post-stroke fatigue such as anxiety, depression, current and recent life events, obesity, irregular thyroid function, electrolyte imbalances, and medication side effects (Winward et al., 2009). To truly measure the impact of post-stroke fatigue on an individual's ability to participate in his or her daily activities, a variety of assessments must be used.

### **Assessments**

De Groot et al. (2003) suggested that the purpose for a physical examination and assessments for fatigue should be twofold. First, assessments determine if the fatigue is typical or pathological. Secondly, it is important to discover if any comorbidities or predisposed factors exist that would intensify the feeling of fatigue (de Groot et al., 2003).

Among these comorbidities is depression. Depression is commonly screened for because this diagnosis can also increase feelings of fatigue. Stokes, O'Connell, and Murphy (2011) found that depression scores are higher in individuals who have had a stroke. However, depression and post-stroke fatigue are independent variables to be assessed individually. Additionally, medications related to treatment of depression can also lessen the symptoms of post-stroke fatigue which could lead to inaccurate assessment data (de Groot et al., 2003).

There are many different assessments that examine fatigue, but a few stand out. Several researchers explored the commonality of fatigue among individuals who had experienced a stroke and how post-stroke fatigue influenced individuals' lives. To assess this, researchers used a large variety of assessments. A number of studies included the Visual Analog Scale (VAS), Barthel Index, and assessments measuring depression, quality-of-life and self-efficacy, in addition to assessments evaluating post-stroke fatigue. These additional assessments were used to rule out symptoms different from fatigue. The most common assessments used by current researchers to measure post-stroke fatigue are the Fatigue Severity Scale (FSS), Fatigue Impact Scale (FIS), Modified Fatigue Impact Scale (MFIS), and the Multidimensional Fatigue Inventory (MFI). An emerging assessment to measure participant self-reported fatigue is the Patient-Reported Outcomes Measurement Information System (PROMIS) Fatigue Short Form 7a. Furthermore, the Canadian Occupational Performance Measure (COPM) has been beneficial in past research to assess self-perceived occupational functioning.

### **Fatigue Severity Scale (FSS)**

The Fatigue Severity Scale (FSS) was originally designed to evaluate the impact of fatigue on the daily life of individuals with a diagnosis of multiple sclerosis (Park et al., 2009). Currently, the FSS is the most commonly used measurement for the impact of fatigue on daily life that has been used in stroke studies. It has also been useful for individuals with a variety of chronic illnesses and diagnoses, as well as with the general public (Chestnut, 2011; Finlayson & Holberg, 2007; Lerdal & Kottorp, 2011; Matuska, Mathiowetz, & Finlayson, 2007; Tseng, Billinger, Gajewski, & Kluding, 2010). The FSS consists of nine items (e.g. *Fatigue interferes with my work, family, or social life.*) in

questionnaire format that is scored on a seven-point Likert scale ranging from *disagree* to *fully agree* (Lerdal & Kottorp, 2011; Park et al., 2009). The higher the mean or total score an individual obtains on the FSS, the more of an impact the fatigue has on daily life activities (Park et al., 2009). One drawback of the FSS's use on individuals with post-stroke fatigue is that it is an assessment measuring mainly physical fatigue, and lacks inclusion of mental fatigue (Amtmann et al., 2012).

#### **Fatigue Severity Scale, 7 item version (FFS-7)**

A shortened version of the FFS, the FFS-7, excludes items one and two (Lerdal & Kottorp, 2011). This was done after analysis showed that both items lacked “goodness-of-fit” with the questionnaire as a whole. Because of this the FFS-7 has been found to have better psychometric properties than the full measure. The person-response validity is 93% effective in demonstrating goodness-of-fit with participants of the study (Lerdal & Kottorp, 2011). Reliability was also supported in Lerdal and Kottorp's (2011) study, because the scores for the individuals as baseline, 6, 12, and 18 months did not vary more than 0.05 points from baseline. In a comparison of the FFS with FFS-7 (Lerdal & Kottorp, 2011), the FFS measurements demonstrated a tendency of underestimating the severity of the fatigue for those on the higher end of the fatigue continuum as well as overestimating the severity for individuals on the lower end (Lerdal & Kottorp, 2011). The FFS-7 allows the researchers best to examine changes in fatigue levels over time (Lerdal & Kottorp, 2011).

#### **Fatigue Impact Scale (FIS)**

Like the FSS, the Fatigue Impact Scale (FIS) was originally designed to assess the impact of fatigue on the quality of life for individuals with multiple sclerosis, but has also

been used in stroke studies (Vanage, Gilbertson, & Mathiowetz, 2003; Mathiowetz, 2003). This 40 statement self-report questionnaire is scored on a four-point Likert scale ranging from *no problem* to *extreme problem* (Mathiowetz, 2003; Vanage et al., 2003). It has been found to have high internal consistency between its physical, cognitive, and social subscales (Fisk et al., 1994). Additionally, the test-retest reliability and convergent validity of the FIS is strong enough to be used in clinical settings and research for individuals with mild to moderate multiple sclerosis (Mathiowetz, 2003). However, the psychometric properties of the FIS have yet to be examined in the population of individuals who have experienced a stroke. By addressing the three subscales (physical, cognitive, and social), the FIS is a more holistic assessment measure for individuals with post-stroke fatigue compared to the FSS. It is able to detect small changes in the levels of fatigues which indicates that the FIS is sensitive to the change that the individuals' experience (Mathiowetz, Matuska, & Murphy, 2001). The FIS is said to be relevant to occupational therapy because it assesses the impact that fatigue has on an individual's ability to complete everyday tasks and activities, and it can be used to measure clinical outcomes for interventions that address fatigue (Mathiowetz et al., 2001).

### **Modified Fatigue Impact Scale (MFIS)**

The Modified Fatigue Impact Scale (MFIS) is a shortened version of the FIS, and like the FIS, measures the impact of fatigue on physical, mental, and psychosocial functioning (Amtmann et al., 2012; Moss-Morris et al., 2012). The MFIS is composed of 21 items which are selected from the original 40 items of the FIS; like the FIS, the items are scored on a four-point Likert scale (Amtmann et al., 2012). The MFIS was recommended over the FSS when measuring fatigue that is experienced both physically



and mentally, and when high levels of fatigue are expected (Amtmann et al., 2012). It was also found that the MFIS had more precision at high levels of fatigue when compared to the FSS. However, one disadvantage to the MFIS over the FSS is that it takes longer to administer (Amtmann et al., 2012).

### **Multidimensional Fatigue Inventory (MFI)**

The Multidimensional Fatigue Inventory (MFI) is a twenty-question self-report assessment composed of the subscales: general, physical, activity-related, motivational, and mental fatigue (Stokes et al., 2011). Individually, the subscales are made up of four questions: two indicating fatigue and two contraindicating fatigue (Christensen et al., 2008). Each subscale is scored out of a possible twenty, with higher scores meaning increased fatigue severity; a score greater than 12 is evidence of clinically significant fatigue (Christensen et al., 2008; Stokes et al., 2011). It has been found to have good internal consistency and construct validity (Stokes et al., 2011). Although MFI is not validated for use with individuals following strokes, it is often used in practice and research (Christensen et al., 2008).

### **Patient-Reported Outcomes Measurement Information System (PROMIS) Fatigue Short Form 7a**

The Patient-Reported Outcomes Measurement Information System (PROMIS) Fatigue Short Form 7a consists of seven questions regarding the subject's fatigue based on a five point Likert scale ranging from *never* to *always* (PROMIS, 2013). The PROMIS Fatigue Short Form 7a was developed to assess patient's self-perceived symptoms of fatigue ranging from subjective feelings of tiredness to overall debilitating exhaustion that negatively impacts one's participation in occupations and social

functioning within the past seven days (PROMIS, 2013). The areas of fatigue assessed include the experience (frequency, duration, and intensity) and the influence of the fatigue on mental, physical, and social activities (PROMIS, 2013). This instrument was designed to be generic rather than disease-specific, and therefore may be used with individuals with a variety of diagnoses including those following a stroke (Cella et al., 2010, PROMIS, 2013). The higher an individual's score on the assessment indicates a greater level of fatigue (PROMIS, 2013).

When assessing fatigue in individuals with osteoarthritis and premenstrual syndrome/premenstrual dysphoric disorder, Christodoulou, Schneider, Junghaenel, Broderick, & Stone (2013) found the fatigue proved to be psychometrically sound when used with diverse diagnoses. In a randomized crossover design, Bjorner et al. (2014) found that subjects reported similar scores regardless of delivery method of the assessment. Furthermore, convergent and discriminant validity of the PROMIS items for fatigue are consistent when administered via different methods, including via phone interactive voice response, paper questionnaire, personal digital assistant, and personal computer (Bjorner et al., 2014). However, overall there is a lack of research studying the psychometric properties of the PROMIS Fatigue Short Form 7a.

### **Canadian Occupational Performance Measure (COPM)**

The Canadian Occupational Performance Measure (COPM) assesses an individual's perceived performance, satisfaction, and importance of various occupations in the areas of self-care, productivity, and leisure through the use of a semi-structured interview (Carswell et al., 2004; Cup, Scholte op Reimer, Thijssen, & van Kuyk-Minis, 2003; Larsen & Carlsson, 2012). During completion of the assessment, individuals are

asked to identify occupations in which he/she is experiencing problems and prioritize these areas by identifying a maximum of five occupations he/she wishes to focus on (Carswell et al., 2004; Cup et al., 2003; Larsen & Carlsson, 2012). Furthermore, the individual then scores importance, perceived performance, and satisfaction with performance for the previously identified five occupations on a ten-point Likert scale ranging from *not important at all* to *extremely important, not able to do it* to *able to do it very well*, and *not satisfied at all* to *extremely satisfied*, with higher scores evidencing greater importance, performance, and satisfaction (Carswell et al., 2004; Cup et al., 2003; Larsen & Carlsson, 2012). When administered to individuals who have previously experienced a stroke, Cup et al. (2003) found the both the performance and satisfaction sub-tests to have good test-retest reliability. Additionally, when compared to other standardized measures, discriminant, construct, and criterion validity of the COPM was confirmed, evidencing good overall validity of the COPM (Cup et al., 2003; McColl, Paterson, Davies, Doubt, & Law, 2000).

### **Interventions**

Initial occupational therapy treatments post-stroke should focus on management of factors that impact fatigue (de Groot et al., 2003). Many of the interventions explained in this review were developed to be used with diagnoses other than post-stroke fatigue. However, the fatigue symptom is anticipated to have similar impacts on occupational performance and quality of life as the fatigue associated with neurological disorders such as multiple sclerosis, chronic fatigue syndrome, post-polio, or stroke. Because of this the following interventions may be beneficial to explore following a stroke. Many of the

interventions for fatigue are designed to include education on fatigue, grading of activities, and energy conservation techniques.

### **Cognitive Treatment and Graded Activity Training (COGRAT)**

A combination of Cognitive Treatment and Graded Activity Training (COGRAT) is an effective intervention for post-stroke fatigue (Zedlitz, Fassotti, & Guerts, 2011; Zedlitz, Rietveld, et al., 2011). COGRAT consists of a 12 week program of cognitive treatments provided by a neuropsychologist based on cognitive behavioral therapy and compensation strategies that addresses pacing and relaxation; the graded activity is completed simultaneously by a physical therapist and consists of walking on a treadmill, strength training, and homework assignments. Upon completion, the COGRAT group has significant reductions in the levels of post-stroke fatigue and the benefits remained stable upon follow-up. However, the participants' physical endurance decreased from an average of 70 meters of walking to 40 meters. The overall, results demonstrated that COGRAT is a viable option for treatment of post-stroke fatigue (Zedlitz, Reitveld, et al., 2011).

### **Managing Fatigue: A Six-Week Course for Energy Conservation**

For persons with multiple sclerosis, a six-week energy conservation course for managing fatigue, developed in 1995 by occupational therapists Tanya Packer, Nicky Brink, and Adele Sauriol, has proven to be effective (Ghahari, Packer, & Passmore, 2010; Matuska et al., 2007). This energy conservation course consists of six sessions discussing the importance of rest, communication of needs, effective body mechanics, organizing the environment, setting priorities, and having a balanced lifestyle (Packer et al., 1995). This course was developed after the authors noted a lack of research on

fatigue severity and the impact it has on occupational productivity especially concerning self-cares, productivity, and leisure (Packer et al., 1995). Occupational therapists are able to address the occupational issues that fatigue causes because they are able to remediate impairments, reduce or even eliminate disability which negatively impacts occupational performance (Packer et al., 1995).

Each session is clearly defined in the manual by the authors and includes a warm-up activity, outline of the session, homework review, teaching session with practice activity and homework assignment, and a conclusion (Packer et al., 1995). The course includes carry over into other settings such as the home and work environment which allows for the information to become more meaningful to the participants (Packer et al., 1995).

When examining the effectiveness of the course, Packer et al. (1995) used the FSS and FIS to establish participants' baseline scores. After completion of the course the FIS scores indicated statistically significant changes ( $p < 0.05$ ) in the physical domain of the assessment (Packer et al., 1995). By course completion, 80% of the participants were able to implement positive changes to their lifestyles including adjusted body position, activity modifications, work and home environment modifications, increased resting periods, and daily planning (Packer et al., 1995). Overall, the course showed positive implications for decreasing fatigue that is secondary to chronic conditions.

Vanage et al. (2003) further tested the effectiveness of the *Managing Fatigue* course specifically with individuals with progressive multiple sclerosis and moderate to severe disability. The *Managing Fatigue* (Packer et al., 1995) course was modified with sessions at one hour each for a total of eight weeks in length (Vanage et al., 2003). The

group sizes were also smaller, three to eight participants instead of the original course recommendation of eight to ten. Additionally, the participants were not required to write out the homework for the sessions but to rather think about their answers to be ready for discussion (Vanage et al., 2003).

In order to assess fatigue levels and the impact of fatigue, the researchers used the FSS and FIS. Initially, Group A took part in the energy conservation course based off of Packer et al. (1995) *Managing Fatigue* course for eight weeks while Group B took part in a support group, and after the eight weeks the Groups switched programs (Vanage et al., 2003). The FIS was re-administered at the end of each eight week course period. After the first eight weeks, Group A demonstrated significant changes in the FIS scores of cognitive, physical, psychosocial, and total ( $p < 0.05$ ) while Group B participants' scores changed minimally (Vanage et al., 2003). There was also no significant changes in fatigue levels eight weeks post-energy conservation course. The results supported the initial hypotheses of the study: the energy conservation course resulted in significantly less fatigue ( $p < 0.01$ ), the fatigue has less impact on participant performance, yet their fatigue levels did not change eight post-intervention when compared to the support group (Vanage et al., 2003).

Holberg and Finlayson (2007) conducted a qualitative study with individuals with the diagnosis of multiple sclerosis who had previously completed the *Managing Fatigue* course via teleconference. It was found that the *Managing Fatigue* course not only decreased the effects of fatigue but it also increases the participants' self-efficacy (Holberg & Finlayson, 2007).

### **Matuska et al. Energy Conservation Course**

Based off the previous energy conservation protocol by Packer, Brink, and Sauriol (1995), Matuska et al. (2007), designed a similar energy conservation protocol to identify use and effectiveness of energy conservation strategies for individuals with multiple sclerosis. They developed a six-week long course, with each session meeting once per week for two hours (Matuska et al., 2007). Sessions were similar to the Packer protocol (Packer et al., 1995) and focused on the importance of rest, communication, body mechanics, principles of ergonomics, environmental modification, setting priorities, analyzing activities, and having a balanced lifestyle (Matuska et al., 2007). The course emphasized fourteen energy conservation strategies throughout the course, and assessed the strategies' effectiveness using a survey after completion of the course. Of the energy conservation strategies, although all were shown to be effective, delegating tasks, planning a balanced day, and resting during lengthy activities were shown to be most effective (Matuska et al., 2007).

### **Cognitive Behavioral Therapy (CBT)**

There is lack of research on the use of cognitive behavioral therapy (CBT) to specifically treat post-stroke fatigue; however, there is evidence to support the possible use of this in the future. As stated earlier, Zedlitz and colleagues developed the effective COGRAT program which uses both cognitive behavioral therapy strategies and graded activity (Zedlitz, Rietveld, et al., 2011). Overall, evidence shows CBT's effectiveness to treat chronic fatigue syndrome and the fatigue associated with multiple sclerosis (Deale, Chalder, Marks, & Wessely, 1997; Lopez et al., 2011; Moss-Morris et al., 2012).

Therefore, CBT's positive influence on other related neurological disorders shows possible effectiveness for treatment of persons with post-stroke fatigue.

Multiple studies have compared effects of using a CBT treatment program to a relaxation program (Deale et al., 1997; Lopez et.al, 2011; Van Rhenen, Blonk, Van Der Klink, Van Dijk, & Schaufeli, 2005). When comparing a CBT intervention to a relaxation intervention, Deale et al. (1997) found that 70% of the individuals who participated in the CBT intervention had decreased fatigue and increased satisfaction with their functional abilities, outcomes, and usefulness of the treatment. This is compared to the 19% of individuals in the relaxation group who experienced significant improvement in the previously listed areas (Deale et al., 1997).

Lopez et al. (2011) found a significant difference in results on the impact on stress, mood disturbances, fatigue symptoms, and quality of life when comparing a 12-week group-based CBT program to a half-day psychoeducation class. Results showed that individuals in the CBT group experienced decreased stress, fatigue symptoms, and improved quality of life for individuals with chronic fatigue syndrome. Similarly, Van Rhenen et al. (2005) compared the effects of a cognition program with emphasis on restructuring irrational beliefs (i.e., rational emotive therapy [RET]-a form of CBT) to a program focusing on physical exercise and relaxation for individuals with psychological complaints, burnout, and fatigue. Van Rhenen et al.'s results showed that each program was successful in reducing psychological complaints, burnout, and fatigue experienced (Van Rhenen et al., 2005). Sixty percent of the individuals enrolled in the cognition program showed improvement and returned to normal functioning by six months after the beginning of the study, compared to the 50% of the individuals enrolled in the physical



exercise/relaxation program (Van Rhenen et al., 2005). The results of Deale et al. (1997), Lopez et al. (2011), and Van Rhenen et al. (2005) all support the use of CBT related treatments over the use of physical exercise and relaxation programs.

The administration of CBT-related interventions has also been delivered using a variety of different modes. A study using a telephone-administered CBT program for individuals experiencing disabilities and depression related to multiple sclerosis found that the program resulted in significant decreases in physical, cognitive, and psychosocial fatigue, as well as improved depression (Mohr, Hart, & Vella; 2007). Because of this and other researchers' findings, telehealth may be an effective mode to treat post-stroke fatigue.

### **Telehealth**

Telehealth is proving to be an effective delivery method for energy conservation interventions. Telehealth is an umbrella term for utilizing technology in healthcare delivery for all healthcare professionals. This is different from telerehabilitation. Telerehabilitation is defined by the American Telemedicine Association as “the delivery of rehabilitation services via information and communication technologies” (Brennan et al, 2011, p. 663). There are a variety of services that may be delivered via telehealth, such as “assessment, monitoring, prevention, intervention, supervision, education, consultation, and counseling” (Brennan et al., 2011, p. 663). The American Occupational Therapy Association (AOTA) states that telehealth is a feasible method for occupational therapists, and other healthcare professionals, to participate in alternative methods of service delivery to assist clients acquire various skills, suggest environmental modifications, and educate on assistive technology/adaptive techniques (AOTA, 2013).

There are many common reasons for implementing a telehealth program. Some of these reasons include benefiting the community, improving treatment outcomes, increasing the knowledge of the healthcare provider, and increasing effectiveness of the clinical process (Silva, Farrell, Shandra, Viswanathan, & Schwamm, 2012). Use of telerehabilitation may also decrease individuals' stay in an inpatient setting and the frequency of outpatient visits (Cikajlo, Rudolf, Golar, Burger, & Matjacic, 2012). According to the AOTA, telehealth assists the occupational therapy profession in removing various barriers for service delivery, such as: travel time/expenses; social, socioeconomic, and cultural barriers/stigmas; and workforce shortages (AOTA, 2013). Telerehabilitation has also been associated with increased satisfaction in healthcare for both clients and healthcare practitioners (Johansson & Wild, 2011).

Various forms of telehealth have been shown to be effective in occupational therapy intervention, including: telephone (Finlayson & Holberg, 2007; Finlayson, Preissner, Cho, & Plow, 2011; Mohr et al., 2007), internet (Moss-Morris et al., 2012), computer programs (Ghahari et al., 2010; Matuska et al., 2007), and interactive videos (Piron et al., 2008). A systematic review, completed by Hailey et al. (2011), found that 71% of studies included had successful outcomes using telerehabilitation. Another systematic review conducted by Johansson and Wild (2011) focused specifically on individuals who had experienced a stroke. According to Johansson and Wild (2011), healthcare professionals, individuals post-stroke, and caregivers were satisfied with interventions delivered via telerehabilitation. Furthermore, individuals post-stroke demonstrated improved outcomes from baseline using telerehabilitation (Johansson & Wild, 2011). Using telerehabilitation technology for treatment after a stroke is becoming

increasingly more common, and researchers have now coined the term ‘telestroke’ to define using telerehabilitation technology with individuals who have experienced a stroke (Silva et al., 2012).

Results of a survey for telestroke programs in the United States show that 97% of treatments using telestroke technology included a physician, followed by registered nurses (38%), and physician assistants (8%) (Silva et al., 2012). Compare this to the 2.7% of rehabilitation professionals, including occupational therapists, physical therapists, and speech-language pathologists, that use telestroke technology (Silva et al., 2012). The positive outcomes associated with telerehabilitation technology could benefit rehabilitation professionals and their clients if the technology were to be used more frequently.

While there are many positives to using telerehabilitation technology, there are also barriers. Some of the barriers include lack of physician licensure, decreased funding and reimbursement, and the need for technology support (Silva et al., 2012). Due to the fact that telerehabilitation is a growing area in healthcare, these barriers may disappear with time and clinician experience. Additionally, some occupational therapists stated it was difficult to build rapport with their clients using telerehabilitation technology (Finlayson & Holberg, 2007). However, as occupational therapists and other healthcare professionals are trained in using telerehabilitation and gain experience with the technology, developing rapport using the technology will likely become more natural.

Because of its emerging nature, current studies on use of telerehabilitation for treatment after a stroke have small sample sizes (Johansson & Wild, 2011). They also typically include individuals who have experienced a mild stroke, as opposed to a severe

stroke (Johansson & Wild, 2011). These are areas recommended to be addressed in future studies.

### **Summary**

In conclusion, fatigue is a common symptom individuals experience following a stroke. These individuals may benefit from treatment provided by occupational therapy focusing on energy conservation for occupational participation, use of graded activity and cognitive behavioral strategies, as well as telestroke methods of service delivery. While there is a general lack of literature regarding energy conservation interventions for individuals who have experienced a stroke, energy conservation techniques have been effective for persons with other neurological disorders, such as multiple sclerosis. Outcomes of service delivery by occupational therapists for persons with post-stroke fatigue may be best measured through the use of gathering information from the individuals pre- and post-intervention using valid and reliable outcome measures such as the COPM, the FIS, and the PROMIS Fatigue Short Form 7a.

## **CHAPTER III**

### **RESEARCH METHODOLOGY**

#### **Research Design**

A quantitative research design was used to address the research question. More specifically, a pilot study using a pretest-posttest single subject design was implemented. A pilot study was used because the principal researchers were studying the effectiveness of using *Managing Fatigue: A Six-Week Course for Energy Conservation* developed by Packer, Brink, and Sauriol (1995) for use with individuals in the stroke population who are experiencing post-stroke fatigue on a small scale. However, if results are conducive with the hypotheses, then further studies on a larger scale may be deemed feasible.

The pretest-posttest design allows for the researchers to collect data from the assessments prior to and following implementation of the *Managing Fatigue* course (Braveman, Suarez-Balcazar, Kielhofner, & Taylor, 2006). With this specific design, the researchers are able to have quantitative data on whether the subjects had any change in assessment scores, evidencing decreased fatigue and increased occupational functioning, after completion of the course. Specific assessments utilized during the study included: the Patient-Reported Outcomes Measurement Information System (PROMIS) Fatigue Short Form 7a, the Fatigue Impact Scale (FIS), and the Canadian Occupational Performance Measure (COPM).

Advantages of the pretest-posttest design are that it is often used for simple, inexpensive, and standard interventions (Braveman et al., 2006). This design also allows

for all subjects to complete the energy conservation course which will potentially have a positive benefit on their day to day lives. However, using this design leaves difficulty in generalization to other similar populations and establishing cause-effect relationships (Braveman et al., 2006). Overall, this design fits the purpose of the study because it shows change over time and will allow for the researchers to assess for subjects' decline in fatigue levels and improved self-perceived performance and satisfaction while completing self-identified prioritized occupations.

### **Sources of Data**

Data was collected from two subjects during initial screening; one subject participated in completion of the six week *Managing Fatigue* course using the assessments of the PROMIS Fatigue Short Form 7a, FIS and COPM. The principal investigator administering the assessments to the subject completed both the initial and final evaluations to increase intra-rater reliability and to continue with rapport that was built during the initial interview.

### **Recruitment and Screening**

Prior to initiation of this study, Institutional Review Board approval was received from both the University of North Dakota and Altru Health System (see Appendix B). Potential subjects were informed about the study by occupational therapists employed by Altru Rehabilitation Center. Interested subjects either contacted one of the principal investigators (with contact information provided to them by the occupational therapist) or asked the occupational therapist to provide one of the principal investigators with their first name and phone number to be contacted. Once contact with one of the principal investigators was made, potential subjects participated in a screening procedure in which

potential subjects were informed about the study, asked demographic questions, and completed the PROMIS Fatigue Short Form 7a.

PROMIS Fatigue Short Form 7a was administered during the screening portion of this study in order to provide an objective measure to the fatigue each individual was experiencing prior to participation in the study. Following completion of the assessment, subjects are required to obtain a minimum score of 21 to meet study inclusion criteria. A total of three individuals were screened for participation in the study. Following administration of the screening procedure, two individuals met inclusion criteria for the research. One individual declined participation in the study, resulting in participation of one individual.

### **Locale of the Study**

The location of the study was different for the researchers and the subjects. Subjects were able to complete the screening, pretest assessments, the *Managing Fatigue* course, and posttest assessments in a location of convenience for them, presumably their home environment, as all phases of the study were completed via telephone. Throughout the research process, the subjects were encouraged to participate in an area in which there would be limited distractions so as to keep their attention on the topic being discussed during each weekly session. The principal investigators and their faculty advisor, Dr. Jan Stube, were located at the University of North Dakota Occupational Therapy Department throughout the research process. Due to potential issues with reserving a private and secure room in the department, the faculty advisor's office and office phone were utilized. By administering the assessments and course via teleconference, the researchers

were able to determine if the method of teleconference is appropriate and feasible delivery method.

### **Population/Sampling**

Recruitment of potential subjects took place at Altru Rehabilitation Center via convenience sampling. Convenience sampling, as defined by Dickerson (2006), is the use of subjects who are easily accessible and agree to participation in the study until a desired number of subjects are obtained. Following education on the study by the principal investigators, occupational therapists working for Altru Rehabilitation Center used their clinical judgment and informed their current and/or past clients of the study. Utilization of occupational therapists at Altru Rehabilitation Center to assist with subject recruitment allowed for appropriate potential subject referrals in a time efficient manner.

Individuals included in the study were living in the state of North Dakota and had a self-reported diagnosis of a stroke. Individuals with mild to moderate stroke were selected for the study due to the current evidence indicators for post-stroke fatigue and the clients' probability of success/benefit in relation to the educational sessions. The individual's past medical history of a mild to moderate stroke was self-reported as the principal investigators did not have access to subjects' medical information. Individuals included in the study were also required to have functional English literacy and functional cognitive capacity for optimal participation in the *Managing Fatigue* course, and therefore to improve the probability of benefit from the course. Subjects included in the study were 41 years of age or older in order to increase likelihood of the benefit of the educational material for this adult generational cohort.



Individuals were also required to be experiencing fatigue secondary to experiencing a stroke. In order to provide an objective means of measuring the amount of fatigue an individual was experiencing, he/she must have scored a 21 or higher on the Patient-Reported Outcomes Measurement Information System (PROMIS) Fatigue Short Form 7a. This PROMIS Fatigue Short Form 7a acts as an objective measure of fatigue and a quick screening tool as it is composed of seven questions related to fatigue and provides insight to an individual's occupational functioning. Subjects were required to be at a baseline of fatigue of 21 or higher on the PROMIS Fatigue Short Form 7a to be included in the study as the educational sessions are specifically addressing methods to combat fatigue and teach energy conservation strategies. Lastly, since the energy conservation course, *Managing Fatigue*, was delivered via teleconference, individuals participating in the study were required to have access to a telephone for one hour per week for eight consecutive weeks in order to include time for pre- and post-assessment sessions. Subjects were required to participate in all treatment sessions as participation in all sessions is optimal for accurate data collections.

Individuals who had a severe stroke, were under the age of 41, who did not experience the symptom of fatigue, and/or had severe cognitive or language impairments were excluded from the study. This was done to better promote subject participation in the *Managing Fatigue* course and, as such, improve the probability of subject benefit from the program in terms of fatigue experienced following a stroke.

### **Instrumentation and Data Collection**

Instruments used to collect data during the initial assessment (or pre-test) phase of the study included: a demographic questionnaire, the FIS, and the COPM. While the

PROMIS Fatigue Short Form 7a and some demographic questions were asked to potential subjects, the COPM and the FIS were administered to the subject meeting inclusion criteria, following completion of informed consent. All instruments used to collect data during the study were administered via telephone by one or both of the principal investigators.

A self-developed demographic questionnaire was given to all subjects participating in the study to gain information on the subjects' gender, age, location/type/severity of stroke experienced, elapsed time since previous stroke, number of strokes previously experienced, race, marital status, residency, living situation, employment status, educational attainment, participation in occupational therapy services, fatigue experienced, and accessibility to a telephone. Information provided on the demographic questionnaire was interpreted using descriptive statistics (further explained under "Tools for Data Analysis"), and compared to study inclusion criteria to ensure potential subjects met criteria necessary for participation in study.

The Canadian Occupational Performance Measure (COPM; Law et al., 2005) was utilized to measure subjects' perception of his/her performance and satisfaction of his/her participation in various areas of occupation prior to and following participation in the *Managing Fatigue* course. As post-stroke fatigue may significantly impair one's ability to participate in areas of occupation, administering the COPM allowed the principal investigators further insight into the impact post-stroke fatigue has on subjects' performance in their prioritized areas of occupation. While administering the assessment, the subject identifies his/her top five most important problems regarding performance in areas of occupation. After identifying these areas, he/she is asked to rank their perception

of his/her performance and satisfaction when completing each problem area previously identified. In order to calculate a total score, performance and/or satisfaction scores for all problems are added together and divided by the number of problems the individual identified. The assessment was also utilized following participation in the course in order to assess for changes in occupational performance and satisfaction. The larger the difference in subjects' perception of performance and satisfaction from pre-intervention to post-intervention in his/her identified problems is proportional to subjects' improvement in perceived occupational functioning.

The Fatigue Impact Scale (FIS) was used to measure the impact one's fatigue has on his/her quality of life. This is a 40 statement self-report questionnaire that is scored on a four-point Likert scale ranging from no problem to extreme problem with questions assessing the effect fatigue has on cognitive, physical, psychological functioning (Mathiowetz, 2003; Vanage, Gilbertson, & Mathiowetz, 2003). Overall score is then calculated based on the Likert scale and is scored out of a possible 160 points. Higher scores on the FIS indicate greater levels of fatigue, and therefore has a greater impact on occupational functioning and quality of life. This assessment was utilized prior to subjects' participation in the *Managing Fatigue* course, as well as following participation in the course in order to assess subjects' change in fatigue experienced.

### **Educational Manual**

Following the initial evaluation, the *Managing Fatigue* course took place once per week for five consecutive weeks via teleconference; sessions two and three were combined. This was done for practical reasons due to similar session content and the teleconference format limiting the ability to complete activity stations as specified in the

manual. During these educational sessions, the principal investigators and their advisor utilized the *Managing Fatigue* manual (Packer et al., 1995). The *Managing Fatigue* manual consists of ten parts including: introduction, planning and preparation, pregroup session, sessions one through six, and a bibliography (Packer et al., 1995). For the purpose of this study, the principal investigators did not utilize the pregroup session section as its purpose is to select subjects which this current study has already accomplished. Sessions covered the topics of the importance of rest, communication and body mechanics, activity stations, priorities and standards, balancing your schedule, and a course review and future plans (Packer et al., 1995). All six sessions are designed with the same format including the purpose of the session, a list of required overhead(s), handout(s), supplies, an outline of the session, teaching notes for therapist, master copies of all overheads and handouts, and therapist worksheets (Packer et al., 1995). The subject in this current study was provided with copies of the handouts via paper copies which were mailed. Using their discretion, the overheads were used as handouts if the principal investigators found the overheads to be a beneficial tool for the subject.

Upon conclusion of the *Managing Fatigue* program, the subject was contacted for a final interview in which the FIS and COPM were completed. Following data collection, the data obtaining during the initial and final evaluation was compiled and interpreted via International Business Machines (IBM)® Statistical Package for the Social Sciences (SPSS)© Version 21.

### **Reliability and Validity**

Reliability was established in various ways during the completion of the study. Interrater reliability was established during completion of the study as the principal

investigators followed a set protocol during the screening, initial and final evaluations, and during the intervention itself. In addition to having this set protocol, the principal investigators also discussed the protocol prior to completion of the study in order to increase consistency between the principal investigators and therefore increase interrater reliability. During the intervention itself (i.e. the completion of the *Managing Fatigue* course), both principal investigators and faculty advisor were present, allowing for increased reliability as there were not any discrepancies between treatment given by principal investigators during the intervention itself. Furthermore, having a set protocol to follow for future sessions also assists in higher test-retest reliability. This protocol for the screening, initial and final evaluations, and the *Managing Fatigue* course allows individuals to complete the intervention, with little to no differences, in future situations. Lastly, internal consistency will be established as all elements of the study are focused on decreasing fatigue one experiences following a stroke, increasing occupational participation, and identifying the effectiveness of service delivery via telehealth.

Validity will also be addressed throughout the course of the study. The principal investigators intend to decrease post-stroke fatigue one experiences and therefore increase participation in areas of occupation. Because of this, assessments utilized and the *Managing Fatigue* course is aimed at assessing fatigue, current occupational performance, and increasing utilization of energy conservation techniques. Furthermore, to assess the effects of service delivery via telehealth technology, all contact and education was completed via teleconference. By maintaining consistency between the principal investigators' purpose of study, and the elements of the study itself, content validity and construct validity are established.

In addition to the protocol adding reliability and validity to the study, as did the assessments utilized. The assessments utilized during this study also reported high reliability and validity. For example, the COPM has good test-retest reliability and discriminant validity when utilized with individuals who had experienced a stroke (Cup, Scholte op Reimer, Thijssen, & van Kuyk-Minis, 2003). Though the psychometric properties of the FIS have yet to be established with the stroke population, it has good test-retest reliability and convergent validity when used with individuals of another neurological diagnosis, multiple sclerosis (Mathiowetz, 2003). Furthermore, the PROMIS Fatigue Short Form 7a has good psychometric properties when assessed with diverse diagnoses and general population (Christodoulou, Schneider, Junghaenel, Broderick, & Stone, 2013). As such, the utilization of these high quality assessments will add to the overall reliability and validity of this study.

### **Tools for Data Analysis**

#### **Descriptive Statistics**

All data obtained was tracked using International Business Machines (IBM)® Statistical Package for the Social Sciences (SPSS)© Version 21 software. Overall, descriptive statistics were utilized to report information found using the demographic questionnaire, the PROMIS Fatigue Short Form 7a, FIS, and the COPM.

#### **Demographics.**

In order to convey the results found in the demographic questionnaire, descriptive statistics were utilized. Subject's gender, location/type/severity of stroke experienced, race, marital status, residency, living situation, employment status, educational attainment, participation in occupational therapy services, fatigue experienced, and access

to a telephone are all topics on the demographic questionnaire that was reported in frequencies. In addition, frequencies were used to report subject's age, elapsed time since previously experienced stroke, and the total number of strokes the subject has experienced.

### **Fatigue Severity.**

The fatigue experienced by the subject was also reported using descriptive statistics. Overall results of the PROMIS Fatigue Short Form 7a for all screened individuals are reported using frequencies. Additionally, the frequencies of subject's results of the FIS prior to the *Managing Fatigue* course, following the *Managing Fatigue* course, and the change in fatigue levels are reported. To obtain more specific information, results of the FIS are also reported in frequencies in the physical, cognitive, and social fatigue subcategories. Frequencies obtained for the physical, cognitive, and social fatigue subcategories of the FIS are presented as reported prior to the *Managing Fatigue* course, following the *Managing Fatigue* course, and the changes in fatigue severity between pretest-posttest.

### **Subject-Perceived Occupational Performance and Satisfaction.**

Subject-perceived occupational performance and satisfaction in areas of occupation were identified using the COPM and reported using descriptive statistics. More specifically, results of the COPM are reported utilizing frequencies. As the COPM will be administered prior to and following participation in the *Managing Fatigue* course, results for each administration are reported, as well as the change in scores between pretest-posttest. As previously stated, during completion of the COPM, the subject identifies his/her top five most important problems regarding performance in areas of

occupation. Therefore, areas of occupation identified are reported using frequencies as it is nominal data. Subject-perceived occupational performance and satisfaction for each prioritized area of occupation will be reported using frequencies as reported prior to and following participation in the *Managing Fatigue* course, as well as changes in reported scores.



## CHAPTER IV

### PRESENTATION, ANALYSIS, AND INTERPRETATION OF DATA

Based on a thorough literature review, the principal investigators formed three hypotheses regarding the effectiveness of *Managing Fatigue: A Six Week Course for Energy Conservation*, developed by Packer, Brink, and Sauriol (1995), to treat fatigue experienced by individuals following a stroke via teleconference. The principal investigators hypothesized that participation in the *Managing Fatigue* course would increase the subject's self-perceived satisfaction and performance in meaningful occupations as well as decrease the subject's fatigue severity. Additionally, it was hypothesized that teleconference would be an effective delivery method for the *Managing Fatigue* course.

Data collected from the self-developed demographic questionnaire, Patient-Reported Outcomes Measurement Information System (PROMIS) Fatigue Short Form 7A, Canadian Occupational Performance Measure (COPM), and Fatigue Impact Scale (FIS) was tracked utilizing International Business Machines (IBM)® Statistical Package for the Social Sciences (SPSS)© Version 21. Following data collection, data was analyzed using descriptive statistics. Results are reported in regards to screening procedure, demographic information, fatigue severity, and subject-perceived occupational performance and satisfaction.

## Screening

A total of three individuals were screened for participation in the current study. Upon completion of the PROMIS Fatigue Short Form 7a, two individuals met inclusion criteria for participation. The PROMIS Fatigue Short Form 7a scores for individuals screened are found on Table 4.1. Of the two individuals meeting inclusion criteria, one declined participation resulting in participation of one individual.

Table 4.1

### *Potential Subject PROMIS Fatigue Short Form 7a Scores*

Participants	PROMIS Scores
Participant 1	12
Participant 2	22
Participant 3	20

## Demographic Information

The subject who participated in the study was a 70 year old male who experienced a left-side ischemic stroke five years prior to the study. He reported a moderate level of stroke severity upon initial evaluation and was not receiving occupational therapy services while the research was taking place. Through completion of the self-developed demographic questionnaire, the subject reported that he is white, widowed, and living alone in a condo. He is currently retired and has completed some college however did not graduate from college with a degree. Upon initial evaluation, he reported that he was experiencing fatigue secondary to his stroke.

### **Subject-Perceived Occupational Performance and Satisfaction**

Upon completion of the COPM during the initial evaluation, the subject prioritized donning compression socks, showering, cutting food, bowling, and golfing as areas of occupation of importance to him in which he was experiencing decreased self-perceived performance and satisfaction. Reported performance and satisfaction scores in each area of occupation may be found on Table 4.2. When calculating overall average performance and satisfaction scores in the aforementioned areas of occupation, the subject had an average performance score of 4.8 and an average satisfaction score of 4.2 out of a possible score of 10. A score of ten indicates best performance and satisfaction. These scores evidence decreased perceived performance and satisfaction in meaningful areas of occupation secondary to fatigue following the subject's stroke.

Following completion of the *Managing Fatigue* course, the subject completed the COPM a second time. Overall, the subject reported consistent and/or improved performance and satisfaction scores in the areas of occupation of donning compression socks, showering, cutting food, bowling, and golfing. Reported performance and satisfaction scores in each area of occupation are summarized in Table 4.2. When calculating overall average performance and satisfaction scores in the aforementioned areas of occupation during the final evaluation, the subject had an average performance score of 5.2 and an average satisfaction score of 5.0 out of 10. A score of ten indicates best performance and satisfaction. When subtracted from scores calculated during the initial evaluation, the subject's average performance score improved by 0.4, while his average satisfaction score increased by 0.8. These final scores evidence improved

performance and satisfaction following the *Managing Fatigue* course in subject-prioritized areas of occupation when compared to scores reported at baseline.

Subject-perceived occupational performance remained consistent and/or improved in each of the subject's prioritized occupations (as evidenced in Table 4.2). Therefore, it is likely that the *Managing Fatigue* course assisted in increasing occupational performance and satisfaction in each of the aforementioned areas. However, due to limitations in the research itself it cannot be inferred that the *Managing Fatigue* course was the cause of the change in data from pretest to posttest.

Table 4.2

*COPM Performance and Satisfaction Scores*

Prioritized Occupations	Performance			Satisfaction		
	Pre	Post	Change	Pre	Post	Change
Donning compression socks	8.0	8.0	0.0	5.0	6.0	+1.0
Showering	4.0	5.0	+1.0	5.0	6.0	+1.0
Cutting food	4.0	4.0	0.0	4.0	4.0	0.0
Bowling	4.0	5.0	+1.0	3.0	5.0	+2.0
Golfing	4.0	4.0	0.0	4.0	4.0	0.0
Overall	4.8	5.2	+ 0.4	4.2	5.0	+0.8

**Fatigue Severity**

Questions included on the FIS address fatigue related to physical, cognitive, and social aspects of fatigue (Community Physical Therapy & Associates, 2011; Finlayson, Preissner, Cho, & Plow, 2011). A higher score on the FIS indicates high fatigue levels (Finlayson, Preissner, Cho, & Plow, 2011). During the initial evaluation, the subject

reported an initial score of 47 out of a possible 160 on the Fatigue Impact Scale (FIS). When divided into physical, cognitive, and social categories, the subject scored 22/56 on questions related to physical fatigue, 17/52 on questions related to cognitive fatigue, and 8/52 on questions related to social fatigue. Following completion of the *Managing Fatigue* course, the subject reported a final score of 13 out of a possible 160 on the FIS. When broken down into physical, cognitive, and social categories, the subject scored 8/56 on questions related to physical fatigue, 4/52 on questions related to cognitive fatigue, and 1/52 on aspects related to social fatigue. These scores are summarized in Table 4.3.

Overall, these scores evidence decreased fatigue in all aspects following participation in the *Managing Fatigue* course. This change in data suggests that the *Managing Fatigue* course may have assisted in decreasing the severity of the impact of the subject's fatigue. However limitations in the research decrease the generalization and significance of the results.

Table 4.3

*Physical, Cognitive, and Social Fatigue Scores on the FIS*

Aspect of FIS	Pre-test	Post-test	Change
Physical Fatigue	22/56	8/56	-14
Cognitive Fatigue	17/52	4/52	-13
Social Fatigue	8/52	1/52	-7

As previously stated, three hypotheses were formed prior to the completion of the current research study. Hypothesis 1, the subject's self-perceived satisfaction and performance in meaningful occupations will increase following participation in the

*Managing Fatigue* course, was supported evidenced by the upward trend in data collected. Both subject-perceived overall occupational performance and satisfaction subtests of the COPM increased following participation in the *Managing Fatigue* course, however it is not inferred that the *Managing Fatigue* course was the cause of this change due to limitations of the study. Hypothesis 2, physical, cognitive, and social fatigue severity will decrease following participation in the *Managing Fatigue* course, was supported evidenced in decreased fatigue severity scores. Though scores in all categories addressed in the FIS decreased following the *Managing Fatigue* course, it cannot be inferred that the *Managing Fatigue* course was the cause of the decreased fatigue severity due to limitations of the study.

Hypothesis 3, teleconference would be an effective delivery method for the *Managing Fatigue* course, was supported by the data analysis. As scores of the FIS and COPM improved following the *Managing Fatigue* course from baseline data collection the results of the research may support the effectiveness of occupational therapy services delivered via teleconference. However, as previously stated, due to the limitations of the study, it may not be inferred that service delivery via teleconference influenced fatigue severity, and subject-perceived occupational performance and satisfaction. Additionally, when the subject was questioned regarding his perception of the teleconference delivery, he felt as though the delivery was adequate but face-to-face delivery would have been his preferred method of service delivery.

## **CHAPTER V**

### **SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS**

#### **Summary of Findings**

A literature review was conducted to identify current gaps in research and to provide knowledge on the prevalence of post-stroke fatigue, current occupational therapy treatment for fatigue post-stroke, and the effectiveness of telehealth in occupational therapy practice. This literature review led to the purpose of the current research: To examine the effectiveness of *Managing Fatigue: A Six Week Course for Energy Conservation*, developed by Packer, Brink, and Sauriol (1995), for post-stroke fatigue via teleconference. The principle investigators hypothesized that completion of the *Managing Fatigue* course would result in decreased levels of fatigue severity, increase satisfaction and subject-perceived occupational performance in prioritized areas of occupation, and that teleconference would be an effective delivery method for occupational therapy services.

To address these hypotheses, a pilot study using a pretest-posttest single subject design was utilized. Following University of North Dakota and Altru Health System Institutional Review Board approval, occupational therapists at Altru Health System assisted in recruiting potential subjects meeting study inclusion criteria. Potential subjects were screened using the Patient-Reported Outcomes Measurement Information System (PROMIS) Fatigue Short Form 7a. The subject meeting inclusion criteria give informed consent and completed the *Managing Fatigue* course in five consecutive weeks via

teleconference. The subject additionally completed an initial and final evaluation utilizing a self-developed demographic questionnaire, the Fatigue Impact Scale (FIS), and the Canadian Occupational Performance Measure (COPM). All participation was completed via teleconference with both of the principle investigators.

A 70 year old male who had experienced a left-side ischemic stroke five years prior to the study was the subject participating in the current research. He reported a moderate level of stroke severity, was experiencing fatigue secondary to his stroke, and was not receiving occupational therapy services during participation in the study. Following completion of the self-developed demographic questionnaire, it was noted that the subject is white, widowed, and living alone in his condo. The subject is retired and stated he had completed some college but did not graduate from college with a degree.

Data obtained via the initial and final evaluations was tracked using International Business Machines (IBM)® Statistical Package for the Social Science (SPSS)© Version 21. The principle investigators hypothesized that the subject's fatigue severity would decrease following participation in the *Managing Fatigue* course when compared to baseline. Though the hypothesis was supported, it cannot be inferred the changes were secondary to the *Managing Fatigue* course due to limitations of the study. The second hypothesis stated that the subject's perceived occupational performance and satisfaction would increase in subject-prioritized areas following completion of the *Managing Fatigue* course. However, although changes support the hypothesis, it cannot be inferred the *Managing Fatigue* course was the cause due to limitations of the study. Lastly, the principle investigators hypothesized that teleconference would be an effective method of occupational therapy service delivery. This hypothesis is supported evidenced by changes



in FIS and COPM scores. However due to limitations in the study the effectiveness cannot be generalized to other populations and research. Furthermore, it was noted that when asked, the subject perceived the delivery of services via teleconference to be adequate, but would have preferred the inclusion of face-to-face service delivery as well. Overall, though changes in data were evident, results may not be concluded that the *Managing Fatigue* course was the cause of the changes in fatigue severity, and subject-perceived occupational performance and satisfaction.

### **Conclusions**

Following participation in the *Managing Fatigue* course, the subject's fatigue severity decreased and overall subject-perceived occupational performance and satisfaction increased. However, due to limitations in the research it cannot be inferred that participation in the *Managing Fatigue* course was the cause of the improvements in fatigue severity and occupational performance. Additionally, due to limitations in the research, it cannot be inferred that the utilization of teleconference was an effective means of occupational therapy service delivery. However, as data following participation in the *Managing Fatigue* course improved compared to baseline, future research is warranted regarding the use of the *Managing Fatigue* course with individuals experiencing post-stroke fatigue using telehealth technology.

### **Limitations**

The limited time for potential subject recruitment posed as a barrier for obtaining a larger sample population. As the principle investigators were limited to three weeks to obtain a sample for the research study, occupational therapist working for Altru Health System had a shortage of time to recruit potential subjects. Additionally, the strict

inclusion/exclusion criteria posed as another barrier for obtaining a larger sample population. Allowing additional time for recruitment and recruiting potential subjects from a larger geographical area will assist in decreasing these limitations in future research. Though the principle investigators screened multiple potential subjects, some individuals did not qualify for the study as they did not meet the minimum score necessary on the PROMIS Fatigue Short Form 7a for inclusion of the study though they were experiencing post-stroke fatigue.

Another reason for the lack of qualifying scores on the PROMIS Fatigue Short Form 7a may be the potential subjects' perceptions on the severity of his/her fatigue. As individuals may have perceived the fatigue he/she was experiencing to be less severe than in reality, scores on the PROMIS Fatigue Short Form 7a may not have been an accurate representation of fatigue severity. This factor can be influenced by the amount of time that has passed since the initial stroke as well as how the subject has adapted and structured his/her life since the event. Individuals who have highly structured schedules may perceive their fatigue levels to be lower than others. Because of this, it would have been beneficial for the principle investigator to ask clarifying questions as well as examples from subjects when administering the assessment to ensure more accurate results.

The pilot study design with a single subject sample size was another limitation of this study as it limits the ability for the researchers to generalize information to larger populations. Additionally the single subject sample size prevents the subject participating in the research from having discussions with other participants throughout the *Managing Fatigue* course. Throughout the *Managing Fatigue* course there are opportunities for participants to discuss alternative methods of completing a task, provide support to one

another, and to validate experiences of others in the course. Since the subject was completing the course individually, he may not have received the same support, knowledge, and validation from the principle investigators as he would have from someone who is experiencing similar post-stroke fatigue.

When following the *Managing Fatigue* course manual, there are activity stations scheduled during each session to reinforce the education discussed during a given topic. Due to the course taking place via teleconference, the subject was not able to participate in the activity stations. Because of this, the education provided by the principle investigators may not have been fully reinforced as it would have been if the *Managing Fatigue* course taken place in person.

### **Recommendations**

Future research studying the effectiveness of the *Managing Fatigue* course including a larger sample size of individuals experiencing post-stroke fatigue is recommended. Inclusion of a larger sample size will provide subjects with the opportunity for discussion with one another during the implementation of the course, as well as provide a sense of moral support and validation of difficulties one may be experiencing. A larger sample size would also assist in the ability to generalize results to a larger population. In order to assist with obtaining a larger sample size, it is recommended that the researchers allow for a greater time period to recruit potential subjects. Furthermore, it may be beneficial to ask clarifying questions while administering a non-standardized assessment to assist in the accuracy of results obtained.

It is also recommended that future research is completed studying the effectiveness of teleconference with the post-stroke population with a larger sample size.

Similar to what was previously mentioned, a larger sample size would allow for greater ability to generalize results to a larger population, and may improve results of the study overall. In addition to teleconference, it is recommended that future research is conducted on the effectiveness of occupational therapy service delivery using other methods of telehealth with the post-stroke population. These methods may include, but are not limited to, teleconference, videoconference, podcasts, and online discussion boards.

## APPENDICES

Appendix A  
Letter of Support for Altru Health System



9/12/2013

Jan Stube, PhD, OTR/L,  
Nicole Gronhøvd, MOTS, &  
Hannah Muehlberg, MOTS  
Department of Occupational Therapy  
University of North Dakota  
Grand Forks, ND 58202-7126

Dear University of North Dakota Institutional Review Board Members:

It is my pleasure to write a letter in support of the clinical research proposal being submitted to the Institutional Review Board at the University of North Dakota and also at this facility by the UND Occupational Therapy researcher, Dr. Jan Stube, and her graduate student advisees, Nicole Gronhøvd and Hannah Muehlberg. The proposed research study is entitled *Examining the Effectiveness of Managing Fatigue Post-Stroke via Telehealth*, beginning with a pilot study and progressing to Dr. Stube's randomized trial. I am the supervisor of the occupational therapy rehabilitation area at Altru Health System in Grand Forks, North Dakota. This is the site at which the occupational therapist volunteers will recruit and refer to the researchers approximately 5-6 patient research study participants over the next 3-4 months for the pilot study, followed by recruitment of a larger number for the randomized trial.

In conclusion, I fully support the efforts of the OT researcher and OT graduate student researchers as they seek approval from the University of North Dakota Institutional Review Board and this facility's research board to conduct clinical research of this important population and self-management of a common symptom post-stroke.

Sincerely,

A handwritten signature in black ink, appearing to read "Brenda Pauley-Colter, OTR/L".

Brenda Pauley-Colter, OTR/L  
Supervisor, Physical Medicine and Therapy Services  
Altru Health System

## Appendix B Institutional Review Board Approval Letters



INSTITUTIONAL REVIEW BOARD  
c/o RESEARCH DEVELOPMENT AND COMPLIANCE  
DIVISION OF RESEARCH  
TWAMLEY HALL ROOM 106  
264 CENTENNIAL DRIVE STOP 7134  
GRAND FORKS ND 58202-7134  
(701) 777-4279  
FAX (701) 777-6708

December 9, 2013

Nicole Gronhovd and Hannah Muehlberg  
2915 Florence Lane NW  
Bemidji, MN 56601

Dear Ms. Gronhovd and Ms. Muehlberg:

We are pleased to inform you that your project titled, "A Pilot Study: Examining the Effectiveness of Managing Fatigue Post-Stroke via Telehealth" (IRB-201312-189), has been reviewed and approved by the University of North Dakota Institutional Review Board (IRB). The expiration date of this approval is December 4, 2014. Your project cannot continue beyond this date without an approved Research Project Review and Progress Report.

As principal investigator for a study involving human participants, you assume certain responsibilities to the University of North Dakota and the UND IRB. Specifically, an unanticipated problem or adverse event occurring in the course of the research project must be reported within 5 days to the IRB Chairperson or the IRB office by submitting an Unanticipated Problem/Adverse Event Form. Any changes to or departures from the Protocol or Consent Forms must receive IRB approval prior to being implemented (except where necessary to eliminate apparent immediate hazards to the subjects or others.)

All Full Board and Expedited proposals must be reviewed at least once a year. Approximately ten months from your initial review date, you will receive a letter stating that approval of your project is about to expire. If a complete Research Project Review and Progress Report is not received as scheduled, your project will be terminated, and you must stop all research procedures, recruitment, enrollment, interventions, data collection, and data analysis. The IRB will not accept future research projects from you until research is current. In order to avoid a discontinuation of IRB approval and possible suspension of your research, the Research Project Review and Progress Report must be returned to the IRB office at least six weeks before the expiration date listed above. If your research, including data analysis, is completed before the expiration date, you must submit a Research Project Termination form to the IRB office so your file can be closed. The required forms are available on the IRB website.

If you have any questions or concerns, please feel free to call me at (701) 777-4279 or e-mail michelle.bowles@research.und.edu.

Sincerely,

A handwritten signature in black ink, appearing to read "Michelle L. Bowles".

Michelle L. Bowles, M.P.A., CIP  
IRB Coordinator

MLB/jle

Enclosures



December 12, 2013

Nicole Gronhovd, MOTS and Hannah Muehlberg, MOTS  
3850 Garden View Drive, Apt. 107  
Grand Forks, ND 58201

RE: Pilot Study: Examining the Effectiveness of Managing Fatigue Post-Stroke via Telehealth.  
(ST-122)

Dear Ms. Gronhovd and Ms. Muehlberg,

We are pleased to inform you that your project has been reviewed and approved by Altru Health System Institutional Review Board (IRB). The expiration date of this approval is December 31, 2014. Your project cannot continue beyond this date without a protocol change.

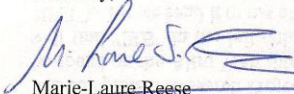
As principal investigator for a study involving human participants, you assume certain responsibilities to Altru Health System and the Altru IRB. Specifically, any adverse events or protocol changes that occur must be reported to the IRB immediately. It is your obligation to inform the IRB in writing if you would like to change aspects of your approved project, prior to implementing such changes.

If your research, including data analysis, is completed before the expiration date, you must submit and complete a Research Project Termination Form so your file can be closed. All our forms can be found on the Altru Web Site: [www.altru.org](http://www.altru.org) (click on "about us", then on "research" and you will find "IRB" in the left column). Or on "AltruNet": (click on "policies and procedures" then "IRB"). Please send it to me at:

Marie-Laure Reese  
IRB, Office 101- Altru Psychiatry Center  
860 S. Columbia Road  
Grand Forks, ND 58201

Also along with the IRB approval, I included your Organizational Approval from Altru. In case of using the Medical Records, they required a copy of the signed IRB approval **two weeks prior** to the start of your research. Please send it to Jan Anderson (Medical Records Department, Altru Hospital, 2<sup>nd</sup> floor).

Sincerely,

  
Marie-Laure Reese  
IRB Coordinator



## Appendix C

### Screening Tool

#### MANAGING FATIGUE

##### SCREENING TOOL

- I am an Occupational Therapy graduate student at the University of North Dakota. Together with another OT student, we will be conducting the research with supervision from our advisor. We would like to conduct a phone screening with you to see if you may meet some criteria to enroll in the project or not. The purpose of our research project is to see if people find it effective to participate in educational sessions to self-manage the symptom of fatigue after a stroke. We plan to use a telephone for individual or conference calls for all portions of the research study. You would be asked to participate for one hour weekly for 8 weeks during the months of late January until March of 2014. The program will include education and homework activities on topics including: rest, communication and body mechanics, activity stations, priorities and standards, balancing your schedule, and future plans. You and up to 9 other people would participate in this educational research study. You will not be paid for this course nor will you need to pay for the information; it is anticipated that you would benefit from the information provided. The total time commitment is 8 hours of your time.
- Does this interest you? Circle: Yes-No Do you have a phone that you are willing to use for this study one time weekly for 8 weeks? Circle: Yes- No Are you over the age of 41? Yes – No (If not over age 41 or if they do not have access to a phone, please thank the caller and ask if you can send them the AOTA pamphlet, “Recovering from Stroke”, gathering their name and mailing address to do so).
- Would you like more information? If so...
  - Prior to beginning your participation in the study, you will be interviewed by one of the occupational therapy students in order to gain demographic information and complete assessments such as the Canadian Occupational Performance Measure, Fatigue Impact Scale, and the Patient Reported Outcomes Measurement Information System. During this time informed consent and HIPAA authorization (i.e., giving permission for revealing health information) will also be explained and obtained. You will not be paid for you participation. Participation in this study is completely voluntary. The UND OT researchers would greatly appreciate your participation. Your participation in the study will help to gather information of the effectiveness of the program in the treatment of post-stroke fatigue and guide occupational therapy practice. If you are interested in participating in this study, please tell me now. You may contact the UND OT researchers if questions arise. Thank you for your consideration.

- If you are interested in participating, let me ask you some screening questions at this time. You are free to answer or not answer any of these 7 questions about fatigue. [The OT Student researcher will add up the caller's points. If 21 or higher, the participant qualifies for the study as a participant]
  - Administer the PROMIS Fatigue Short Form 7a
- If PROMIS points do not indicate fatigue as a symptom, the OT student researcher will let the caller know that they are fortunate to not have significant amounts of fatigue. Therefore, they do not need the education program but can be sent a flyer from the American Occupational Therapy Association on "Recovering from Stroke". Are they interested? Yes/No If so, please gather their name and address to send the flyer by mail to them. Either Yes or No, Please thank them for their interest and information provided today. Assure them that their answers provided to the questions today will not be published nor connected with their name in any way.
- If PROMIS points sum to 21 or greater, let the caller know that they qualify for the research project and ask if they are interested in pursuing the voluntary activity of participating in this upcoming research study. If yes, please gather the following demographic information. If not, please thank them for their interest and information provided today. Assure them that their answers provided to the questions today will not be published nor connected with their name in any way. You may also ask them if they would like to receive a flyer from the American Occupational Therapy Association on "Recovering from Stroke". Are they interested? Yes/No If yes, please gather their name and address to send the flyer by mail to them.

### SCREENING TOOL

Name: \_\_\_\_\_ Age: \_\_\_\_\_ Date: \_\_\_\_\_

Telephone Number #: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

PROMIS score: \_\_\_\_\_ of 31

## Appendix D

### Demographic Questionnaire

## DEMOGRAPHIC INFORMATION

By answering these questions, you will be assisting us in determining your eligibility for this study. Information from this form may be used in the study report but no identifying information will be reported.

**Initials:** \_\_\_\_\_ **Age:** \_\_\_\_\_ **Date of birth:** \_\_\_\_\_

Gender (circle):    M       F

**Date of stroke:** \_\_\_\_\_ **Number of strokes experienced:** \_\_\_\_\_

**Location of most recent stroke (circle):** Right Hemisphere      Left Hemisphere

Type of stroke (circle): Ischemic      Hemorrhagic      Transient Ischemic Attack

**Please rate your most recent stroke (circle):**      Mild      Moderate      Severe

**Race (circle):**

White Alaska Native Other:

Black Asian

American Indian                      Pacific Islander

**Marital Status (circle):**

Married                      Divorced                      Other:

Never Married                      Widowed

**Type of Housing (circle):**

House	Apartment	Group home
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Mobile Home                      Nursing Home                      Other: \_\_\_\_\_

**Living Situation (circle):**

Living Alone                      Living with relative(s)                      Other: \_\_\_\_\_

Living with Spouse	Sharing home with nonrelative(s)	
1	1	1
2	2	2
3	3	3
4	4	4
5	5	5
6	6	6
7	7	7
8	8	8
9	9	9
10	10	10
11	11	11
12	12	12
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17	17	17
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89	89	89
90	90	90
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92	92	92
93	93	93
94	94	94
95	95	95
96	96	96
97	97	97
98	98	98
99	99	99
100	100	100

## Living with Child

**Employment Status (circle):**

Full-time

Retired

Other: \_\_\_\_\_

Part-time

Student

Unemployed

On disability

**Educational Attainment (circle):**

Less than high school  
diploma

High school graduate

College degree or more

Some college, no degree

Other: \_\_\_\_\_

**Are you currently receiving occupational therapy services? (circle)    Yes    No**

**Are you currently experiencing fatigue secondary to your most recent stroke? (circle)**

Yes

No

**Do you have access to a telephone one hour per week for six consecutive weeks to participate in this research study? (circle)    Yes    No**

## Appendix E Informed Consent

1

### **The University of North Dakota Consent to Participate in Research**

**TITLE:** A Pilot Study: Examining the Effectiveness of Managing Fatigue Post-Stroke via Telehealth

**PRINCIPAL INVESTIGATORS:** Nicole Gronhøvd, MOTS & Hannah Muehlberg, MOTS

**STUDENT ADVISOR:** Jan Stube, Ph.D., OTR/L, FAOTA

**PHONE #s:** 218-760-2528 (Gronhøvd); 218-282-0307 (Muehlberg); 701-777-3099 (Stube)

**DEPARTMENT:** Occupational Therapy (OT), University of North Dakota, School of Medicine & Health Sciences

#### **STATEMENT OF RESEARCH**

A person who is to participate in the research must give his or her informed consent to such participation. This consent must be based on an understanding of the nature and risks of the research. This document provides information that is important for this understanding. Research projects include only subjects who choose to take part. Please take your time in making your decision as to whether to participate. If you have questions at any time, please ask.

#### **WHAT IS THE PURPOSE OF THIS STUDY?**

You are being invited to take part in a research study about the effectiveness of a *Managing Fatigue* course for post-stroke fatigue because of your experience with fatigue following your stroke. We will be using teleconferencing and telephone calls for the educational sessions.

The purpose of this research study is to study the influence of energy conservation techniques using the *Managing Fatigue* course developed by Packer, Brink, and Sauriol in 1995 on individuals with post-stroke fatigue. Additionally, fatigue experienced following a stroke is an understudied area in occupational therapy (OT) literature that needs to be addressed in healthcare and research. Lastly, results on the influence of teleconferencing technology for post-stroke populations is likely to be a beneficial means of delivery of the information in the course.

#### **HOW MANY PEOPLE WILL PARTICIPATE?**

There will be a maximum of ten people in this study at the University of North Dakota. You are selected to be a part of this research study because of your experience with post-stroke fatigue. To be in this study, all participants must 41 years of age or older, have experience a mild to moderate stroke in the last three years, currently experiencing fatigue due to a stroke, and have

Date: \_\_\_\_\_  
Subject Initials: \_\_\_\_\_

access to a telephone one hour per week for eight consecutive weeks. Your participation is important to this research and we thank you for your time.

#### **HOW LONG WILL I BE IN THIS STUDY?**

Your participation in the study will last approximately eight weeks, taking a total of 8.5 hours. You will need to complete an initial interview with one of the OT graduate student principal investigators to be educated on the study itself and complete initial assessments regarding demographic information, current level of fatigue, and your perception of your performance in daily activities. This initial interview will last approximately one hour in length. In addition to the initial interview, you will need to participate in an energy conservation course held via teleconference once per week (for six consecutive weeks). Each session will last approximately one hour in length. You may complete these treatment sessions at a location of your choosing. Following the course, you will be required to complete a second interview with one of the principal investigators to complete final assessments regarding level of fatigue and perception of your performance in daily activities following completion of the course. Similarly to the initial interview, this second interview will last approximately one hour in length.

#### **WHAT WILL HAPPEN DURING THIS STUDY?**

During this study, you will partake in a *Managing Fatigue* course administered via teleconference by the OT graduate student principal investigators, under the supervision of their OT faculty supervisor at UND. The course sessions will take place once per week for six consecutive weeks. You will also be asked to complete an assessment prior to and following the course sessions concerning current level of fatigue and your perception of your performance in daily activities. While completing these assessments, you are free to skip any questions that you prefer not to answer. Throughout the course, you will be educated on the importance of rest, communication, body mechanics, ergonomics, setting priorities, and balancing schedules. The *Managing Fatigue* course has been currently used with individuals experience fatigue secondary to multiple sclerosis, rather than following a stroke.

#### **WHAT ARE THE RISKS OF THE STUDY?**

The study is minimal risk, which means the risk during the study is no more than the risk taken during daily activities. However, you may experience mild frustration or mild discomfort that can be experienced when completing assessments or during discussion in the course sessions. However, such risks are not viewed as being in excess of “minimal risk”. If you become upset by questions, you may stop at any time or choose not to answer a question.

Date: \_\_\_\_\_  
Subject Initials: \_\_\_\_\_

### **WHAT ARE THE BENEFITS OF THE STUDY?**

You may not benefit personally from being in this study. It is possible that by participating in this study, you will gain insight into your strengths and limitations following your stroke. You will be provided with written information on energy conservation techniques that may assist you in managing fatigue and reintegrating into your previous lifestyle. Additionally, we hope that, in the future, other people may benefit from this study as it will provide additional information for the occupational therapy profession on the *Managing Fatigue* program, post-stroke fatigue, and the influence of teleconference technology for post-stroke populations.

### **WILL IT COST ME ANYTHING TO BE IN THIS STUDY?**

Foreseeable costs associated with this study include personal telephone costs totaling 8.0 hours.

### **WILL I BE PAID FOR PARTICIPATING?**

You will not be paid for being in this research study.

### **WHO IS FUNDING THE STUDY?**

The University of North Dakota School of Medicine and Health Sciences and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

### **CONFIDENTIALITY**

The records of this study will be kept private to the extent permitted by law. In any report about this study that might be published, you will not be identified. Your study record may be reviewed by Government agencies, the UND Research Development and Compliance office, and the University of North Dakota Institutional Review Board.

Initial identifying information will be collected in the screening process only. Thereafter, all names will be removed from the information collected by the faculty member prior to any study analysis. There will be no storage of names on any of the information or assessment forms completed. At no time will your name appear in the OT researchers' database nor on any reports or publications generated. In any written report of this study, the researchers will describe the study results in a summarized, grouped manner so that you cannot be identified individually.

### **IS THIS STUDY VOLUNTARY?**

Your participation is voluntary. You will not have to provide information that you do not wish to share, or answer questions you prefer not to answer. You may choose not to participate or you

Date: \_\_\_\_\_  
Subject Initials: \_\_\_\_\_

may discontinue your participation at any time without penalty or loss of benefits to which you are otherwise entitled. Your decision whether or not to participate will not affect your current or future relations with the University of North Dakota or Altru Health System.

#### **CONTACTS AND QUESTIONS**

The principal investigators conducting this study, Nicole Gronhovd, MOTS and Hannah Muehlberg, MOTS, are in their final year in the Master's of Occupational Therapy Program at the University of North Dakota. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Nicole Gronhovd at (218)760-2528/ Nicole.Gronhovd@my.und.edu or Hannah Muehlberg at (218) 282-0307/ Hannah.Muehlberg@my.und.edu at any time. The students' faculty advisor, Dr. Jan Stube, professor in the University of North Dakota's Occupational Therapy Department, may also be contacted at anytime with questions at (701) 777-3099/ jan.stube@med.und.edu during the day.

If you have questions regarding your rights as a research subject, you may contact The University of north Dakota Institutional Review Board at (701) 777-4279. Please call this number if you cannot reach the OT researchers or you wish to talk with someone else. Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subject's Name: \_\_\_\_\_

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Date

Date: \_\_\_\_\_  
Subject Initials: \_\_\_\_\_



Appendix F  
Permission Letter for *Managing Fatigue*

**From:** Tanya Packer [<mailto:Tanya.Packer@Dal.Ca>]  
**Sent:** Sunday, February 02, 2014 6:14 PM  
**To:** Stube, Jan  
**Subject:** RE: Permission for Managing Fatigue

Dear Dr. Stube

Thanks so much for your email. I am very pleased that you are considering using the program for people with stroke. Please use the program with my best wishes. I am assuming you have a copy of the protocol even though it is out of print now. I will be very interested to hear of your progress in both studies.

The online work was very interesting - we had to figure out how to capture the vicarious learning and peer modeling with asynchronous groups. I did this work in Australia and now am back in Canada. We are hoping to mount more studies but have come across an interesting problem - as we are licensed by province, we cannot treat patients in other provinces. This makes online programs difficult as people do not observe provincial boundaries online!

If I can be of any help in your work, please do not hesitate to contact me, even if just for a chat. It is really nice to be in contact with other OT academics with similar research interests.

Tanya

Tanya L. Packer, PhD, BSc(OT), OT Reg (NS)  
Professor and Director, School of Occupational Therapy  
Dalhousie University  
Halifax, Canada  
phone: + 902 494-8804  
fax: + 902 494-1229  
email: [tanya.packer@dal.ca](mailto:tanya.packer@dal.ca)

Appendix G  
Permission Letter for CMOP-E Diagram



Canadian Association of Occupational Therapists  
Association canadienne des ergothérapeutes

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**CAOT Publications ACE**  
**Copyright Request**

January 20 2014

Nicole Gronhøvd  
570 Carleton Ct. #208  
Grand Forks  
ND 58203  
USA

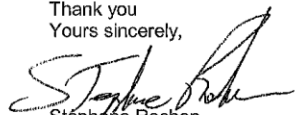
Dear Ms.Gronhøvd

According to your request, you would like permission to reproduce the CMOP-E diagram to be used in your study called " A Pilot Study: Examining the effectiveness of managing fatigue post-stroke via Telehealth" at the University of North Dakota.

Figure1.3 (CMOP-E) Canadian Model of Occupational Performance in Polatajko H., Townsend E., Craik, J. (2007). *Enabling Occupation II: Advancing an Occupational Therapy Vision for Health, Well-Being, & Justice through Occupation*. Ottawa, ON, CAOT Publications ACE. p. 23.

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Thank you  
Yours sincerely,



Stéphane Rochon  
CAOT Publications Administrator

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