

5-2018

Managing Fatigue with Technology for Individuals with Multiple Sclerosis

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<https://doi.org/10.33015/dominican.edu/2018.OT.06>

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Recommended Citation

Grant, Janie; Gamueda, May Anne; Ortega, America; and Song, Jordan, "Managing Fatigue with Technology for Individuals with Multiple Sclerosis" (2018). *Graduate Master's Theses, Capstones, and Culminating Projects*. 294.
<https://doi.org/10.33015/dominican.edu/2018.OT.06>

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Managing Fatigue with Technology for Individuals with Multiple Sclerosis

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A Culminating Project Submitted in Partial Fulfillment of the Requirements for the degree
Master of Science Occupational Therapy School of Health and Natural Sciences Dominican
University of California

San Rafael, California

May 2018

MANAGING FATIGUE WITH TECHNOLOGY

This project, written under the direction of the candidate's faculty advisor, Dr. Susan Morris, Ph.D., OTR/L and approved by the chair of the Master's program, Dr. Julia Wilbarger, Ph.D., OTR/L, has been presented to and accepted by the Faculty of the Occupational Therapy Department in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy. The content, project, and research methodologies presented in this work represent the work of the candidates alone.

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Acknowledgements

We would like to thank all the individuals contributing to the success of this capstone project. First and foremost, we would like to thank Dr. Susan Morris, OTR/L for her relentless support and guidance throughout our entire project. Dr. Susan Morris's encouragement and nurturing feedback helped our team reach the highest potential for ability and accomplishment through our progression as student researchers. We would also like to thank Dr. Kitsum Li, OTR/L for giving us additional advice as our second reader and Dr. Julia Wilbarger, OTR/L for her positive evaluation of our poster presentation. We are indebted to Michelle Ranae Wild, Ph.D. and the Making Cognitive Connections team for developing this wonderful product and their permission for us to implement it as the foundation of our study. We would like to thank them additionally for their time and knowledge shared to us and for graciously donating free versions of their wonderful product for our implementation. We would also like to thank the National MS Society of Northern California and the Corte Madera MS Support Group for allowing us to recruit all our willing participants through their extensive network and for giving us their endorsement for our project as well. We are grateful for all our participants who kindly sacrificed the time in their day to come on to our campus and agreeing to take part in our study. It was a pleasure to work with each of you and to hear your stories and testimonies as part of our project. Finally, we would like to thank our family and friends for their unconditional love, guidance, and support.

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Abstract

OBJECTIVE: The purpose of this study was to investigate whether the use of a mobile health application (mHealth app) in conjunction with energy conservation management techniques will result in a decrease in fatigue for adults with multiple sclerosis.

METHOD: Using a quantitative, exploratory, pre-posttest design, we examined outcomes associated with the use of the mHealth app, Pace My Day, by seven participants during one chosen task over two weeks. The app reinforced the use of energy conservation management techniques during the chosen task. Outcome measures included Modified Fatigue Impact Scale (MFIS) and Canadian Occupational Performance Measure (COPM).

RESULTS: There was a significant decrease in the MFIS scores indicating a decrease in fatigue over the two-week period $t(6) = 5.75, p = 0.001$. Additionally, there was a significant increase in satisfaction with performance of the chosen task as measured by the COPM over the two-week period $t(6) = -3.359, p = 0.015$.

CONCLUSION: The use of a mHealth app to support energy conservation management education was found to significantly reduce levels of fatigue and increase self-perceived performance and satisfaction with task execution.

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Introduction

Every year, over 2.5 million individuals are diagnosed with multiple sclerosis (MS) worldwide (Faguy, 2016). MS is a chronic, life-long disabling condition affecting nerve fibers in an individual's brain and spinal cord, significantly impacting participation in daily life. According to the Mayo Foundation for Medical Education and Research (2017), MS symptoms range in severity, intensity, and duration depending on the extent and location of nerve damage. Fatigue is one of the most common and debilitating symptoms among individuals with MS. Fatigue is an overwhelming feeling of weariness and tiredness limiting an individual's ability to carry out everyday activities (Smith, Lai, & Cella, 2010). Additionally, decreased cognition and pain have a significant impact on the ability to engage in daily occupations due to physical limitations, exhaustion, decreased personal autonomy, and depression.

The National Multiple Sclerosis Society (2016) states that MS significantly impacts individuals' ability to fully participate and engage in everyday occupations. The American Occupational Therapy Association (AOTA) defines an occupation as an everyday activity in which an individual participates that is both meaningful and purposeful (AOTA, 2014). Fatigue often restricts participation in daily occupations. Pharmacological and nonpharmacological interventions can be used to help manage fatigue to allow a higher level of engagement in everyday life (Tur, 2016). Pharmacological interventions include medications such as amantadine and modafinil (National Multiple Sclerosis Society, 2016). Nonpharmacological interventions include physical activity such as exercise and yoga, as well as cognitive and psychological treatments such as relaxation techniques, energy conservation management, and cognitive behavior therapy (Tur, 2016).

The advancement of technology creates potential new avenues of interventions for conditions like MS. Recent advances in technology have resulted in communication and network

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technologies that are used directly by the patient. Such technologies are called mobile-health technology (mHealth), which brings communication and network technologies directly to the patient. One of the most popular forms of mHealth is incorporated into mobile smart phones as application features (apps). These mHealth apps can be utilized by both healthcare providers and patients to help monitor and manage symptoms effortlessly, track important health care information privately and conveniently, and save on growing health care costs effectively (Silva, Rodrigues, Diez, López-Coronado, & Saleem, 2015).

An emerging area of practice in occupational therapy is the use of technology as a part of interventions. The role of occupational therapists (OT) are to promote health, well-being, and participation in daily activities (or occupations). OTs are able to enhance participation and optimize occupational performance through the use of assistive technology. OTs frequently include energy conservation management (ECM) techniques when educating clients on how to improve occupational performance and manage symptoms of fatigue. Combining the use of activity analysis and occupational performance education with technology may result in better client outcomes and improved adherence to self-management strategies. To examine the use of technology as part of an occupational therapy intervention with adults with MS, this study evaluated the effectiveness of a mHealth app, Pace My Day (PMD) in combination with ECM education.

Literature Review

Multiple Sclerosis Defined

MS is a chronic and progressive neurodegenerative disorder affecting an individual's central nervous system (CNS) (Faguy, 2016). The disease causes the demyelination of the CNS, disrupting the nerve impulses traveling to and from the brain and spinal cord (Faguy, 2016). The location of demyelination and the severity of axonal damage differs among individuals, resulting

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in the patient experience of MS being unique and complex (Dirette, 2012; Foti, 2013). There is currently no cure for MS. Eventually, axonal degeneration occurs leading to long-term disability and neurological impairments affecting one's physical, sensory, mental, and emotional activity (Yang, Wang, Deng, & Yu, 2017).

The cause of MS is unknown, but there are several factors that may be involved. Ongoing research is looking into immunologic, environmental, infectious, and genetic factors (National Multiple Sclerosis Society, 2017-a). Current research suggests genetic and environmental factors that may increase an individual's likelihood of developing the disease. Individuals with a family member who has MS have an increased risk of developing the disease. Furthermore, environmental risk factors can influence the development of MS in individuals with genetic susceptibility. The environmental risk factors include an infection with Epstein-Barr virus, ultraviolet light exposure, cigarette smoking, and geographic location (Bishop & Rumrill, 2015). Epidemiological studies have found that there is a higher rate of MS in individuals of northern European ancestry and lower rate of MS in individuals from tropical and subtropical regions. However, research suggests that individuals who move to a higher risk region in early childhood adopt the risk level in the geographic area. This finding supports the theory that the risk for MS can be influenced by exposure to environmental risk factors in early childhood (Bishop & Rumrill, 2015).

According to the National Multiple Sclerosis Society (2016), more than 2.3 million people are affected by MS globally. There are approximately 450,000 individuals in the United States with MS (Bishop & Rumrill, 2015). An estimated 10,000 new cases of MS are diagnosed each year in the United States. Seventy percent of those individuals newly diagnosed with MS are between the ages of 20 and 40 years old (Wenneberg & Isaksson, 2014; Faguy, 2016). MS

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commonly affects more women than men, and of those affected by MS, most are of Caucasian decent (Habibi & Kuttab, 2016).

Patterns of multiple sclerosis. The progression of MS affects each individual differently, which means that the course and prognosis of MS are both highly unpredictable (Dirette, 2012). In 1996, the National Multiple Sclerosis Society Advisory Committee on Clinical Trials in MS created disease-course definitions (Lublin et al., 2014). Originally, there were four courses, or patterns, of MS: relapsing-remitting (RRMS), primary progressive (PPMS), secondary progressive (SPMS), and progressive relapsing (PRMS). In 2013, after advances in research and magnetic resonance imaging (MRI) technology, the classifications of MS were revised. The committee retained three patterns of the disease course: RRMS, PPMS, SPMS, and added Clinically Isolated Syndrome (CIS) (National Multiple Sclerosis Society, 2017-b). The committee eliminated PRMS because they believed the term was vague and overlapped with other disease subtypes. Individuals previously diagnosed with PRMS are now included in the PPMS category (Lublin et al., 2014).

RRMS. RRMS is the most common form of MS. Approximately 85% of individuals with MS are initially diagnosed with this pattern (Faguy, 2016; Habibi & Kuttab, 2016). An individual experiencing RRMS has periods of acute exacerbations of symptoms, known as relapses, followed by partial or complete recovery where symptoms decrease or disappear, known as remissions (Dirette, 2012). Recovery between relapses and remissions are different for each person, with over half of individuals experiencing some residual deficits such as neurological impacts and increases in levels of fatigue (Maurer et al., 2016). RRMS can be categorized as “active,” when the individual is experiencing relapse or showing evidence of disease activity through MRI, or “not active,” when the individual is in remission. “Not active”

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can be further described as “worsening” if there is an increase in disability after relapse or “not worsening” or “stable” if there is no evidence of an increase in disability after relapse (Lublin et al., 2014).

PPMS. PPMS makes up about 10 to 15% of individuals with MS (Faguy, 2016). PPMS mostly affects individuals diagnosed with MS in their late forties and affects more men than women (Habibi & Kuttub, 2016). PPMS is characterized by a steady decline in neurologic function from the onset of symptoms without initial relapses or remissions (Lublin et al., 2014). Up to 15% of individuals with PPMS may never experience any remission period (Noonan et al., 2010; Foti, 2013). Like RRMS, PPMS can be described as “active” and “not active.” Both “active” and “not active” can be further described as “with progression”, if there is objective evidence of sustained worsening over time, or “without progression”, if there is no observable increase in disability (Lublin et al., 2014). PPMS is the most debilitating type of MS impacting upper and lower extremity function which affects an individual’s ability to ambulate independently. Additionally, PPMS causes eating and swallowing deficits such as dysarthria, and bowel and bladder deficiencies (Foti, 2013).

SPMS. Following an initial relapsing-remitting course, SPMS becomes more steadily progressive with or without relapses. SPMS is diagnosed retrospectively based on the worsening of the disease course (Lublin et al., 2014). At least 50% of individuals who are initially diagnosed with RRMS develop SPMS (Bishop and Rumrill, 2015). Like PPMS, SPMS can be described as “active” or “not active” and “with progression” or “without progression” depending on relapse and worsening of disability (Lublin et al., 2014).

CIS. CIS is a new disease course and is recognized as the first clinical presentation of neurologic symptoms that lasts at least 24 hours and is caused by inflammation and

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demyelination in the CNS. Individuals who experience CIS are considered at a higher risk of developing full-blown MS (Lublin et al., 2014). CIS can be a monofocal episode meaning the person experiences a single neurological sign or symptom caused by one lesion. CIS can also be a multifocal episode meaning the person experiences more than one sign or symptom caused by lesions in more than one place. Like MS, CIS affects more women than men and 70% of those diagnosed with CIS are between the ages of 20 and 40 years (Lublin et al., 2014).

Symptoms of MS. Symptoms present differently for every individual depending on the onset of the disease, the area of the CNS affected, symptoms experienced, and the progression of the condition (Maurer et al., 2016). When lesions occur in the frontal and parietal lobe, cognition and emotions are affected. When lesions occur in the cerebrum, brainstem, and spinal cord, physical functioning of the extremities are affected. When lesions occur on the optic nerve or occipital lobe, vision is affected (Bishop and Rumrill, 2015). The most common symptoms of MS include fatigue, pain, numbness or tingling, muscle stiffness and weakness, emotional lability and vision impairments (Foti, 2013; Faguy 2016). As the disease progresses into more severe stages, more body systems are impacted, which further impairs an individual's quality of life.

MS and cognitive impairment. Cognitive impairment and dysfunction occur in all types of MS (Rogers & Panegyres, 2007). Cognitive impairments affect 40–70% of individuals with MS with difficulties in memory, sustained attention, information processing speed, and executive functions (D'Amico, Leone, Hayrettin, & Patti, 2016). Depression is more common in individuals with MS who experience cognitive impairments (Nunnari et al., 2015). Individuals with MS have decreased speed and capacity to process information which may correlate to memory and attention deficits. An individual's difficulty with attending to simple or complex

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tasks for long periods of time is associated with an individual's decreased capability to store information in the brain. Additionally, an individual with MS may have deficits in executive function which often results in difficulties with the ability to problem solve, plan, and self-monitor tasks (Rogers and Panegyres, 2007). Treatments to improve executive functioning include managing cognitive impairments and ameliorating psychosocial symptoms.

MS and fatigue. MS-related fatigue is a decline in motor and cognitive capacities associated with decreased motivation and an increased need to rest (Ayache & Chalah, 2017). MS-related fatigue differs from general fatigue in that it occurs early in the morning and worsens as the day progresses. It is also worsened by heat and humidity, and is more likely to hinder participation in daily responsibilities (National Multiple Sclerosis Society, 2016). According to Noonan et al. (2012), 53-92% of individuals with MS identified fatigue as the most immobilizing and incapacitating symptom. Fatigue has been described as multi-dimensional, affecting an individual's physical, psychosocial and cognitive functioning (DeLuca, Genova, Hillary & Wiley, 2010). Cognitive fatigue is common among individuals with MS and is defined as an increase in mental effort and limited mental endurance (Bruce, Bruce, & Arnett, 2010).

In a qualitative inductive study by Wenneberg and Isaksson (2014), 61 participants diagnosed with MS discussed the impact MS had on their quality of life. The average participant was 42 years old, and five years post diagnosis. In the study, 37 individuals were diagnosed with RRMS, 17 individuals were diagnosed with SPMS and seven individuals were diagnosed with PPMS. Participants were asked specific questions regarding how MS had affected their quality of life, changed their point of view, and impacted their lives (Wenneberg & Isaksson, 2014). Data were collected, transcribed, coded, and themed, into the following four major categories: (1) Experience of ill-health, (2) Experience of health in spite of illness, (3) Psychosocial

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consequences of having MS and (4) Different ways of managing MS (Wenneberg & Isaksson, 2014). Participants reported that endurance and stamina affected their ability to ambulate. This led to a decrease in their personal autonomy and overall quality of life. In addition, participants reported abstaining from work and leisure activities due to the effects of MS. The study concluded that living with MS was challenging, often debilitating, and affected both emotional and physical well-being.

Similarly, Eilertsen et al. (2015) conducted a qualitative study of interviews and evaluated the similarities and differences of fatigue among 95 individuals, 66 women and 29 men, diagnosed with fibromyalgia, MS, and ankylosing spondylitis (AS). Researchers sought to identify common themes among the participants regarding their experience of fatigue in relation to their diagnosis. During the first phase of data analysis researchers analyzed initial themes independently from one another. Throughout the second phase, researchers compared and analyzed the initial themes and grouped them by fatigue levels and condition. Results revealed participants expressed fatigue as a sense of weariness, or an overwhelming feeling of tiredness throughout the body (Eilertsen et al., 2015). An increased need to sleep was also reported by all participants in the study. Fatigue often left participants unable to engage in roles and occupations such as finishing work or chores around the home. In addition, fatigue kept participants from maintaining close relationships with friends and family members, and often, resulted in a feeling of being a burden to themselves or others. Lastly, participants discussed the negative impacts that fatigue had on their memory and concentration. Their inability to remember information hindered everyday tasks, such as grocery shopping. Participants noticed the inability to concentrate on tasks at work, forcing members to give up meaningful occupations, and reestablish priorities (Eilertsen et al., 2015). Similarly, Maitra et al. (2010) found that progressive

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symptoms of MS, such as cognitive deficits or physical fatigue, frequently led to increased hospital stays and an additional need for medical services.

Current Treatments for Managing MS Related Fatigue

Fatigue is one of the main complaints of individuals with MS as it restricts individuals from participating in their daily occupations (Blikman et al., 2013). Fatigue can be managed by using pharmacological and nonpharmacological approaches, enabling individuals to participate more fully in their lives (Tur, 2016).

Pharmacological

Amantadine, modafinil, and pemoline are medications that have been evaluated in clinical trials to treat MS related fatigue (Asano & Finlayson, 2014). The most commonly used pharmaceutical treatments are amantadine and modafinil (Tur, 2016). Yang, Wang, Deng and Yu (2017) conducted a meta-analysis and found amantadine, an antiviral medication, to be the only commonly used drug with sufficient evidence supporting a benefit in treating MS-related fatigue. Modafinil, another commonly used drug for MS-related fatigue, is a wakefulness-promoting medication (Niepel et al., 2013). In a study of 26 subjects by Niepel et al. (2013), modafinil was found to have an impact on excessive daytime sleepiness associated with fatigue. However, neither amantadine or modafinil have been approved by the Food and Drug Administration for use in individuals with MS (National Multiple Sclerosis Society, 2016). Furthermore, a meta-analysis by Asano and Finlayson (2014), compared 10 exercise intervention randomized control trials, 8 educational intervention randomized control trials, and 7 pharmacological randomized control trials. Results indicated that the pharmacological approach was least effective in managing fatigue in individuals with MS. The rehabilitation interventions of exercise and education had a more significant effect in reducing patient-reported fatigue (Asano & Finlayson, 2014).

Nonpharmacological

Nonpharmacological approaches are commonly used to manage fatigue and can be generally described as physical and psychological or cognitive approaches (Tur, 2016). Physical approaches include exercise and yoga. Psychological or cognitive approaches include relaxation techniques, cognitive behavior therapy (CBT), and energy conservation management (ECM).

Exercise. Exercise is an approach to reduce fatigue in individuals with MS. Petruzzello and Motl (2011) conducted a moderate-intensity cycling exercise program with 25 female participants diagnosed with MS. The researchers measured fatigue using the Profile of Mood States, which measures fatigue in short-term experimental settings. The researchers also measured fitness by measuring peak oxygen consumption, carbon dioxide production, ventilation, respiratory exchange ratio, and heart rate. During the first session of exercise, participants biked at a work rate of 0 watts and continually increased the work rate by 15 watts until volitional exhaustion occurred, where participants were too fatigued to continue biking. During the second exercise session, participants completed a warm-up with no resistance, followed by 20-minute cycling at a work rate individualized for each participant to reach peak oxygen consumption at 60%, and finishing with a five-minute cool-down with no resistance. Results found self-reported fatigue was reduced 20 to 60 minutes after participating in the 20-minute round of moderate-intensity cycling exercise. Results indicate that short bouts of exercise can help improve levels of fatigue and can lead to the development of exercise as a prescriptive therapy for managing fatigue in persons with MS (Petruzzello & Motl, 2011).

Schmidt and Wonneberger (2014) studied the long-term effects of an individualized aerobic endurance exercise program on 89 patients with MS. Fatigue was measured using the Fatigue Severity Scale and exercise was measured through oxygen consumption and carbon dioxide expiration, heart rate, and body fat percentage. The exercise program consisted of three

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training sessions per week for 30 minutes. Participants were asked to keep a training diary and to use the provided heart rate monitor to record heart rate data. The results of the 12-month study found that there was no significant reduction of the Fatigue Severity Scale over the entire study duration. This study failed to show any significant effects that exercise has on reducing fatigue in patients with MS. However, there are other nonpharmacological approaches that research has shown to help decrease fatigue in individuals with MS. Therefore, although evidence supports exercise in the community sample, the relationship between fatigue and exercise in individuals with MS remains to be understood.

Psychological or Cognitive Approaches.

Relaxation Techniques. Relaxation techniques help to reduce stress and sensitivity to fatigue. One type of relaxation technique that has benefitted individuals with chronic disease is Progressive Muscle Relaxation Technique (PMRT) (Dayapoglu & Tan, 2012). PMRT is the “voluntary stretching and relaxation of large muscle groups in the human body” (Dayapoglu & Tan, 2012, p. 984). In Dayapoglu and Tan’s (2012) study, PMRT was found to reduce fatigue in patients with MS who were part of the intervention group. While relaxation can be helpful in relieving stress, a study by Kos et al. (2016) evaluated and compared an energy conservation intervention and a relaxation intervention. The study was a single-blind randomized controlled trial with 31 patients. The self-management intervention was a program called SMOoTh, a self-management occupational therapy program teaching strategies to support clients in taking control of their performance of activities. The relaxation intervention consisted of education on stress management. Using the Canadian Occupational Performance Measure, both the self-management intervention and relaxation intervention improved in performance and satisfaction after the intervention was completed. A three-month follow-up found that more than 70% of

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patients who participated in SMOoTh, the self-management intervention, perceived better performance in desired activities using ECM compared to 27% of the participants in the relaxation group.

Cognitive Behavioral Therapy. CBT is a form of psychotherapy that works on negative or false beliefs and restructuring them into more positive or helpful thoughts (National Alliance on Mental Illness [NAMI], n.d.). Knoop, van Kessel and Moss-Morris (2012) studied 70 patients with MS using CBT as intervention to reduce fatigue and a relaxation group as control. A cognitive-behavioral model of MS-related fatigue has been formulated in which negative cognitive, behavioral and emotional responses to MS-related fatigue can worsen the fatigue. CBT for MS-related fatigue consisted of increasing self-efficacy, promoting scheduling activities to prevent all-or-nothing behavior, addressing the catastrophizing of symptoms and beliefs that symptoms signal damage to the body, promoting good sleep hygiene, addressing coping skills for negative emotions, and promoting social support. Both CBT and the relaxation group reduced fatigue, however results from the CBT group showed a greater effect in decreasing fatigue due to a change in participant's perception of fatigue. The participants viewed fatigue as more controllable and time limited which helped to change the negative representation of fatigue and lessen the severity of fatigue (Knoop, van Kessel and Moss-Morris, 2012).

ECM. ECM uses education to teach individuals how to analyze and modify activities with the objective of reducing fatigue when engaging in activities (Jalon, Lennon, Peoples, Murphy & Lowe-Strong, 2012). A systematic review and meta-analysis by Blikman, et al. (2013) assessed six full-text articles regarding the effectiveness of ECM on reducing fatigue in individuals with MS. The study looked at four randomized and controlled trials and two controlled clinical trials. Two short-term studies used the quality of life scale on the Medical

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Outcomes Study 36-Item Short Form Health Survey (SF-36). The meta-analysis of the two studies showed improvement in three quality of life subscales of the SF-36 indicating ECM was effective in improving participation in daily activities when compared to no treatment. The meta-analysis of all six studies indicated that in the short-term, ECM treatment was more effective than a support group, placebo treatment, or no treatment in reducing fatigue. Long-term reduction in fatigue, however, was not established as there have been no randomized control studies with a long-term follow up (Blikman, et al., 2013). Matuska, Mathiowetz, and Finlayson (2007) conducted a study investigating which ECM techniques were most frequently used by individuals with MS after attending a six-week energy conservation course. The six-week course was developed by Packer, Brink, and Sauriol (1995) and consists of multiple strategies used to help individuals conserve energy. The study included 169 patients with MS who received ECM education or training from certified OTs in community settings. A total of 14 ECM techniques were emphasized in the course. After six weeks, participants were given a survey to identify which techniques they had used as a result of the course and how effective each technique was. The techniques used by more than 80% of the participants included changing body positions, planning a balance of work and rest, modifying frequency of activities and outcomes of activities, including rest period throughout the day, simplifying activities, asking for assistance, and resting during longer activities. The ECM techniques used the least were changing the time of day an activity took place and using adapted equipment or devices. The primary reason why participants reported not using certain strategies was due to an increase in using strategies prior to the course. In addition, all 14 strategies were rated as effective ways of conserving energy, with delegating tasks, balancing rest and work, and resting during longer activities being rated the highest. The assumption associated with ECM training is that learning and using ECM

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techniques will reduce fatigue and lead to a better quality of life. ECM is a tool of empowerment for individuals with MS to become a gatekeeper of his or her own energy and using it for activities deemed meaningful and valuable. This in turn, encourages behavioral changes that can improve participation in everyday activities (Blikman, et al., 2013).

Technology

Mobile Technology in Healthcare. Worldwide, mobile phones have become a vital part of everyday life for many people. In the United States, 95% of Americans own a cellphone and of those Americans, 77% own a smartphone (Pew Research Center, 2017). With the development of apps in the turn of the 21st century, the mHealth platform has quickly emerged as the new edge in health care innovation, informational outreach, and monitoring for both patients and health care providers. As mobile phones become more advanced, researchers have taken advantage of the technical capabilities in developing various health interventions strategies within apps. Thus, the majority of mHealth apps now include strategies allowing users the ability to track and gather health information, self-document to monitor personal results, receive remote coaching and reminders, and access health information (Klasnja & Pratt, 2012). To evaluate this emerging field of healthcare, researchers from John Hopkins University investigated the impact of consumer health informatics applications on health outcomes (Gibbons et al., 2009). The study investigated 121 studies of consumer health apps with various purposes ranging from managing physical fitness, diabetes, and mental health. The results showed that consumer health applications may effectively engage consumers, enhance traditional clinical interventions, and improve both intermediate and clinical health outcomes (Gibbons, et al., 2009).

Technology Use in Self-Help Management. In addition to tracking and gathering patient data, customization features of mHealth apps may improve efficacy and client satisfaction by addressing factors that are important to effective self-management. Five focus groups were asked

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to identify what features were important to them in a self-management mobile app. Two of the groups consisted of people with human immunodeficiency virus (HIV) who were asked to focus on medication adherence, stress management, substance abuse and sexual risk behaviors. The three other groups consisted of young mothers who were asked to focus on diet, stress, and exercise. Feedback from all five focus groups was used to inform the design of mobile apps for self-monitoring and self-managing health behaviors and risk factors. All five groups identified goal setting, motivational messaging and feedback, and reminders as potentially valuable for adherence to self-management strategies (Ramanathan, Swendeman, Comulada, Estrin, Rotheram-Borus, 2013).

The efficacy of self-management features was assessed in a randomized control study investigating Sweet Talk, a motivational support network that uses text messaging software to provides self-management reminders for individuals with Type 1 diabetes (Franklin, Waller, Pagliari, & Greene, 2006). Participants who had type I diabetes were either allocated to a conventional insulin therapy (CIT) group, CIT group with Sweet Talk or intensive insulin therapy with Sweet Talk. Participants were able to create personal diabetes self-management goals and Sweet Talk provided schedule automated delivery of appropriate messages, motivational reinforcements, and reminders of the goals set in clinic. The outcome measures of the study included glycemic control and behavioral changes. The Sweet Talk results did not demonstrate a significant impact on improving glycemic control, however, they did indicate that Sweet Talk is positively associated with psychological measures predictive of adherence. Participants who received Sweet Talk and CIT scored significantly higher on self-efficacy for management of their diabetes than the participants who received solely CIT. Of the participants who received Sweet Talk, 81% felt that it helped with diabetes self-management during the

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study. Even more encouraging, 90% of participants wanted to continue using the app following the study. The results of this study demonstrated that technology can potentially increase adherence and encourage self-management of conditions (Franklin, Waller, Pagliari, & Greene, 2006).

Technology Used to Manage Fatigue

A study in New Zealand examined the types of mobile devices used, the different methods used to access the internet, and the impact of fatigue on daily life among individuals with MS (Van Kessel, Babbage, Reay, Miner-Williams, & Kersten, 2017). Fifty-one individuals with MS participated in the study. The study found that 86% of participants reported having a mobile phone, 75% of participants frequently used apps, and 92% had access to internet from their home. Among these participants, 84% reported experiencing significant fatigue. Some participants reported that symptoms of MS including visual problems, weakness, fatigue, numbness in fingers, and excessive tremors in the upper extremities affected their use of technology. These findings indicate that there is a need for accessible interventions for people with MS due to severe fatigue symptoms. Furthermore, these findings indicate a need to consider how symptoms of MS could affect an individual's use of mobile technology and methods to make mobile technology more accessible. As most participants report having a mobile phone, there is a market for mHealth technology to deliver health care interventions to address MS-related fatigue (Van Kessel et. al., 2017).

PMD. The use of mHealth apps to help manage symptoms of fatigue in chronic conditions can be an important component in occupational therapy home programs to promote behavioral changes and continued client health maintenance (Costa, Cambell, Yarvi, & Cardell, 2014). One example is the mHealth app, Pace My Day (PMD), developed by Michelle Rane Wild, PhD, to help people who suffer from over-exertion and fatigue when performing their

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activities of daily living due to chronic illness. PMD strives to help individuals self-manage their level of fatigue by utilizing ECM techniques in their daily lives. Features of the app include planning the day according to how one feels, tracking energy levels, scheduling breaks and organizing daily tasks in accordance to fatigue status.

A pilot study investigated whether participants with cognitive impairments are able to master the complexity of the PMD mHealth app (Visone, Wild, Pasino, Patterson, & Trofimova, 2015). Seven participants with acquired brain injury (ABI) from the Coastline ABI Program reviewed 12 PMD training videos over the period of four days. A posttest was administered to evaluate if the participants had learned to use the app by utilizing features from the app on 21 tasks spanning three categories. More than 70% of the participants had the capacity to learn, use, and implement the PMD app over a short period of time (Visone et al., 2015). The main limitation in this study was the small sample size of only 7 participants. Since the study only included individuals with ABI, it is unknown if the app would also help manage fatigue in other chronic conditions such as MS.

My MS Manager. A similar mHealth app, My MS Manager was endorsed by the Multiple Sclerosis Association of America. The app was developed to help individuals with MS and their healthcare providers manage changes in symptoms of the disease. The app utilizes features that help users track their condition, manage and store information regarding their symptoms, manage medications, and manage fatigue levels through self-documentation (Moore, 2016). Unlike PMD, My MS Manager does not have a reminder system to notify users when to incorporate breaks during their tasks. Thus, users are unable to actively manage their exertion levels or incorporate ECM techniques in the middle of a task, limiting the app's role for self-management purposes. Among the strength of the app, however, is that it includes links to

educational resources and support.

The Role of Occupational Therapy

Role of Occupational Therapy in Traditional Intervention. OTs are professionals that help individuals across the lifespan to do the things they want and need to do through the therapeutic use of daily activities or occupations (AOTA, 2014). OTs play an important role in the evaluation and treatment process for individuals with MS. Occupational therapy treatment focuses on improving the quality of life of individuals by optimizing participation in daily occupations, which for many individuals with MS includes learning how to manage symptoms of fatigue. Occupational therapy interventions for MS include ECM techniques, time management, body mechanics and suggesting assistive devices to improve task performance (Eyssen et al., 2013).

The aim of these interventions is to minimize impairments or increase performance in meaningful activities, by providing environmental support and reducing social environmental barriers, and by enhancing personal coping strategies (Preston, Haslam and Lamont, 2012). OTs are also clinically trained to assess the appropriate level of difficulty for an activity and how to grade those activities to maximize success. OTs can achieve this by adapting how activities are conducted, such as incorporating ECM techniques to maximize performance (Preissner, Arbesman, and Lieberman, 2016). However, research has shown that only 30% of individuals with MS are referred to occupational services (Preston, Haslam & Lamont, 2012). This is due to individuals with MS only being referred to occupational therapy when their symptoms are exacerbated or when they report a decline in their occupational performance in activities of daily life (Preston et al., 2012). Though more clinical trials have been conducted to support the use of occupational therapy for MS symptom management, a lack of awareness exists regarding the

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scope of practice and the purpose of occupational therapy intervention when working with individuals with MS (Preston, et al., 2012).

Role of Occupational Therapy and Technology. OTs are skilled in activity analysis and providing modifications and assistive technology for enhancing participation. Technology can be used as a part of interventions to support function and meaningful engagement in occupations (Goodrich & Garza, 2015). The use of mHealth apps is not currently common practice in occupational therapy intervention, however, mHealth apps can offer a highly accessible and cost-effective means of supporting self-help management programs. There are over 30,000 mHealth apps available that could be incorporated into occupational therapy intervention. Many qualified self-management apps can be found in the AOTA online app database, which is periodically updated with the latest technology (Costa et al., 2014). Once an appropriate mHealth app is chosen, the OT can help educate and motivate their clients in utilizing this assistive technology correctly and routinely.

A systematic review of 24 mHealth studies found that the average user retention rate for smartphone usage throughout the interventions was at 79.6% (Payne, Lister, West, & Bernhardt, 2015). Furthermore, users felt a sense of satisfaction through accomplished tasks and a feeling of privacy when using mHealth apps in public (Payne, Lister, West, & Bernhardt, 2015). The clinical implications of using mHealth apps to track patients' life experiences, such as physiological data, adherence to routines, and quality of life data can allow the OT and other health practitioners to evaluate and assess patients' performance on specific treatment goals. OTs' can utilize aspects of mHealth apps such as its privacy features and motivational reminders to empower their clients to continue with treatment goals privately, remotely, and on their own time in the future (Costa et al., 2014).

Statement of Purpose

Based on the evidence, ECM techniques can help to lower levels of fatigue in individuals with MS. Furthermore, evidence suggest the incorporation of mHealth apps can be beneficial in encouraging compliance and accurate use of self-management strategies for various chronic diseases. However, few studies have investigated the efficacy of using a mHealth app in managing fatigue levels in individuals with MS. Therefore, the purpose of this study is to investigate whether the mHealth app, (PMD app) in conjunction with ECM techniques will result in a decrease of fatigue in adults with MS. Our hypothesis is that the PMD app will assist and/or encourage participants to incorporate use of a mHealth app and ECM techniques into their daily tasks resulting in overall lower fatigue and an increase in occupational performance and satisfaction.

Theoretical Framework

Developed by Law, Cooper, Stewart, Letts, Rigby and Strong (1996), the Person-Environment-Occupation (PEO) model explores the transactional relationship by and among persons, their environments and their occupations, and how these three concepts affect occupational performance. The PEO model explores how a person, his environment, and his occupation overlap and interconnect (adjust to maintain an optimal fit) across an individual's lifespan. Changes in one area of person, environment, and/or occupation influence an individual's overall occupational performance. Dunbar (2007) illustrates one of the primary assumptions of PEO is that optimal occupational performance is attained when all three components of person, environment, and occupation interconnect across an individual's lifespan. Using the PEO model's theoretical framework to address the specific variables of a person, environment, and occupation, this research study explores the effectiveness of using the PMD app to help individuals achieve optimal occupational performance (Law et al, 1996).

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The first component, person, is a distinct and holistic being with unique experiences. A person encompasses specific mind, body, and spirit virtues that impact an individual's experiences (Brown, 2014; Law et al., 1996). Across a person's lifespan, he or she participates in different roles that continuously change based on the significance of the role, and a person's cultural background, individuality, and overall life experiences. A person's abilities and skills, cognitive capabilities, social and emotional skills, and health all affect his or her occupational performance, quality of life, and well-being (Brown, 2014; Law et al., 1996). The use of the PMD app in conjunction with ECM techniques allows the person to engage in meaningful activities impacted by fatigue. The PMD app can increase the person's self-efficacy and personal satisfaction to complete daily tasks and fulfill their roles. In addition, use of the PMD app can be motivating for the person to participate in chosen activities. When he or she feels a sense of accomplishment, his or her perceptions of self and abilities are changed.

The next component, environment, recognizes a person's location and the context in which a specific event occurs (Law et al., 1996). Specific considerations for a person's environment include an individual's cultural background and experiences, as well as an individual's specific values and beliefs. Other considerations for an individual's environment include natural and built surroundings, virtual context (such as communication through airwave transmission), temporal context (including experiences over an individual's lifespan), and socio-economic and social values (Brown, 2014; AOTA, 2014). Environment is directly related to where a person lives, his or her community, and his or her personal prescriptive. A person's environment can either inhibit or enhance his or her occupational performance and participation (Law et al., 1996). Using the PMD app while incorporating ECM techniques can be used to modify the individual's environment. Through notifications, the PMD app can remind an

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individual to utilize strategies such as use of adaptive equipment or proper positioning in order to conserve energy throughout the task. The PMD app gives individuals the ability to monitor and track their progress throughout the day. Individuals can also virtually communicate with their health professionals by electronically sending their progress reports through the app.

The final component, occupation, is an activity or task in which an individual engages, which is both purposeful and meaningful. Individuals participate in daily activities that are needed to live functional lives (Brown, 2014; Law et al., 1996). Occupations are self-directed tasks undertaken by a person over his or her lifetime. An individual participates in unique and meaningful occupations within various contexts to reach self-maintenance, attain essential needs, and achieve fulfilment (Law et al., 1996). Examples of occupations include work, activities of daily living (such as grooming or bathing), instrumental activities of daily living (such as household management tasks (such as cooking, cleaning, and doing laundry), and leisure activities (such as riding a bicycle, hiking, or participating in sports). Using the PMD app and ECM techniques can modify the user's occupations so he or she can successfully complete the task. PMD allows the user to choose their optimal task duration based on the user's current energy level to perform a task and still have energy left over. PMD enables users to modify the occupation by completing only a portion of the task. Furthermore, the PMD app can encourage users to plan out their day and prioritize tasks according to when they have the most energy.

The PEO model is based on the assumption that in order to achieve occupational performance, there must be a goodness of fit between the variables of person, environment, and occupation. Goodness of fit is determined when person, environment, and occupation overlap to maximize participation and satisfaction in occupational performance (Brown, 2014; Dunbar, 2007; Law et al., 1996). A person, environment, and occupation have both an enabling and

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constraining effect on each other. Environments shape how a person interacts with different aspects of life and ascribe meaning and purpose to an individual's life. The more closely each component fits together, the greater the optimal occupational performance. However, if one component changes or becomes incompatible with the other two components, the fit among the three components decreases and a person's occupational performance is minimized. The PEO model provides OTs with an increased understanding of the relationships among the three components, increasing awareness of a person's physical, emotional abilities, and environment in order to facilitate optimal occupational performance and fit.

The theoretical framework of the PEO model guides this research study by considering a person, his or her environment, and occupation using a client-centered approach. The client-centered approach encourages an individual to self-direct and self-monitor tasks using the PMD app in order to achieve optimal occupational performance. An individual with MS may find it difficult to participate in daily life roles and complete tasks throughout the day because of fatigue, therefore, decreasing success in occupational performance. PMD may help self-manage energy levels throughout the day while the individual performs tasks. The customizability of the app allows individuals to plan activities throughout their day based on personal preference and the amount of energy required to complete a specific task. The PMD app allows a person to maintain energy and minimize fatigue by reminding the user to take frequent breaks during tasks and recommends inputted ECM techniques to increase occupational performance. Using the PMD app may help increase an individual's self-efficacy, utilize ECM techniques, and decrease levels of fatigue for individuals with MS.

The PEO model guides the identification of an individual's strengths and weaknesses in occupational performance, assesses performance components, environmental factors,

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occupations, and uses these findings to plan interventions (Law et al., 1996). The PEO model supports this research study by investigating whether the PMD app helps an individual to achieve optimal occupational performance, by using functions that consider a person's individual skills, environmental supports, task demands, occupations, and barriers that may prevent completion of a task.

Methodology

Design

This study used a quantitative, exploratory pretest-posttest design to examine whether individuals with MS report decreased levels of fatigue and consistent use of ECM techniques after using the mHealth intervention over a two-week period. Originally, the student researchers planned to utilize a quantitative, randomized control design comparing the outcomes between individuals with MS using a mHealth intervention on an iPhone and a control group without the mHealth intervention. Due to the small number of participants recruited, the study design was changed to a single-arm, pretest-posttest design, where all participants were enrolled in the mHealth intervention group. Over a 14-day period, all participants used the mHealth intervention (PMD app) for a single chosen activity each day while using ECM techniques. Pretest and posttest measures included the Canadian Occupational Performance Measure (COPM) and Modified Fatigue Impact Scale (MFIS). Additionally, posttest measures included post study questionnaires related to use of PMD app and ECM techniques.

Participants

Participants in this study included ten adults between the ages of 36 to 72 diagnosed with MS who live in Marin County. They were recruited from the National Multiple Sclerosis Society, Northern California Chapter and the Corte Madera MS support group through advertisements and snowball sampling. An electronic flyer was distributed through a mass email

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among all members affiliated with the National Multiple Sclerosis Society, Northern California Chapter (Appendix A). Twenty individuals who responded via email were prescreened for eligibility, and recruited through a 30-minute screening phone call (Appendix B). Inclusion criteria included individuals who: a) spoke English, b) were adults between the ages of 18 and 75, c) were able to follow step-by-step directions, d) had daily access to an iPhone e) self-reported ability to use smartphone applications, f) had been diagnosed with MS by a medical professional, g) self-reported mental and physical fatigue, and h) were able to walk independently, with or without use of an assistive device. If the inclusion criteria were not met, individuals were excluded from the study. There were no restrictions based on gender, race, ethnicity or socioeconomic status.

Ethical and Legal Considerations. Student researchers obtained approval to conduct the study from the Dominican University of California Institutional Review Board for the Protection of Human Participants (IRBPHP #10563) on February 15, 2017. The study followed the specific guidelines of the IRBPHP and all student researchers followed the American Occupational Therapy Association Code of Ethics, which upholds the principles of beneficence, autonomy and confidentiality and social justice for ethical decision making.

Under the principles of beneficence and nonmaleficence, all researchers must protect the well-being and security of participants by ensuring that no harm comes to them, protecting their rights, and promoting a positive recruitment and study environments (AOTA, 2015). Prior to commencing the study, the student researchers provided participants with a list of possible risks, which included emotional distress and frustration using the PMD app and potential increase in attention to fatigue levels. Researchers directed participants to the PMD website to watch training videos, and gave each participant a handout with a list of frequently asked questions

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(FAQ) regarding use of the app (Appendix C). If a participant became frustrated or was unable to use the PMD app, researchers directed him or her to watch training videos on the PMD website in order to decrease the participant's frustration. Participants were informed that if they wished to leave the study at any point, they could do so without repercussions. All research was conducted in a safe and confidential manner to ensure the safety of all participants.

AOTA (2015) explains that the principle of autonomy and confidentiality require respecting participant's rights, choices, and values while keeping identifying information confidential. Student researchers treated each participant with dignity and respect. Student researchers' responsibilities included creating a trusting, unbiased and collaborative relationship with the participants while providing individualized care for participants by listening to, and addressing their concerns. The student researchers allowed each participant to determine the best way to customize his or her own PMD app, enabling each participant to input specific tasks that cause the most fatigue and customized break suggestions. The individualized approach to the PMD app promoted further client participation in his or her own treatment. Allowing the participant to exercise his or her freewill ensured a lasting and supportive environment between researchers and all participants.

The principle of social justice requires that researchers provide services to every participant that are fair and equal (AOTA, 2015). Student researchers demonstrated the principle of social justice by advocating for participants, making the PMD app available and free for all participants. Moreover, all participants in the local MS community were encouraged to participate in the study.

To ensure informed consent, participants were provided with an overview of the study, and the opportunity to provide legal consent by signing a Consent to Be a Research Subject

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(Appendix D) form prior to the start of the study. Participants also received a copy of their Bill of Rights (Appendix E). Participants understood the nature of the research study and were notified that they could withdraw from the study at any time. To ensure confidentiality of the participants, no names were used during data collection or analysis. Each participant was assigned a letter that would be used on all data forms. A master list of the participants' names and letter was stored in a locked room in a locked drawer on-site at Dominican University of California. Only the student researchers and a faculty advisor were provided access to the data.

Description of Measures

This study utilized the Modified Fatigue Impact Scale (MFIS) and Canadian Occupational Performance Measure (COPM) to measure the benefits of using PMD and ECM techniques for adults with MS. One functional activity was determined with the COPM during pre-test. The MFIS determined levels of fatigue at baseline and during the final study visit. After the intervention, the COPM was administered and MFIS was completed to determine changes in self-perception of satisfaction and performance in the chosen activity and levels of fatigue.

Occupational performance and satisfaction measure. Self-perceived occupational performance and satisfaction were measured using the COPM. The COPM includes three different categories: self-care, productivity and leisure. The student researchers administered the COPM, pre and post intervention, through a semi-structured interview and structured scoring method. Two summary scores are derived from the COPM, one indicating self-perceived occupational performance and the other satisfaction with performance. The scores ranged from one to ten with ten being the highest level of self-rated satisfaction or performance.

Administration time for the COPM is about 20-40 minutes. Carswell, McColl, Baptiste & Law (2004) found strong test-retest reliability for both the performance and satisfaction scores when

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tested one week apart. The study reported correlation coefficients of 0.89 ($p < 0.001$) for performance and 0.88 ($p < 0.001$) for satisfaction.

Fatigue measure. Fatigue was measured using the MFIS. The MFIS is a 21-item instrument that measures physical, cognitive and psychosocial fatigue, specifically in individuals with MS and traumatic brain injury. Each item is answered on a 5-point Likert scale ranging from: never, rarely, sometimes, often, or almost always. A total score is obtained by summing the scores for each of the 21 items. Individual subscale scores are then categorized into: psychosocial, cognitive and physical fatigue. Higher scores indicate a higher level of experienced fatigue over a two-week period. The total administration time for the MFIS is about 20 minutes. The literature demonstrates that the MFIS has excellent internal consistency, reliability and adequate validity for measuring physical, cognitive and psychosocial domains of fatigue (National Multiple Sclerosis Society, 2016). The reported internal consistency Cronbach α values for each subscale were as follows: cognitive 0.95, physical 0.91 and psychosocial 0.81 (Larson, 2013).

Use of ECM measure. The participant's use of ECM will be measured by administering a post-study questionnaire (Appendix F). This questionnaire was developed by the student researchers and therefore, no initial psychometric properties have been established. The questionnaire consists of nine questions regarding each participant's experience using ECM techniques, their level of satisfaction after using the ECM techniques, and which techniques were found to be most useful.

Use of PMD app measure. Participants completed a PMD post-study questionnaire (Appendix G), developed by the student researchers, after the two weeks of using the app. The questionnaire consists of a total of eight questions, five of the questions are answered on a Likert

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scale ranging from zero to ten and three of the questions are self-reported responses. Data retrieved and analyzed from this questionnaire were used to determine whether the participants found the PMD app helpful in managing fatigue and if they were satisfied using the app or would consider recommending the app to others as well.

Study Process

Upon enrollment, participants were invited to the Dominican University of California campus to attend an orientation. The informed consent form and bill of rights were reviewed and signed by all participants. Participants who consented to participate were briefed on the purpose of the study, introduced to ECM techniques and oriented to the PMD app.

Measure administration. The student researchers administered the COPM and participants completed the MFIS to measure baseline levels of perceived performance and satisfaction in daily activities and levels of physical, cognitive and psychosocial fatigue within the past two weeks. Based on the results from the COPM, participants were asked to choose one activity as the focus of intervention to use the PMD app and ECM techniques with for two weeks.

Training on use of the app and ECM. After completion of the COPM and MFIS, the student researchers introduced ECM techniques and the PMD app. The student researchers based the ECM information on “Managing fatigue: a six week course for energy conservation” (Packer, Brink, & Sauriol, 1995) and received permission from Tanya Packer for using the information (Appendix H). The student researchers used the PMD app as part of the intervention with permission from the developer, Michelle Ranae Wild (Appendix I). During the training, the student researchers presented PowerPoints on ECM techniques (Appendix J) and the PMD app (Appendix K). Participants were given an ECM handout (Appendix L) to take home as a

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reminder to incorporate ECM techniques while performing their selected task. Several techniques were shared such as scheduling rest breaks, using proper body mechanics, and planning and prioritizing daily tasks. Next, participants downloaded PMD to their personal devices and were trained on how to utilize the app using training videos, and through demonstrations led by the student researchers. After the training, participants inputted his or her chosen task, how much time he or she thought it took to accomplish the task, and personal ECM techniques to use during a break, with assistance from the student researchers as needed. Student researchers instructed participants to set their current energy level and chose either an *optimal* or *modified* duration of time to complete the task. An *optimal* duration of time is the typical duration it takes the participant to complete a task when they are most energized. A *modified* duration of time is a shorter time period, derived by the PMD, based on the energy level the participant describes at the time of activity initiation when it is other than “most energized”. The participant is not expected to complete the task during the modified duration as the purpose of the modified time period is to incorporate a break sooner into the task to prevent fatigue. If the participant stops the task early on the app due to fatigue, he or she is prompted to take a break, encouraged to incorporate an ECM technique, and prompted to continue the task after.

Participants are also given the option to stop the timer on the app if the task is completed early, if he or she feels too tired, or if something interrupts the activity. Participants showed competency using the PMD app by demonstrating to the student researchers how to input tasks, start and end the tasks, and generate reports independently within the app. During the two-week intervention, participants were required to set their chosen task within the PMD app and perform that task when prompted by the app once a day. After the two-week period, the participants returned to Dominican University of California for a post-study follow up.

Data Collection

Raw data from the COPM and MFIS were collected on standardized assessment forms and stored in a locked drawer at Dominican University of California campus in the office of the faculty advisor. Participant demographic data, COPM, MFIS, and post-study questionnaires data were entered in a Microsoft Excel sheet, and analyses were conducted using SPSS.

Data Analysis

Data analyses using Statistical Package for the Social Sciences (SPSS) created descriptive statistics of quantitative data from the COPM, the MFIS, ECM and the PMD app post-study questionnaires. Next, a paired sample t-test was conducted to compare pretest and posttest scores of fatigue from the MFIS, and participant's overall performance and satisfaction in their chosen activity from the COPM. A two-tailed t-test was used to determine if there was a significant difference in the means of the pretest and posttest scores at a .05 significance level.

Results

The ages of participants ranged from 36 to 72 years. The mean age was 52 years. A total of ten participants were recruited for this study (nine females and one male) (Table 1). Out of the ten participants, two withdrew from the study after one week for personal reasons. One participant, prior to the change of the study design, was randomized into the control group and received instruction in ECM techniques without use of the PMD app. A total of seven participants completed the two-week intervention including the pretest and posttest assessments.

Table 1 Participant Demographics

	Age	Gender	Type of MS	Activity Chosen
All enrolled participants				
A	63	F	Relapse-Remitting	Home management
B	52	F	Relapse-Remitting	Dog walking
C	59	F	Relapse-Remitting	Financial management
D	44	F	Relapse-Remitting	Exercise/gym
E	36	F	Relapse-Remitting	Home management
F	61	F	Primary Progressive	Work
G	43	M	Relapse-Remitting	Running
H	72	F	Relapse-Remitting	Painting
I	50	F	Relapse-Remitting	Showering
J	47	F	Relapse-Remitting	Meal preparation

Note. n=10

Fatigue. Levels of fatigue decreased over the course of the two-week intervention. Using the MFIS to measure fatigue, participants reported a significant difference over the two-week period in their overall fatigue scores from pretest ($M = 43.86$, $SD = 7.15$) to posttest ($M = 25.29$, $SD = 13.49$), $t(6) = 5.75$, $p = 0.001$. Reduction in the average level of fatigue was indicated within all three categories of the MFIS. There was a decrease in physical fatigue from pretest ($M = 23.57$, $SD = 3.78$) to posttest ($M = 15.86$, $SD = 8.315$) resulting in a significant decrease $t(6) = 3.128$, $p = 0.015$. In addition, there was a significant decrease in cognitive fatigue from pretest ($M = 17.14$, $SD = 3.237$) to posttest ($M = 7.14$, $SD = 4.298$), $t(6) = 6.684$, $p = 0.001$. There was a decrease in psychosocial fatigue from pretest ($M = 3.14$, $SD = 0.80$) to posttest ($M = 2.29$, $SD = 1.380$), however this decrease was not significant $t(6) = 1.072$, $p = 0.325$ (Figure 1). These results suggest that use of the PMD app over the course of two weeks resulted in a lower level of fatigue.

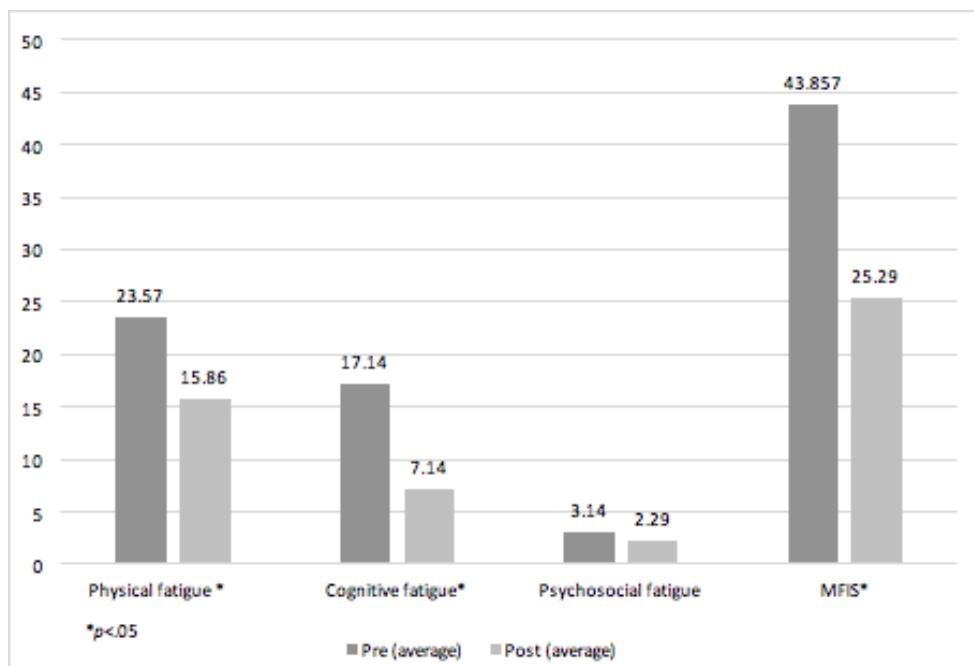


Figure 1. Results from the MFIS, pretest and posttest average scores for physical, cognitive and psychosocial fatigue.

Functional Performance and Satisfaction. The results of the COPM scores also showed a higher level of occupational satisfaction between the pretest ($M = 4.286$, $SD = 1.345$) and the posttest ($M = 7.000$, $SD = 3.266$), $t(6) = -3.359$, $p = 0.015$ (Figure 2). A higher number in satisfaction scores indicates an increase in self-perceived satisfaction in performance of their chosen activity. There was an increase in the self-perceived occupational performance of the chosen task from pretest ($M = 6.714$, $SD = 1.704$) to posttest ($M = 7.857$, $SD = 1.345$) with a marginal trend toward significance $t(6) = -2.066$, $p = 0.084$. Results compared individual's pretest and posttest scores from the MFIS and COPM (Table 2).

Table 2. Pretest and Posttest MFIS and COPM

	Mean	Standard deviation	Mean	Standard deviation	t-value	p-value
Total Fatigue	43.857	7.1514	25.29	13.487	5.753	.001*
Physical Fatigue	23.57	3.780	15.86	8.315	3.128	.020*
Cognitive Fatigue	17.14	3.237	7.14	4.298	6.684	.001*
Psychosocial Fatigue	3.14	2.116	2.29	1.380	1.072	.325
Satisfaction with Task	4.286	3.0394	7.000	3.2660	-3.359	.015*
Performance of task	6.714	1.7043	7.857	1.3452	-2.066	.084

Note. Data was analyzed for seven participants. * $p < .05$.

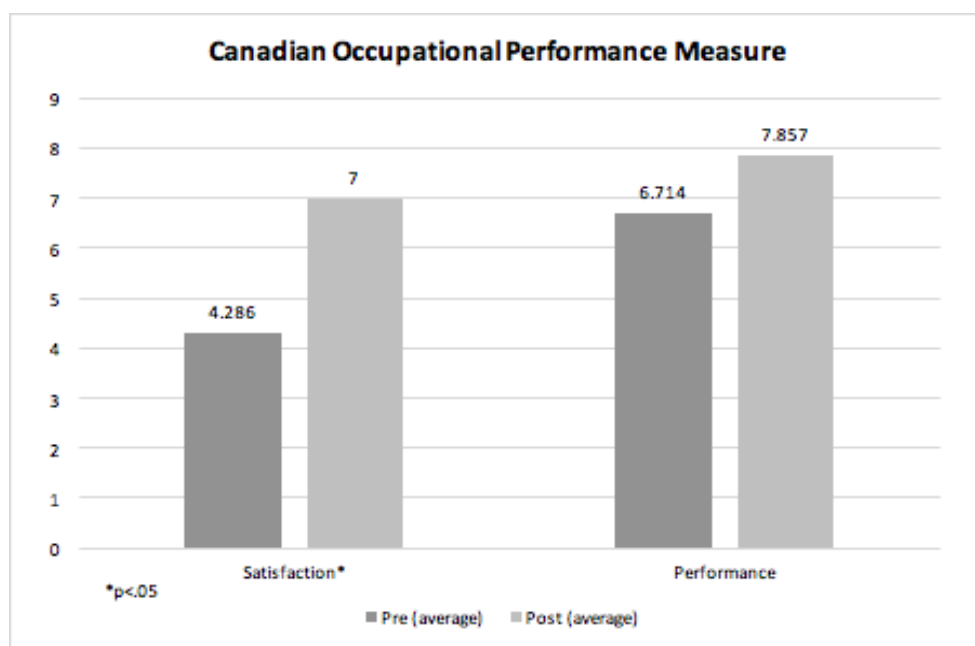


Figure 2 . Results from the COPM, pretest and posttest average scores for satisfaction and performance.

Testimonials

Testimonials from all participants were obtained using the PMD and ECM questionnaires during the post-study follow up session. The participants' testimonials were examined to determine their opinions about the ECM techniques and the PMD app. The participants' general consensus was that the ECM reminders built into the PMD app were helpful in managing their fatigue during their chosen task. Examples of reminders they felt were helpful were those that reminded them to take breaks, to use their ECM techniques and when to start the task. Participant F stated, "I like the concept of it and ideas of reminders and notifications" when asked about the most helpful part of the PMD app. Participant B reported that she found reminders within the app helpful in that they "adjusted my sleep patterns". A sense of increased responsibility was also reported by participant D stating, "It made me responsible" in regards to completing an exercise task.

Participants also identified what they least liked about the app and gave suggestions on how to improve navigation of the app. A common theme mentioned was that they experienced difficulty in navigating the app, which prevented some of the participants from engaging in their desired tasks. A suggestion to improve the navigability of the app was to "make the interface easier." Participant H indicated "I kept forgetting to start the actual task" as an issue she had while using the app. "Reminders were not consistent" was another complaint of the app reported by participant I.

Participants noted the specific ECM techniques they used most frequently during the two-week period as rest breaks, body mechanics, and prioritization. Additionally, participant A identified "breathing techniques", participant C said she used "balance training and meditation" and participant H reported "having snacks" as useful. A common suggestion reported by

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participants was that diet should have been included in the ECM technique orientation and handout. Another common report was that participants would recommend the ECM techniques to other individuals with MS.

In addition to identifying which ECM techniques the participants found helpful, the participants were asked to rate how often they used ECM during the task. Two participants indicated they “almost always” used ECM and five participants indicated they “sometimes” used ECM during their task. Furthermore, the participants were asked how satisfied they were with their experience in using ECM to help complete their task. Two of the participants were “extremely satisfied” and two other participants were “somewhat satisfied” with their experience using ECM to help complete their task. Two participants were “neither satisfied nor dissatisfied” and one was “somewhat dissatisfied” with their experience using ECM to help complete their chosen task.

Discussion

Results from this study support our hypothesis that use of mHealth apps decrease global levels of fatigue and increase performance and satisfaction in performance in activities. The primary objective of this study was to investigate whether a mHealth app in conjunction with ECM techniques will result in a decrease in MS-related fatigue. A secondary objective was whether a mHealth app would help increase performance and satisfaction levels in one’s chosen task.

There was a significant decrease in levels of physical, cognitive and global fatigue over the two-week intervention, therefore, confirming our hypothesis that use of a mHealth app paired with ECM techniques decreases levels of fatigue among individuals with MS. This finding suggests that physical fatigue can be decreased when incorporating ECM techniques such as proper positioning and body mechanics during tasks. Taking short, frequent breaks such as rest

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breaks throughout activities to conserve and restore energy can also decrease levels of physical fatigue. The PMD app allowed participants to manage and plan their day according to their level of physical fatigue and prompted participants to maximize their energy level by choosing the optimal duration of time needed to efficiently accomplish their task.

Additionally, results indicated a significant reduction in cognitive fatigue over the two-week intervention. These results indicate that using the PMD app with ECM techniques may have assisted participants focus their attention on one specific task, thus allowing them to organize their thoughts at their own pace. When breaks were prompted, the app gave participants an opportunity to incorporate mindfulness strategies such as meditation, listening to music or viewing a personal photo gallery. Integrating breaks throughout their day allowed participants to think more clearly, organize their thoughts more efficiently, and focus on task completion leading to decreased cognitive fatigue. Participants were able to break down their cognitively challenging tasks into smaller, more manageable components to be completed throughout the day. Breaking down tasks into steps appears to prevent individuals from becoming overwhelmed or stressed, promotes clear thoughts, and enhances the ability to problem solve and complete tasks.

Results also indicated a significant increase in levels of self-reported occupational satisfaction during the course of the study, suggesting that use of a mHealth app may increase satisfaction in one's chosen task. Participants identified that they were happier with their own overall level of satisfaction with performance for their chosen task which was indicated with a higher satisfaction score on the COPM. This may be due to the PMD app's ability to track and manage energy levels. Participants were able to use the customizable features of the app to identify the optimal length of time he or she wanted to complete the chosen task, but still have

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enough energy left over to participate in meaningful occupations, ultimately leading to increased satisfaction. Incorporating ECM techniques including breaks during the chosen task allowed participants to engage in their chosen task and attain their goal. Additionally, participants were able to utilize PMD to simplify their chosen task into manageable steps and pace themselves in order to conserve their energy before completing the next portion of the task.

Results also revealed that mean self-reported occupational performance was more positive in the posttest, although the results were not significant. These results suggest that although participants were able to complete their task, which may have resulted in a higher level of satisfaction, they may not have been able to meet their own performance expectations. This outcome may be due to a variety of factors. Based on participants' testimonials, participants felt that the app's reminders helped them initiate and complete the chosen task which may have helped to improve occupational performance. However, many factors contribute to level of occupational performance, including challenges associated with MS. Future studies utilizing a larger sample size, may help to shed light on factors contributing to the lower effect size for occupational performance.

Furthermore, results from this study corroborated past study results in which features in the mHealth design helped participants improve their personal goals. Reminders, notifications, personalization, and accessibility all appeared to help promote the use of ECM techniques, resulting in lower levels of MS-related fatigue. Participant testimonials support the effectiveness of these features in encouraging use of ECM techniques. The app allows the user to customize settings and input their own ECM strategies, resulting in more control in managing progress and task completion. As a result, these features of the PMD app, combined with the use of ECM

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techniques, are likely to contribute to improved levels of fatigue, which may increase self-efficacy and increase quality of life.

These current findings suggest that use of a mHealth app and ECM techniques can be an effective intervention in managing fatigue. Further research is needed to identify the long-term effects of mHealth apps on overall satisfaction and performance in a variety of activities, not just one activity performed throughout the day.

Implications for Occupational Therapy Practice

The results from this study indicate that individuals with MS would benefit from use of technology in the form of a mHealth app to support ECM techniques. Currently, many ECM techniques are for managing physical fatigue such as using proper body mechanics, pacing, and prioritizing. However, individuals with MS experience both physical and cognitive fatigue. OTs can create energy conservation programs specifically for individuals with MS that address different types of fatigue. OTs' knowledge on task analysis can help in designing individualized plans that manage cognitive fatigue for individuals with MS by incorporating strategies that participants suggested such as diet and meditation. Meditation and mindfulness techniques may reduce signs of stress, increase body awareness, self-awareness and improve concentration. Nutrition and maintaining a healthy diet may promote healthy brain development, increasing cognitive functioning. Incorporating personal strategies to into the mHealth app to decrease cognitive fatigue would allow OTs to create client-centered goals addressing global fatigue.

The notification and reminder aspects of mHealth apps can help individuals adhere to their intervention plan to improve occupational performance. The tracking and automatic documentation features of mHealth apps like PMD, allow individuals to track the status of their goals. Apps are a convenient and cost-effective tool for OTs to follow client progress and compliance towards short and long-term goals. For this reason, OTs are well suited to design

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future apps with more customizable notifications features that support client-centered interventions.

Limitations

The study aimed to analyze the effectiveness of the PMD app in combination with ECM techniques in decreasing levels of fatigue in adults with MS. Although the study has yielded preliminary findings, the study is not without limitations, as this study was a pilot program. An underlying limitation was the small sample size (n=7). All participants who participated in the study were recruited from Northern California. The small sample size was relatively homogenous and all seven participants were Caucasian female. Therefore, these results may not be generalizable to other individuals with MS including individuals with SPMS or CIS. Additionally, attrition was n=2 or 20% of the sample, which may threaten internal validity as the only male was one of the participants that dropped out. For future research, the researchers consider a larger sample size and expanding to multiple counties.

In addition to the small sample size, a lack of a control group was another limitation of this study. Low enrollment of participants led to a change in the overall design of the study, from a quantitative, randomized control design to a single-arm, pretest-posttest design which did not include a control group. Future research using a randomized control trial (RCT) may be able to assess the effectiveness of adherence to ECM techniques when using a mHealth app intervention compared to no mHealth intervention.

Conclusion

The ubiquity of having a smart phone and access to the internet has helped to promote the popularity of using mHealth apps as a form of assistive technology. As technology continues to make advancements, OTs will need to evaluate and incorporate assistive technology in the form

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of apps to decrease levels of MS-related fatigue and increase occupational performance and satisfaction in meaningful activities for individuals with MS. Engagement in occupations brings meaning and value to an individual's life. Unfortunately, for individuals with MS, MS-related fatigue significantly impacts participation in meaningful activities. While there are both pharmacological and nonpharmacological treatments to help manage fatigue, the effectiveness of these strategies remain to be established.

Fortunately, advancements in healthcare technology have led to the development of mHealth apps that can provide self-management strategies on a personal smartphone. ECM is a common and effective non-pharmacological approach that OTs use to help individuals manage fatigue when engaging in occupations. Using mHealth apps can be an effective tool for supporting ECM intervention. Overall, the student researchers found a significant reduction in global fatigue and an increase in self-perceived occupational performance and satisfaction with performance during everyday activities. These findings indicate that use of a mHealth app can potentially provide non pharmacological support to self-management strategies that decrease or even prevent fatigue.

The occupational therapy profession was founded on the vision that there is therapeutic value in occupations to maintain health. OTs enable individuals to achieve meaning and satisfaction in all areas of their lives. OTs are skilled in using activity analysis to grade activities and provide assistive devices to help support participation when necessary. Use of mHealth apps to support occupational therapy intervention is not currently common practice, however, the results from this study suggest that mHealth apps can be useful assistive technology tools. MS-related fatigue limits individuals with MS from fully engaging in activities that are meaningful to them. The use of a mHealth app coupled with ECM helped to decrease total fatigue, and allowed

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the participants to participate in his or her chosen occupations. Thus, the use of mHealth apps supports the vision of the occupational therapy profession as it supports meaningful engagement in life.

References

- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1-S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- American Occupational Therapy Association. (2015). Occupational therapy code of ethics. *American Journal of Occupational Therapy*, 69(Suppl. 3), 6913410030. doi:10.5014/ajot.2015.696S03
- Asano, M., & Finlayson, M. L. (2014). Meta-analysis of three different types of fatigue management interventions for people with multiple sclerosis: Exercise, education, and medication. *International Journal of Medicinal Chemistry*, 1-12. doi:10.1155/2014/798285
- Ayache, S., & Chalah, M. (2017). Fatigue in multiple sclerosis-insights into evaluation and management. *Clinical Neurophysiology*, 47, 139-171.
- Blikman, L., Huisstede, B., Kooijmans, H., Stam, H., Bussmann, J., & Meeteren, J. (2013). Effectiveness of energy conservation treatment in reducing fatigue in multiple sclerosis: A systematic review and meta-analysis. *Archives of Physical Medicine and Rehabilitation* 94, 1360-1376.
- Bishop, M., & Rumrill, P. D. (2015). Multiple sclerosis: Etiology, symptoms, incidence and prevalence, and implications for community living and employment. *Work*, 52(4), 725-734. doi:10.3233/WOR-152200
- Brown, C. (2014). Ecological models in occupational therapy. In Schell, B., Gillen, G., & Scafa, M. (Eds.), *Willard and spackman's occupational therapy 12th edition* (pp. 494-503). Philadelphia, PA. Lippincott Williams & Wilkins.
- Bruce, J., Bruce, A., & Arnett, P. (2010). Response variability is associated with self-reported

- cognitive fatigue in multiple sclerosis. *Neuropsychology*, 24(1), 77-83. doi: 10.1037/a0015046
- Carswell, A., McColl, M., Baptiste, S., Law, M. (2004). The canadian occupational performance measure: A research and clinical literature review. *The Canadian Journal of Occupational Therapy*, 71(4), 210-222.
- Costa, D., Campbell, M. Yarvi, M. Cardell, B. (2014). Personal Assistance: Using Mobile Apps and other Technology with Brain injury. *OT Practice*, 19(17), 19-20. Retrieved from <http://www.aota.org/~media/Corporate/Files/Secure/Publications/OTP/2014/OTP%20Vo19%2019%20Issue%2017.pdf>
- D'Amico, E., Leone, C., Hayrettin, T., & Patti, F. (2016). Can we define a rehabilitation strategy for cognitive impairment in progressive multiple sclerosis? A critical appraisal. *Multiple Sclerosis Journal*, 22(5), 581-589. doi:10.1177/1352458516632066
- Dayapoglu, N., & Tan, M. (2012). Evaluation of the effect of progressive relaxation exercises on fatigue and sleep quality in patients with multiple sclerosis. *Journal of Alternative & Complementary Medicine*, 18(10), 983-987. doi:10.1089/acm.2011.0390
- DeLuca, J., Genova, H., Hillary, F., & Wylie, G. (2010). Neural correlates of cognitive fatigue in multiple sclerosis using functional MRI. *Journal of the Neurological Sciences*, 270, 28-39. doi:10.1016/j.jns.2008.01.018
- Dirette, D. (2012). Progressive neurological disorders. In Atchison, B., & Dirette, D. (Ed.), *Conditions in occupational therapy* (pp 210-212). Philadelphia, PA: Lippincott Williams & Wilkins.
- Dunbar, S.B. (2007). Occupational therapy models for intervention with children and families. Thorofare, NJ: Slack, Inc.

MANAGING FATIGUE WITH TECHNOLOGY

Eilertsen, G., Ormstad, H., Kirkevold, M., Mengshoel, A. M., Söderberg, S., & Olsson, M.

(2015). Similarities and differences in the experience of fatigue among people living with fibromyalgia, multiple sclerosis, ankylosing spondylitis and stroke. *Journal of Clinical Nursing, 24*(13-14), 2023-2034.

Eyssen, I., Steultjens, M., de Groot, V., Steultjens, E., Knol, D., Polman, C., & Dekker, J.

(2013). A cluster randomized controlled trial on the efficacy of client-centered occupational therapy in multiple sclerosis: good process, poor outcome. *Disability and Rehabilitation, 35*(19), 1636-1646.

Faguy, K. (2016). Multiple sclerosis: An update. *Radiologic Technology, 87*(5), 529-553.

Foti, D. (2013). Degeneration Diseases of the Central Nervous System. In Mchugh, P., &

Schultz-Krohn, W. (Ed), *Pedretti's occupational therapy: Practice skills for physical dysfunction. 7th edition* (pp. 936-938). St. Louis, MO: Mosby Elsevier.

Franklin, V. L., Waller, A., Pagliari, C., & Greene, S. A. (2006). A randomized controlled trial of

Sweet Talk, a text-messaging system to support young people with diabetes. *Diabetic Medicine, 23*(12), 1332-1338.

Gibbons, M. C., Wilson, R. F., Samal, L., Lehmann, C. U., Dickersin, K., Lehmann, H. P., ... &

Bass, E. B. (2009). Impact of consumer health informatics applications.

Goodrich, B., & Garza, E. (2015). The role of occupational therapy in providing assistive

technology devices and services. Retrieved from <https://www.aota.org/About-Occupational-Therapy/Professionals/RDP/assistive-technology.aspx>

Habibi, M., & Kuttub, H. M. (2016). Management of multiple sclerosis and the integration of

related specialty pharmacy programs within health systems. *American Journal of Health-System Pharmacy, 73*(11).

MANAGING FATIGUE WITH TECHNOLOGY

- Jalón, E. G., Lennon, S., Peoples, L., Murphy, S., & Lowe-Strong, A. (2012). Energy conservation for fatigue management in multiple sclerosis: A pilot randomized controlled trial. *Clinical Rehabilitation*, 27(1), 63-74. doi:10.1177/0269215512446495
- Klasnja, P., & Pratt, W. (2012). Methodological Review: Healthcare in the pocket: Mapping the space of mobile-phone health interventions. *Journal of Biomedical Informatics*, 45, 184-198. doi:10.1016/j.jbi.2011.08.017
- Knoop, H., van Kessel, K., & Moss-Morris, R. (2012). Which cognitions and behaviours mediate the positive effect of cognitive behavioural therapy on fatigue in patients with multiple sclerosis? *Psychological Medicine*, 42(1), 205-213. doi:10.1017/S0033291711000924
- Kos, D., Duportail, M., Meirte, J., Meesus, M., D'hooghe, M., Nagels, G, ... NijS., J (2016). The effectiveness of a self-management occupational therapy intervention on activity performance in individuals with multiple sclerosis-related fatigue: a randomized-controlled trial. *International Journal of Rehabilitation Research*, 39(3), 252-262.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment occupational model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*. 63(1), 2-23.
- Larson, R. (2013). Psychometric properties of the modified fatigue impact scale. *International Journal of MS Care*, 15(1), 15-20. doi:10.7224/1537-2073.2012-019
- Lublin, F., Reingold, S., Cohen, J., Cutter, G., Sorensen, P., Thompson, A., Wolinsky, J.,...Polman, C. (2014). Defining the clinical course of multiple sclerosis. *Neurology*, 83, 278-286.
- Maitra, K., Hall, C., Kalish, T., Anderson, M., Dugan, E., Rehak, J., et al. (2010). Research Scholars Initiative— Five-year retrospective study of inpatient occupational therapy

MANAGING FATIGUE WITH TECHNOLOGY

- outcomes for patients with multiple sclerosis. *American Journal of Occupational Therapy*, 64, 689–694. doi: 10.5014/ajot.2010.090204
- Matuska, K., Mathiowetz, V., & Finlayson, M. (2007). Use and perceived effectiveness of energy conservation strategies for managing multiple sclerosis fatigue. *American Journal of Occupational Therapy*, 61(1), 62-69. doi:10.5014/ajot.61.1.62
- Mäurer, M., Comi, G., Freedman, M. S., Kappos, L., Olsson, T. P., Wolinsky, J. S., . . . O'Connor, P. W. (2016). Multiple sclerosis relapses are associated with increased fatigue and reduced health-related quality of life – A post hoc analysis of the TEMSO and TOWER studies. *Multiple Sclerosis and Related Disorders*, 7, 33-40.
doi:10.1016/j.msard.2016.02.012
- Mayo Foundation for Medical Education and Research (2017). Multiple Sclerosis. Retrieved from <http://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/home/ovc-20131882>
- Moore, C. (2016). 'My MS Manager' Named One of Best Apps for MS for 4th Year. Retrieved September 27, 2016, from <https://multiplesclerosisnewstoday.com/2016/07/28/my-ms-manager-named-one-of-the-best-ms-apps-of-2016/>
- National Alliance on Mental Illness. (n.d.) *Psychotherapy*. Retrieved from <http://www.nami.org/Learn-More/Treatment/Psychotherapy>
- National Multiple Sclerosis Society. (2016). Retrieved from <http://www.nationalmssociety.org/>
- National Multiple Sclerosis Society. (2017-a). What causes MS. Retrieved from <https://www.nationalmssociety.org/What-is-MS/What-Causes-MS>
- National Multiple Sclerosis Society. (2017-b). Types of MS. Retrieved from <https://www.nationalmssociety.org/What-is-MS/Types-of-MS>

MANAGING FATIGUE WITH TECHNOLOGY

- Niepel, G., Bibani, R. H., Vilisaar, J., Langley, R. W., Bradshaw, C. M., Szabadi, E., & Constantinescu, C. S. (2013). Association of a deficit of arousal with fatigue in multiple sclerosis: Effect of modafinil. *Neuropharmacology*, *64*, 380-388.
- Noonan, C.W., Williamson, D.M., Henry, J.P., Indian, R., Lynch, S.G., Neuberger, J.S., et al. (2010). The prevalence of multiple sclerosis in 3 US communities. *Preventing Chronic Disease*, *7*(1). Retrieved from <http://www.cdc.gov/pcd/Issues/2010>.
- Noonan, V. K., Cook, K. F., Bamer, A. M., Choi, S. W., Kim, J., & Amtmann, D. (2012). Measuring fatigue in persons with multiple sclerosis: Creating a crosswalk between the modified fatigue impact scale and the PROMIS fatigue short form. *Quality of Life Research*, *21*(7), 1123-1133. doi:10.1007/s11136-011-0040-3
- Nunnari, D., De Cola, M., D'Aleo, G. Rifici, C., Russo, M., Sessa, E.,... Marino, S. (2015). Impact of depression, fatigue, and global measure of cortical volume on cognitive impairment in multiple sclerosis. *BioMed Research International*, doi:10.1155/2015/519785
- Packer, T. L., Brink, N., Sauriol, A. (1995) Managing fatigue a six-week course for energy conservation. Tucson, AZ: Therapy Skill Builders
- Payne, H. E., Lister, C., West, J. H., & Bernhardt, J. M. (2015). Behavioral functionality of mobile apps in health interventions: a systematic review of the literature. *JMIR mHealth and uHealth*, *3*(1), e20.
- Petruzzello, S. J., & Motl, R. W. (2011). Acute moderate-intensity cycling exercise is associated with reduced fatigue in persons with multiple sclerosis. *Mental Health And Physical Activity*, *4*(1), 1-4. doi:10.1016/j.mhpa.2011.04.002
- Pew Research Center. (2017). Mobile Fact Sheet. Retrieved from

MANAGING FATIGUE WITH TECHNOLOGY

<http://www.pewinternet.org/fact-sheet/mobile/>

- Preissner, K., Arbesman, M., & Lieberman, D. (2016). Occupational therapy interventions for adults with multiple sclerosis. *American Journal of Occupational Therapy, 70*(3). doi: 10.5014/ajot.2016.703001
- Preston, J., Haslam, S., & Lamont, L. (2012). What do people with multiple sclerosis want from an occupational therapy service? *British Journal of Occupational Therapy, 75*(6), 264-270.
- Ramanathan, N., Swendeman, D., Comulada, W. S., Estrin, D., & Rotheram-Borus, M. J. (2013). Identifying preferences for mobile health applications for self-monitoring and self-management: Focus group findings from HIV-positive persons and young mothers. *International journal of medical informatics, 82*(4), e38-e46.
- Rogers, J. M., & Panegyres, P. K. (2007). Cognitive impairment in multiple sclerosis: evidence-based analysis and recommendations. *Journal of Clinical Neuroscience, 14*(10), 919-927.
- Schmidt, S., & Wonneberger, M. (2014). Long-term endurance exercise improves aerobic capacity in patients with relapsing–remitting multiple sclerosis: Impact of baseline fatigue. *Journal Of The Neurological Sciences, 336*, 29-35. doi:10.1016/j.jns.2013.09.035
- Silva, B. M., Rodrigues, J. J., de la Torre Díez, I., López-Coronado, M., & Saleem, K. (2015). Mobile-health: a review of current state in 2015. *Journal of biomedical informatics, 56*, 265-272.
- Smith, E., Lai, J., & Cella, D. (2010). Building a measure of fatigue: the functional assessment of chronic illness therapy fatigue scale. *American Academy of Physical Medicine and Rehabilitation, 2*, 359-363.
- Tur, C. (2016). Fatigue management in multiple sclerosis. *Current Treatment Options In*

Neurology, 18(6), 1. doi:10.1007/s11940-016-0411-8

Turner, A. P., Hartoonian, N., Sloan, A. P., Benich, M., Kivlahan, D. R., Hughes, C., et al.

(2016). Improving fatigue and depression in individuals with multiple sclerosis using telephone-administered physical activity counseling. *Journal of Consulting and Clinical Psychology*, 84(4), 297-309.

Van Kessel, K., Babbage, D. R., Reay, N., Miner-Williams, W. M., & Kersten, P. (2017). Mobile technology use by people experiencing multiple sclerosis fatigue: Survey methodology. *JMIR mHealth and uHealth*, 5(2).

Visone, C., Wild, M., Pasino, J., Patterson, T., & Trofilmova, S. (2015). Learning to implement the ManageMyFatigue app in brain injury rehabilitation. Retrieved from:

<http://managemyfatigue.com/home/research/learn-to-implement-PMD/>

Wenneberg, S., Isaksson, A., & Rn. (2014). Living with multiple sclerosis: The impact of chronic illness. *Nordic Journal of Nursing Research & Clinical Studies / Vård i Norden*, 34(3), 23-27.

Yang, T. T., Wang, L., Deng, X. Y., & Yu, G. (2017). Pharmacological treatments for fatigue in patients with multiple sclerosis: A systematic review and meta-analysis. *Journal of the Neurological Sciences*, 380, 256-261.

Appendix A- Flyer to Participants



Dominican University Occupational Therapy Study



MICHELLE, DIAGNOSED IN 2001

"Do you experience chronic fatigue as a result from multiple sclerosis (MS)?"

"Would you like to learn how to utilize your smartphone to help manage fatigue and overexertion?"

Dominican University occupational therapy research team is currently looking for adults that have been diagnosed with MS who experience daily fatigue to participate in a research study on the benefits of using mobile health apps in managing fatigue.

Study Details

The entire study will take place over the course 2 weeks. Participants will be invited to the Dominican university campus for an initial interview and to download the app along with training on energy conservation and how to use the app itself. After two weeks of using the app, participants will be invited back on campus for a post interview and data collection.

Benefits of participating in this study

1. A chance to enhance your everyday participation in activities through new strategies
2. A complimentary download of the app as well as a chance to win prizes (gift card drawing).
3. Education about energy conservation strategy techniques to help manage fatigue.
4. An opportunity to connect with others with MS in the community.

Eligibility

We are looking for Adults (18+) who have been diagnosed with MS and currently experiencing fatigue as a result. Participants should have their own smartphone (iPhone), have reliable transportation to the campus, and be fluent in English.

Sign Up

If interested, please email: America Ortega at capstonefatigue@gmail.com

Appendix B- Recruitment Screening Questions

RECRUITMENT SCREENING QUESTIONS

Screening questions will be incorporated to help determine Inclusion/Exclusion criteria for the research study.

Target population: MS individuals (over 18). Have cognitive ability to use mobile phone apps. Demonstrate some level of fatigue in daily tasks.

Script:

Hello thank you for reaching out to us: We are calling to talk with you about the research study addressing the use of technology to manage fatigue and to determine you if you meet the criteria to participate. on behalf of the research team at Dominican University. If you are a good fit we would like to ask if you would be interested in participating in a research study addressing technology and fatigue in MS. Is this a good time to talk right now?

(If Yes, proceed to next question. If no, thank them for their time and terminate call)

Thank you I will ask you the following questions to determine if you would be a good fit for this study. You can simply answer Yes or No or go into more detail if you wish.

1. Have you been diagnosed with multiple sclerosis? Can you tell me when? (optional)

(if Yes, proceed to next question. If no, thank them for their time and terminate call)

2. Has fatigue from MS affected any aspect of your performance in your daily living routine?

(if Yes, proceed to next question. If no, thank them for their time and terminate call)

3. Do you currently use an iPhone and its applications (such as Facebook, online banking)?

(if Yes, proceed to next question. If no, thank them for their time and terminate call)

4. Would you be interested in learning how to better manage your fatigue using a mobile app?

(If Yes, but inquiries about more detail about the app (ex. “tell me more”)

- **The app is known as *Pace My Day* a self-management app that helps organize your tasks throughout the day according to your optimal energy level.**

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- **The app also can help manage your fatigue by monitoring how long you have been working on a task (also known as time on task) and including notifications to take a break when needed**
- **For example, if one was planning to undergo a strenuous task such as mowing the lawn, the app can be set up to give personalized reminders and notifications as to when to take a break or use pre-planned strategies to conserve energy such as simplifying the task by breaking up the activity into smaller tasks.**

-

(if Yes and with no details requested, proceed to next question. If no, thank them for their time and terminate call)

5. Do you have reliable transportation to come in for an afternoon orientation at our Dominican University campus in San Rafael? The orientation will provide training on the use of the app and some energy conservation strategies as well as an interview on how fatigue affects your everyday life? **(If Yes, but inquiries about more detail about the orientation)**

- **We require that you join us for an afternoon orientation session where you will get to learn more about the app and some OT strategies for energy conservation for MS.**
- **The entire session should take no longer than 2 hours and will include a presentation on the use of the app itself, energy conservation strategies, and an interview to address your individual needs (COPM).**

(if Yes with no details requested, proceed to next question. If no, thank them for their time and terminate call)

6. Upon arrival to our campus for the orientation, you will have a chance to learn more about our study and then decide whether to participate or not by signing an informed consent form at the end of the orientation. Does that seem clear to you?

(if Yes with details requested)

You will have the opportunity to decide at any time during the orientation not to participate in this study and withdrawal whenever you please, however if you would like to be a part of this study you will be required to review and sign an informed consent form allowing us to acknowledge you as a research participant and subsequently gather necessary data for our research study

If no, thank them for their time and terminate call)

7. You are over 18 correct?

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(if Yes through 1-7, give information about the study, its purpose, and timeline. Thank them and ask about their availability.)

Thank you for your time and cooperation.

Appendix C- FAQ Handout

Pace My Day FAQ Handout

If you do not see one of your questions below, feel free to write down questions and bring to the next meeting.

Why should I use the PMD app?

- PMD is designed to help individuals dealing with low energy, fatigue, and pacing issues. It helps keep you on track and prevents you from overdoing it to the point of wiping yourself out.

What kind of tasks should I put in the PMD app?

- You should include tasks in the PMD app that you believe deplete your overall energy. The app allows you to customize its categories and tasks.

Why do I have to categories my tasks?

- Categorizing tasks will help you find specific tasks easier, especially when you have more than just a few tasks.

Should I set Task Reminders in the Settings area?

- Setting task reminders will help you remember to check the app throughout the day to monitor what you have worked on and what you still need to do.

Should I set PMD to add tasks to my calendar?

- This is a very popular feature and will allow you to see patterns by just looking in your Calendar app.

Where can I go to watch PMD tutorials?

- <https://bestconnections.org/>

What happens if I can't finish my tasks for the day because of fatigue?

- The great thing about the PMD app is you can set up and complete tasks based on your amount of energy. If you are unable to finish tasks, don't try and push through. Try modifying the optimal duration time to complete the task so you still have energy left over. Additionally, try taking a short break from your task and complete the rest of the task when you can. Nothing says that you have to complete all tasks in one sitting.

What if I don't have the energy to finish or return to a task?

- The PMD app allows you to input strategies and notes about certain tasks to help you get started, stay on track, and help keep you are track. Refer to the Energy Conservation handout for an additional list of strategies to help maximize energy levels.

What are some signs of fatigue?

- Chest pain, shortness of breath, irregular or fast heartbeat, feeling that you might pass out, severe abdominal, pelvic or back pain.

Appendix D- Consent form to be a Research Participant**DOMINICAN UNIVERSITY OF CALIFORNIA
CONSENT FORM TO BE A RESEARCH PARTICIPANT**Purpose and Background

May Anne Gamueda, Janie Grant, America Ortega, and Jordan Song, students from the Department of Occupational Therapy at Dominican University of California are conducting a research study designed to assess if the use of the mHealth app Pace My Day (PMD) can increase use of energy conservation strategies to reduce levels of fatigue among adults with multiple sclerosis. This research is a capstone research project for Ms. May Anne Gamueda, Ms. Janie Grant, Ms. America Ortega, and Mr. Jordan Song at Dominican University of California, California. This research project is being supervised by Dr. Susan Morris, PhD, OTR/L, Assistant Professor, Occupational Therapy, Dominican University of California.

Procedures

If I agree to be a participant in this research study, the following will occur:

1. I understand that all of the study's procedures will take place at Dominican University of California, located at 50 Acacia Avenue, San Rafael, California or at my home.
2. I understand the PMD app is an app that will assist me in my self-management goals and learning energy conservation strategies that will help me manage my fatigue.
3. I understand that participating in this research study will involve taking part in a two week study. I understand I will be asked for approximately one hour of my time for the initial training session and for one hour of my time for the final meeting session.
4. I understand that participation in this study will involve a 30 minute in-person assessment sharing thoughts and feelings of living with multiple sclerosis.
5. I understand I will spend time learning how to use the PMD app and energy conservation techniques.
6. I understand that I will use the PMD application for approximately one hour a day on a task of my choosing and complete the task to the best of my abilities. I understand that I must document and report my breaks, strategies used, optimal duration (in minutes) it took me to complete the task, required energy levels, and notes regarding the task.
7. I understand I will be asked for approximately 3-5 minutes of my time each night for two weeks to fill out the bedtime questionnaire on the app.

Risks and/or Discomforts

1. I understand that I will be discussing topics of a personal nature and that I may refuse to answer any question that causes me distress or seems an invasion of my privacy.
2. I understand that my participation in this study involves no physical risks using the PMD application itself. I understand that the PMD app may be difficult to use and/or may experience an increase in fatigue levels as a result of increased attention to fatigue. If I

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experience any problems or distress due to my participation, I will look frequently asked questions handout and write down any questions or concerns to take with me to the follow-up meeting.

3. I understand that I may refuse to participate and withdraw from the study at any time before, during, or after the study begins without any adverse consequences.

Benefits

The anticipated benefits of this study include:

1. I may see improvements in levels of fatigue and increased self-management of symptoms when completing everyday tasks.
2. I may learn energy conservation strategies that will greater increase independence in my daily occupations.
3. I may provide support and help for other individuals with MS in my community.

Questions

I understand that if I have any further questions about the study, I may contact the student researchers at capstonefatigue@gmail.com or their faculty supervisor, Dr. Susan Morris at Department of Occupational Therapy, Dominican University of California at susan.morris@dominican.edu.

If I have further questions or comments about participation in this study, I may contact the Dominican University of California Institutional Review Board for the Protection of Human Participants (IRBPHP), which is concerned with the protection of volunteers in research projects. I may reach the IRBPHP Office by calling (415) 482-3547 and leaving a voicemail message, by FAX at (415) 257-0165 or by writing to the IRBPHP, Office of the Associate Vice President for Academic Affairs, Dominican University of California, 50 Acacia Avenue, San Rafael, CA 94901.

Consent:

I have been given a copy of this consent form, signed and dated, to keep for my future reference.

I understand participation in this research study is voluntary. I understand I can withdraw my participation at any time without fear of adverse consequences. All procedures related to this research project have been satisfactorily explained to me prior to my voluntary election to participate.

I have read and understand all of the above explanation regarding this study. I voluntarily give my consent to participate.

I HAVE READ AND UNDERSTAND ALL OF THE ABOVE EXPLANATION

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REGARDING THIS STUDY. I VOLUNTARILY GIVE MY CONSENT TO PARTICIPATE. A COPY OF THIS FORM HAS BEEN GIVEN TO ME FOR MY FUTURE REFERENCE.

PARTICIPANT'S NAME (PRINTED)

Date

PARTICIPANT'S SIGNATURE

Date

STUDENT RESEARCH'S SIGNATURE

Date

Appendix E- IRBPHS Research Participant's Bill of Rights**IRBPHS RESEARCH PARTICIPANT'S BILL OF RIGHTS**

Every person who is asked to be in a research study has the following rights:

1. To be told what the study is trying to find out;
2. To be told what will happen in the study and whether any of the procedures, drugs or devices are different from what would be used in standard practice;
3. To be told about important risks, side effects or discomforts of the things that will happen to her/him;
4. To be told if s/he can expect any benefit from participating and, if so, what the benefits might be;
5. To be told what other choices s/he has and how they may be better or worse than being in the study;
6. To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study;
7. To be told what sort of medical treatment is available if any complications arise;
8. To refuse to participate at all before or after the study is stated without any adverse effects. If such a decision is made, it will not affect him/her rights to receive the care or privileges expected if s/he were not in the study.
9. To receive a copy of the signed and dated consent form;
10. To be free of pressure when considering whether s/he wishes to be in the study.

If you have questions about the research you may contact us at capstonefatigue@gmail.com. If you have further questions you may contact my research supervisor, Dr. Susan Morris, susan.morris@dominican.edu or the Dominican University of California Institutional Review Board for the Protection of Human Subjects (IRBPHS), which is concerned with protection of volunteers in research projects. You may reach the IRBPHS Office by calling (415) 482-3547 and leaving a voicemail message, or FAX at (415) 257-0165, or by writing to IRBPHS, Office of Associate Vice President for Academic Affairs, Dominican University of California, 50 Acacia Avenue, San Rafael, CA 94901

Appendix F- Post-Study Questionnaire for Energy Conservation

Energy Conservation Management Questionnaire

On a scale from 0 to 10, how would you rate the helpfulness of the energy conservation workshop from orientation?

0 being not helpful at all and 10 being very helpful

0 1 2 3 4 5 6 7 8 9 10

On a scale from 0 to 10, how would your rate the helpfulness of the energy conservation handout in managing your fatigue during your task?

0 being not helpful, 10 being very helpful, and N/A being handout was lost

0 1 2 3 4 5 6 7 8 9 10 N/A

How often did you to refer to the energy conservation strategies handout during your task?

Always Almost always Sometimes Almost Never Never

On a scale from 0 to 10, how beneficial would notifications or reminders be in incorporating energy conservation strategies into your task?

0 being not beneficial to 10 being very beneficial to have reminders

0 1 2 3 4 5 6 7 8 9 10

How often did you use energy conservation strategies during your task?

Always Almost always Sometimes Almost Never Never

What was one energy conservation strategy that worked best?

If you did not use energy conservation strategies, what other strategies did you use to complete your task?

Overall, how satisfied were you with your experience using energy conservation handout and

Appendix G- Post-Study Questionnaire for Pace My Day

Pace My Day App Questionnaire

On a scale from 0 to 10, how would you rate the helpfulness of the Pace My Day App in helping to manage your fatigue?

0 being not helpful at all and 10 being very helpful

0 1 2 3 4 5 6 7 8 9 10

On a scale from 0 to 10, how would your rate the helpfulness of the Pace My Day App in helping you remember energy conservation techniques to use in completing your task?

0 being not helpful and 10 being very helpful

0 1 2 3 4 5 6 7 8 9 10

On a scale from 0 to 10, how would you rate the ease of using the app?

0 being not easy to use and 10 being very intuitive to use

0 1 2 3 4 5 6 7 8 9 10

What did you like most about the Pace My Day app?

What did you like the least about the Pace My Day app?

If you could change one thing about the app, what would it be and why?

Overall, how satisfied were you with your experience using the Pace My Day app to help complete your task?

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Extremely Satisfied

Somewhat Satisfied

Neither Satisfied nor Dissatisfied

Somewhat Dissatisfied

Extremely Dissatisfied

How likely are you to recommend the Pace My Day app to someone with multiple sclerosis?

Extremely Likely


Very likely

Moderately Likely

Slightly Likely

Not at all

Appendix H- Permission Email from Tanya Packer

 **Tanya Packer** 4:01 PM (18 hours ago) ☆ [Reply](#) ▾
to me ▾

Dear May Anne

I give permission for you to include the information that you have sent to me in your thesis. I note that it has been properly referenced and therefore, I am happy for you to include this in your thesis.

I would also be very interested to read your thesis. Would you be able to send me a link to the electronic version of your thesis? We are about to embark on a study comparing online, individual and group formats. Your work may provide us with additional information and considerations.

Good luck with the final stages of your degree.

...

Tanya

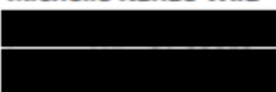
Tanya Packer, PhD, OT Reg(NS)
Professor
Director (Interim), School of Health Administration
Assistant Dean, Partnerships (Interim), Faculty of Health
Vice Chair, Student Affairs, Dalhousie Senate

Appendix I- Permission Letter from Michelle Ranae Wild



Connecting you to the BEST training, techniques, and technology for your brain

Michelle Ranae Wild



michelle@bestconnections.org

6th February 2017

Janie Grant



Dear Janie,

This letter is to confirm my approval of your use of the PaceMyDay app and all of its components, including the Bedtime Questionnaire for research purposes.

Please let me know if you have any questions or need anything else. I'm happy to help in anyway I can be of assistance.

Sincerely,

Michelle Wild

Michelle Ranae Wild
Brain Education Strategies and Technology
ID 4 the Web

Appendix J- Energy Conservation Management PowerPoint

Managing Fatigue

Welcome!

- Introductions
- Energy Conservation Tips
- Energy Conservation Bingo

Introductions

What is your name?

Where are you from?

One fun fact

What is "Fatigue"?

"Fatigue is a sense of physical tiredness and lack of energy, distinct from sadness or weakness."
(Krupp et al. 1988)

What is "fatigue" to you?

Energy Conservation - Banking Energy -

To bank energy is to conserve energy

What are ways you use to bank energy?

Banking Energy

Rest	Planning activities
Proper body mechanics	Pacing
Organization	Technology
Simplification	

Rest

Rest is a way to conserve energy

Rest is also a way to restore energy

Ways to Rest

- Sit down
- Lie down
- Quiet activities

How do you like to rest?

Rest

Rest before becoming fatigued

Take short rests frequently

Different types of rest are appropriate at different times of the day or during different activities

Schedule rest into your day

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Proper Body Mechanics

Standing

- Feet shoulder width apart, weight even in both feet
- Bend knees slightly
- Relax arms close to body

Sitting

- Feet flat on floor
- Hips and knees bent at 90-degree angle
- Sit close to desk

Proper Body Mechanics

Lifting and carrying

- Use strongest muscles - your legs!
- Squat
- Hold object close to body - near chest

Avoid it by:

- Using a cart
- Using a bag
- Sliding

Planning and Prioritizing

Questions to ask yourself when planning and prioritizing your day:

- What needs to be done?
- What do I like to do?
- What is expected of me today?
- How much energy does each activity take?
- What can I eliminate?
- Who else can do this activity?

Creating a balanced life

When planning your day it is important to create a balance among:

- Self-care
- Productivity
- Leisure

Take away

- Alternate light and heavy activities
- Change positions
- Use strongest muscles
- Consider rest as an activity and schedule it into your day
- Rest before you become fatigued

BINGO!


Reference

Packer TL, Brink N, Sauriol A. Managing fatigue: a six-week course for energy conservation. Tucson (AZ): Therapy Skill Builders; 1995.

Appendix K - Pace My Day Training Program PowerPoint

Welcome to Pace my Day

Jordan, Janie, America, May Anne



Can you relate?

"I don't have enough energy to do things that I enjoy."

"I power through without breaks, and then I'm exhausted!"



"I feel like I can never get caught up because I'm always tired."

"I just don't have as much energy as I used to."

"I don't stop when I'm tired because I'm afraid I'll forget where I left off."

What is Pace my Day?


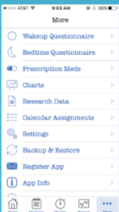
Mobile health app developed by Dr. Michelle Ranae Wild who works with adults with brain injuries at Coastline College.

Developed for her patients who suffer daily fatigue in order to help them


Strategically plans each day according to energy level.

Help monitor how they felt throughout the day

Help them evaluate and optimize their energy for daily success.

What our Goal is?

- To help you incorporate the use of energy conservation strategies into your daily lives to help self manage your fatigue
 - To help you tackle the tough and challenging tasks and to properly work through them with brakes prompted by the PMD app.
 - Help you strategize and prioritize the daily tasks you have to maximize your optimal energy levels
 - Able to use the PMD app to help you keep track of your daily level of fatigue and energy to improve performance for the future.
- 

Quick Overview video and Time to Download!



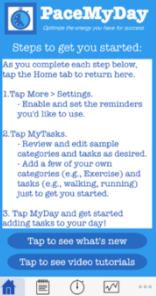
If you need assistance with download procedure please raise your hand.

<https://www.youtube.com/watch?v=QXM-huDngKo>

Are we ready to get Started?





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Steps to get you started:
As you complete each step below, tap the Home tab to return here.

1. Tap More > Settings. Enable and set the reminders you'd like to use.
2. Tap MyTasks. Review and edit sample categories and tasks as desired. Add a few of your own categories (e.g., Exercise) and tasks (e.g., walking, running) just to get you started.
3. Tap MyDay and get started adding tasks to your day!

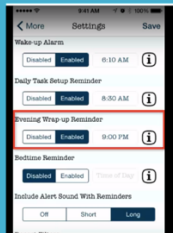
Tap to see what's new
Tap to see video tutorials




Home Page

- My Tasks- Helps you set up new tasks
- My Day- Helps you organize your frequently performed tasks into your day.
- Report- Helps tracks each day's progress
- More- leads your bedtime/morning questionnaires, settings.

Let's start with settings





Click More----> Settings

Wake up alarm: sets up Morning questionnaire to set optimal energy level

Daily Task Reminder: reminds you to do the scheduled tasks on hands

Evening Wrap up Reminder (ENABLE): Prompts you to wrap up your day and notifies you to fill out Bedtime questionnaire survey. Required!


Bedtime reminder: is optional

Setting up my personal Tasks, And Breaks

<https://www.youtube.com/watch?v=2CRbf1MnuOk>


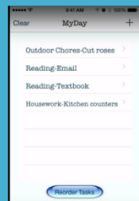
Overview:

- Creating your own categories of types of work/duties (Office work)
- Adding specific tasks under that category (Respond emails)
- Adding in notes, and specific strategies (Respond school, delete junk)
- Include expected durations of how long to complete task (30 minutes)
- Add in specific breaks.



Adding task to your Daily plan


- Plan your day with the tasks you hope to achieve that day
- Remember not to overschedule task!
- Allows your reorder, add, and delete tasks for the day
- -For research purposes: please follow through with at least One and the same task assigned per day.

Doing the task.

https://www.youtube.com/watch?v=n_a6jCFMIBI

- Overview:
- Pick a task
- Choose a fatigue level
- Choose a Duration (modified (based off fatigue), or optimal)
- At end pick fatigue level after the task. (take a short break recommended)
- Pause is for break, Stop task (will be identified why you stopped task)



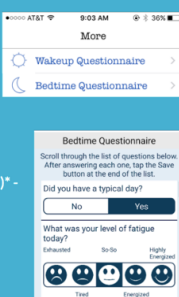
Bedtime questionnaire

Located under the "More" category

Should be prompted by app from the "evening wrap up reminder"

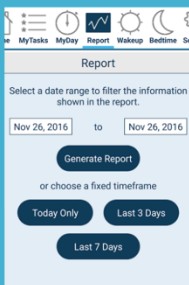
Rate your level of Fatigue at the end of the day (question 2) *

Very important to our research!



How to track, Generate Report


- Under "Report" tab
- Tracks your questionnaires, and tasks you completed on a day by day basis.
- Can customize exact dates
- For the purposes of this study: you will generate a Email report to a team member twice.



Thank You!

And of course feel free to contact us anytime for assistance.

Any Questions?



Appendix L - Energy Conservation Handout

Energy Conservation Strategies

Rest

- Rest before becoming fatigued
- Take short rests frequently
- Schedule rest into your day
- Examples of rest include: sitting down, lying down, a quiet activity such as listening to music

Proper Body Mechanics

Standing

- Feet shoulder width apart, weight evenly in both feet
- Bend knees slightly

- Relax arms close to body

Sitting

- Feet flat on floor
- Hips and knees bent at 90-degree angle
- Sit close to desk or table

Lifting and carrying

- Use strongest muscle groups - your legs!
- Squat
- Hold object close to body near your chest
- Use a cart, use a bag, slide items

Planning and Prioritizing

When planning your day/week ask yourself:

- What needs to be done?
- What do I like to do?
- What is expected of me today?
- How much energy does each activity take?
- What can I eliminate?
- Who else can do this activity?

Creating Balance

Creating balance in your day is important! Along with productive activities make sure you schedule in:

- Rest
- Leisure activities