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A Multiple Sclerosis Education Module to Promote Patient Activation and Efficacy

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Submitted in Partial Fulfillment for the Doctor of Nursing Practice Degree

Regis University

February 11, 2016

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Executive Summary

A Multiple Sclerosis (MS) Education Module to Promote Patient Activation and Efficacy

Problem

It is estimated that over 572,000 people in the United States have MS, with approximately 200 new cases being diagnosed each week (National Multiple Sclerosis Society, n.d.). In order to increase self-care, reduce the level of impairment, and ultimately, cost to the healthcare system, the consistent use of a targeted educational intervention should be implemented. The problem statement describing the capstone project was: Will the implementation of a structured educational program enhance the knowledge of MS patients and their caregivers regarding the disease process of MS, resulting in increased patient activation and self-efficacy?

Purpose

The purpose of the project was to examine whether an educational module related to the disease process of MS would improve patient activation and self-efficacy of MS patients and their caregivers with the goal being the creation of a uniform curriculum that can provide patients with enhanced knowledge of MS as well as an increased confidence related to self-care activities.

Goal

The goal of this project was to determine the impact of patient education on self-efficacy and patient activation on MS patients.

Objectives

Project objectives included the provision of a learning opportunity for MS patients to enhance their knowledge of the disease process and self-efficacy. Additionally, the project created a sustainable, reproducible patient education program, which would hopefully lead to an improvement in self-efficacy and patient activation, and potentially show improvement in their quality of life and delay disability.

Plan

In order to assess the effectiveness of the educational intervention that was introduced in this project, a pre- and post-intervention design was utilized, comparing the scores that were achieved on both the Multiple Sclerosis Knowledge Questionnaire (MSKQ) and the Patient Activation Measure (PAM). The MSKQ has been found to be a reliable and valid method for the assessment of knowledge in regards to MS symptomatology, treatment options, and prognosis (Giordano et al., 2010). The PAM has been shown to be a valid and highly reliable method for measuring patient activation (Hibbard, Stockard, Mahoney, & Tusler, 2004).

Outcomes and Results

The results from the study indicate that the educational intervention was effective in increasing the level of knowledge participants possessed with respect to the symptoms of MS. Based on the data obtained, the effect size between the pre- and post-test conditions in regards to the PAM, the Cohen's *d* was 0.49, which is considered to be a medium effect size (Polit, 2010). The difference between the pre- and post-test conditions in regards to the MSKQ scores provided a Cohen's *d* of 1.37, which is considered to be a relatively large effect size. Such a result would suggest that the educational intervention program used in the current study was effective in expanding the knowledge base of the participants in regards to MS.

Acknowledgements

Although only my name appears on the cover of this dissertation, a great many people have contributed to its production. I owe my deepest gratitude to my husband, Bob, for his unconditional love and support as I complete this Doctorate of Nursing journey. Thank you for believing, inspiring, and encouraging me to persevere in the pursuit of my dream and life goal. I will forever be grateful to Dr. Colleen McCallum and the DNP faculty of Regis University for their encouragement, support, and ongoing commitment to excellence. Without their guidance, this project would not have been possible. Special thanks to Tamara Miller, M.D. and Multiple Sclerosis Center of the Rockies for allowing me to complete my project at your facility.

Finally, I would like to dedicate this project to my father, L.J. Conner. Despite that he is unable to witness this accomplishment in person, he is with me in spirit. He bequeathed me an undying quest for education and the confidence to conquer. I know he and my son, Jared, are looking down proudly on my accomplishment.

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A Multiple Sclerosis Education Module to Promote Patient Activation and Efficacy

Multiple sclerosis (MS) is a debilitating disease with symptoms such as numbness and weakness in the limbs, cerebral lesions leading to blurred vision, bowel dysfunction, and even affective disorders such as depression and anxiety. While the onset of the disease may not inhibit the movements or result in a severe disability, by the time a patient has lived with MS for 20 years, the majority of individuals are no longer fully ambulatory (MS Coalition, 2014). One method to effectively treat symptoms are programs designed to teach patients strategies to deal with symptomology, however, these educational programs are not uniform in the delivery of information presented and frequently do not provide patients with pathophysiology of the disease process. Additionally, the programs are not offered routinely upon diagnosis of the disease.

Despite extensive research, it is difficult to verify the exact number of people with a definitive diagnosis of MS. There is currently no national or global registry for MS cases, therefore, figures are only estimates. It is estimated that more than 572,000 people in the United States have MS, with approximately 200 new cases being diagnosed each week (National Multiple Sclerosis Society, n.d.). According to the National Multiple Sclerosis Society (NMSS), MS is the most widespread disabling neurological condition of young adults in the US and worldwide. Compared with other chronic conditions, MS ranks second only to congestive heart failure in terms of costliness (National Multiple Sclerosis Society, n.d.). Additionally, few current articles speak to disease education.

The prevalence of MS suggests that it is a global epidemic. Worldwide, it is estimated that MS affects 30 in 100,000 individuals; in the United States, the prevalence is estimated at 135 in 100,000; more than the worldwide prevalence, and places the United States at the top of the global rates of prevalence (Fox, 2010). In the United States, the annual mean cost, including

patient care, alterations to home and vehicle, medications, purchase of special equipment, and loss of earnings, was \$69,000 per patient in 2010. This figure translates to a national annual cost of \$28 billion in the United States (National Multiple Sclerosis Society, n.d.) and a mean lifetime cost of \$3.4 million per patient (Kobelt, Berg, Atherly, & Hadjimichael, 2006). There is significant evidence in primary care that the promotion of health care self-management programs can improve elements of health status, while reducing costs in populations with diverse chronic diseases (Lorig, Sobel, Stewart, Brown, Bandura, Ritter, Gonzales, Laurent & Holman, 2008).

Problem Recognition and Definition

Presently, there are a variety of programs that have been introduced in order to educate both patients and healthcare professionals on the various treatment options available for symptom management. Although some programs appear to be beneficial, there remains a need for a more personal and comprehensive educational curriculum that could ideally, be implemented in local practices. The optimal educational program would include an emphasis on the pathophysiology of the disease (including brain anatomy and immunology), symptom expectations, treatment options, and prognosis. Through the involvement of patients as well as caregivers, a program could be developed and implemented.

A great number of the MS programs currently in use involve outpatient education on topics such as exercise, nutrition, lifestyle, stress management, and responsible health behavior (Ennis, Thain, Bogglid, Baker, & Young, 2006). There are currently other programs focusing on education regarding disease-modifying therapies for patients who have been newly diagnosed (Solari et al., 2010). Despite the target demographic of the programs previously implemented, the underlying theme, which seems to be the most beneficial in terms of patient outcomes and quality of life, is the role that patient activation, self-efficacy, and education play in the treatment

and management of MS symptoms. Similar to self-efficacy, patient activation is defined as the knowledge, skills and confidence essential to managing one's own health and healthcare (Greene & Hibbard, 2012). A search of the literature related to patient education suggested that increased knowledge may decrease the likelihood of unrealistic expectations of patients in regards to their disease processes (Coulter, Entwistle, & Gilbert, 1999). Additionally, patient education may provide the confidence patients need to participate in treatment choices (Kasper, Kopke, Muhlhauser, & Heesen, 2006; Greene & Hibbard, 2012), which may ultimately impact adherence, symptom management, the course of the disease, as well as the quality of life (Heesen, Kasper, Kopke, & Muehlhauser, 2007). With these benefits in mind when creating an educational intervention, the patient can remain the priority.

Statement of Purpose

The program developed for this capstone project was aimed to educate newly diagnosed MS patients regarding the pathophysiology of the disease process, current treatments, symptom management and prognosis, resulting in increased knowledge regarding the disease process and therefore, more self-efficacy and confidence to participate in their care. As early as 2003, the Institute of Medicine looked at programs to change patients' behavior by increasing the patients' self-efficacy and knowledge. The thought behind these programs claimed improved behaviors were expected to lead to better disease control, which should lead to better patient outcomes and reduced utilization of healthcare services, particularly preventable emergency room and hospitalizations, and ultimately to reduce costs (Pearson, Mattke, Shaw, Ridgely, & Wiseman, 2007).

The program utilized research supporting previous educational interventions promoting self-management practices, which have been shown to improve self-efficacy, health status, and

reduce the burden placed on hospitals for the care of patients with chronic and progressive diseases (Lorig et al., 2001). Therefore, the purpose of this capstone project was to examine if the implementation of a structured educational program enhanced the knowledge of MS patients and their caregivers regarding the disease process of MS resulting in increased patient activation and self-efficacy. Similar to self-efficacy, patient activation is defined as the knowledge, skills, and confidence essential to managing one's own health and healthcare (Greene & Hibbard, 2012).

The main objective of the MS educational program was to provide education, which would enhance the scope of knowledge, encourage self-management and treatment, in anticipation of improved clinical outcomes. By providing quality education, presented through a simple approach, a better understanding of the disease process can be gained (Lillyman & Farquharson, 2013). Education may increase the likelihood of realistic expectations of the disease process and therefore, decrease fear, allowing patients to experience fewer exacerbations and improve symptom management (Coulter, Entwistle, & Gilbert, 1999).

Statement of Problem

Newly diagnosed MS patients are usually uneducated regarding their disease process, which may cause anxiety and poor coping skills, leading to poor self-care practices. Currently, most healthcare systems have no provision for patient education regarding the very complicated disease of MS. With current physician visit times averaging 21 minutes for a specialty practice (Shaw, Davis, Fleischer, & Feldman, 2014), an independent patient education program is necessary in order to provide adequate disease information to patients. The ideal educational program would include an emphasis on the pathophysiology of the disease (including brain anatomy and immunology), symptom expectations, treatment options, and prognosis.

A great number of MS programs described in the literature involve outpatient education on topics such as exercise, nutrition, lifestyle, stress management, and responsible health behaviors (Ennis, Thain, Bogglid, Baker, & Young, 2006). The role of proper disease education appears to be lacking. Furthermore, the underlying theme, which would seem to be the most beneficial in terms of patient outcomes and quality of life, the role of patient activation and self-efficacy, is missing from most programs.

Literature pertaining to patient education suggests that increased knowledge of the symptoms and prognosis of a disease may decrease the likelihood of unrealistic expectations of patients in regards to their disease process (Coulter, Entwistle, & Gilbert, 1999). Additionally, patient education may provide the confidence patients need to participate in treatment choices (Kasper, Kopke, Muhlhauser, & Heesen, 2006; Greene & Hibbard, 2012), which may ultimately have an impact on adherence, symptom management, the course of the disease, as well as the quality of life (Hessen et al., 2007).

There is significant evidence in primary care settings that the promotion of health management programs can improve the health status of patients, while at the same time reducing costs associated with the management of chronic diseases such as MS (Lorig et al., 2001). By keeping the following findings from research while creating an educational intervention, the patient remains the priority:

- Patient education is an important responsibility for any disease, but especially important with MS, where the symptoms are so varied.
- Knowledge of problematic symptoms helps to encourage early treatment with the potential to reverse symptoms before they become permanent.

- Knowledge of realistic expectations allows patients to approach the disease with a reasonable attitude, with a positive outlook, and without unnecessary fears of the unknown.
- Knowledge of others' coping skills with regard to various problems that may arise with MS allows for maximal functioning within the disability.
- Promotion of understanding from family and friends prevents unnecessary suffering and establishes a valuable support system (Lorig et al., 2008).

PICO Statement

This project is an evidence-based practice (EBP) project in which a quality improvement plan, program evaluation, or simple educational or standard of care intervention will be completed. In most cases, a simple pre-test and post-test evaluation will assess the effect of the intervention. The project will be internal to an agency and will inform the agency of issues regarding health care quality, cost, and patient satisfaction. The results of this project are not meant to generate new knowledge or be generalizable across settings but rather seek to address a specific population, at a specific time, in a specific agency. These projects translate and apply the science of nursing to the greater healthcare field. Projects utilize the acronym "PICO", rather than stating a formal research hypothesis. The acronym stands for: Population or Disease (P), Intervention or Issue of Interest (I), Comparison group or Current Practice (C), and Outcome (O) and is usually framed as a question (Melnik and Fineout-Overholt, 2011, p. 31).

Based on the needs assessment of the chosen population, the question about the population, intervention, comparison, and outcome was developed:

Will the implementation of a structured educational program enhance the knowledge of MS patients and their caregivers regarding the disease process of MS resulting in increased patient activation and self-efficacy?

P: Patients currently diagnosed with MS receiving treatment at a neurological clinic.

I: The establishment of a formal, structured, educational curriculum, which will include pathophysiology, symptom expectations, treatment of symptomatology, as well as the disease process and prognosis.

C: Currently, there are no structured programs within the proposed location.

O: The enhancement of knowledge in patients regarding the disease process of MS and the increased confidence related to self-care activities following the educational intervention.

Variables

The independent variable for the current research project was the educational curriculum given to the patients, caregivers, and staff who elected to take part in the project. The information presented was based on the format recommended by the NMSS, which included modules on pathophysiology, realistic symptom expectation, treatment options, and the prognosis of the disease.

The project also contained two dependent variables, which were composed of the knowledge level of the patients and participants regarding MS, as well as the confidence the patients had related to the self-care activities and self-efficacy that is hypothesized to accompany structured educational interventions (Rigby Domenech, Thornton, Tedman, & Young, 2003). The Multiple Sclerosis Knowledge Questionnaire and the Patient Activation Measure, respectively were used to measure these variables. These particular variables were selected as the impact they potentially have on the quality of life, which has been suggested as a key

identifying factor in the ability of a patient to cope with the often-debilitating effects of MS (Taraghi & Ilali 2010). These two dependent variables were assessed individually in order to determine if there was a correlation between the amount of knowledge gained through the educational intervention and the level of self-confidence present to assume the increased responsibility associated with self-care of the symptoms associated with the chronic disease.

Schematic Model of PICO Variables

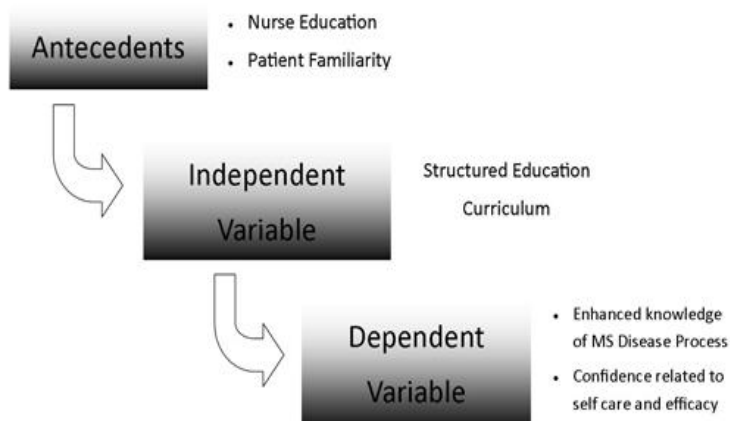


Figure 1. PICO Variables

Project Significance, Scope, and Rationale

There is a significant gap in the literature focusing on disease process knowledge and patient activation for MS patients (Demaille-Wlodyka, Donze, Giveron, & Gallien, 2011). Given the gap in the literature, in addition to the current impetus for patients to become more active and effective managers of their health care (Greene & Hibbard, 2012), it is hopeful that this quasi-experimental study will address the literature gap and improve patient outcomes. Another

significant benefit of the project is the opportunity to evolve Advanced Practice Nursing (APN) translation of research into practice (Terry, 2012).

Theoretical Foundation

Encouraging self-efficacy among patients who have been diagnosed with MS can assist them in coping with the disease progression and symptom management, as well as additional life stressors that may occur that are not disease-related. Self-efficacy has been identified in various research literature sources as being a significant predictor of positive engagement in health promoting behaviors among patients diagnosed with MS (Stuifbergen et al., 2000). Self-efficacy is a social cognitive concept introduced by Albert Bandura (1993), consisting of four processes: cognitive, motivational, affective, and selection. According to Bandura (1993), self-efficacy plays a major role in whether or not an individual achieves a successful outcome in his or her goals, tasks, and challenges throughout life. Bandura (1994) described self-efficacy as the beliefs held by an individual in his or her ability to succeed in a given situation, with the beliefs being influenced by things such as how an individual thinks (cognitive), plans (motivation), feels (affective), and behaves (selection). If an individual is presented with a situation in, which he or she feels confident in the ability to succeed, the likelihood of a positive outcome and achievement of a goal is increased (Bandura, 1994). Likewise, if an individual is not confident in his or her abilities, the goal will, most likely, not be met. Individuals who have a strong sense of self-efficacy are more likely to view challenges as tasks and opportunities to be mastered, develop a deep interest in the activities in which they take an active role, and recover more quickly from a setback. In comparison, those with low senses of self-efficacy are reticent when facing challenges, focus on negative outcomes of previous attempts, and believe that tasks, which are difficult, lay outside the realm of their abilities.

Self-efficacy is also thought to play a role in treatment adherence among patients who have been diagnosed with various diseases (Stuifbergen et al., 2012). Additional research into the role self-efficacy plays in the management of MS symptoms suggests quality of life can be improved when physical activity is maintained, even when physical mobility is compromised secondary to the effects of the disease (Motl & Snook, 2008). Activities such as aerobics and yoga have been shown to be beneficial in increasing the quality of life among individuals who are experiencing the physical and cognitive symptoms associated with MS (Motl & Snook, 2008). While self-efficacy may not be directly related to an improved quality of life, it appears to play a pivotal role in supporting health-related activities that can contribute to a better outlook, thus resulting in increased enjoyment and effective coping skills ultimately translating to improved quality of life.

In addition to Bandura's theory, Margaret Newman's theory of health as expanding consciousness provides a strong nursing foundation for the project. Newman's theory was designed for the patient for whom full health may never be a reality. This theory is significantly applicable, as patients participating in the project will have a chronic progressive disease process. Newman asserted each individual has a predestined path, and no matter how difficult, it is part of a greater plan. This greater plan includes finding meaning in life, regardless of one's circumstances as well as meaning and or connection with others in the universe (McEwen & Willis, 2011).

Newman went on to elaborate that humans are constantly in contact with the environment, and therefore constantly changing in response to the environment. Each person will develop an individual pattern of consciousness. McEwen and Willis (2011) quoted Newman in their text, stating, "Persons as individuals, human beings as a species, are identified by their

patterns of consciousness... the person does not possess consciousness, – the person *is* consciousness” (p.184). According to this assumption, a person’s illness would then be simply his or her unique pattern of consciousness. In Newman’s theory, consciousness includes cognitive as well as affective awareness, and a connection with the environment, which includes maintenance of health and illness (Newman, 2013).

Newman’s definition of health as expanding of consciousness, inclusive of illness, encompasses ongoing changes in harmony with the ever-evolving energy of the environment. Expanding consciousness includes the entire pattern of consciousness, and refers to the awareness and the development of self, in conjunction with the environment. It is the process of assisting patients to realize and obtain their full potential (McEwen & Willis, 2011). Newman postulated health and illness should be as one. In fact, both states together should be viewed as the entity of health. Health is determined to be a pattern; patterns are pieces of a whole and pattern recognition is essential to health awareness. Pattern recognition involves being able to look past the pieces and parts of our lives in order to recognize patterns when combined, will produce expanded consciousness. Pattern recognition will come from self-awareness, is unique to each individual, and will change over the course of time (McEwen & Willis, 2011). The hope is for each patient to be able to look within himself or herself and find the inner strength to deal with a chronic progressive disease. It is hopeful that this revelation will come about through increased knowledge of the disease process.

Literature Selection and Scope of Evidence

Much of the research in the field of MS has focused on the disease, rather than on how to assist the patient to cope effectively with the diagnosis and the progressive nature of the disease. There appears to be a lack of studies that examine therapeutic patient education (Demaille-

Wlodyka et al., 2011), which not only impacts the lives of those diagnosed with MS, but also the family, support system, and healthcare providers.

In order to assess the literature that has been published on the topic, various databases were utilized. These consisted of the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Cochrane, Google Scholar, Medline, OVID, and PubMed. The following search terms were used to find appropriate and applicable literature sources: care coordination, chronic disease, cost utilization, decision making, decision support system, disease management, evidence based medicine, health knowledge, health promotion, informed choice, MS, patient activation, patient autonomy, patient education, patient empowerment, self-care, self-efficacy, and self-management. Utilizing these search parameters, 97 articles were located with 36 articles evaluated according to the levels of evidence. Eighteen met the criteria for Level I, seven for Level II, three for Level III, three for Level IV, four for Level V, and one for Level VII research (Houser & Oman, 2011).

Review of Evidence

Background of Problem

The National MS Society, certified MS nurses, as well as the National Institute of Neurological Disorders and Stroke have all agreed that the lack of disease education for newly diagnosed MS patients can lead to a less than optimal outcome in regards to both patient health prognosis and the monies spent annually on both direct and indirect costs associated with MS. In 2014, the National MS Society assembled a group of researchers, MS professionals, as well as patients who had been living with the symptoms of MS, to evaluate the current body of research regarding diet, exercise, and emotional wellness, aimed at identifying the gaps in knowledge on these topics, in order to develop educational resources and support programs for MS patients,

families, caregivers, and healthcare professionals who work with MS patients (National Multiple Sclerosis Society, n.d.).

Several gaps in knowledge were identified in regards to MS programs that are currently in place, which, if left unaddressed, could allow the cost of direct and indirect treatment care to continue to escalate. The committee discovered that there was a lack of continuity in the determined efficacy and effectiveness of the numerous wellness programs that are currently in place, particularly in regards to symptom management, the reduction of comorbid health conditions, and methods used to enhance the impact the disease-modifying therapies currently use for the treatment of MS (NMSS, n.d.).

Three recommendations arose from the study conducted by the NMSS in 2014:

- Engage research design experts to address the challenges identified within and across wellness areas.
- Stimulate collaborative research efforts, similar to what has been done in the areas of genetics, nervous system repair, and progressive MS, to ensure that the best minds are working with speed and effectiveness in wellness research.
- Identify funding partners who share the interest of increasing knowledge about wellness interventions in MS.

Systematic Review of Literature

According to a review of the literature addressing educational interventions for patients with MS, it seems the current methods may be insufficient, as many of the therapeutic, educational programs lack both standardization and assessment of efficacy (Demaille-Wlodyka et al., 2011). Despite these shortcomings, however, the numerous benefits of an educational intervention have been noted. The use of educational therapy has been shown to reduce the

impact of the disease symptoms that are associated with MS, such as cognitive and self-care disturbances (Demaille-Wlodyka et al., 2011). Such educational programs are also thought to have a positive effect on self-care practices (Lillyman & Farquharson, 2013). Through teaching patients what to expect and the treatment options that are available, a sense of dignity and self-efficacy can be maintained despite the challenges that may accompany the progressive nature of the disease. By educating patients and their families regarding the possible psychological, physical, emotional, and cognitive changes that can accompany MS, an accurate understanding of the disease can be gained.

Kopke, Richter, Kasper, Muhlhausr, Flachenecler and Heeson (2012) enlisted 261 MS patients to participate in a study related to relapse and relapse therapy, providing them with four hours of instruction in addition to a comprehensive brochure. Perceptions of autonomy for treatment decision-making were considerably higher for patients receiving an educational intervention than a control group. The study additionally confirmed MS patients were able to cope with information about uncertainties of the disease process as well as treatment options. Interestingly, the study documented frequent fears and objections by physicians providing patient instruction.

In a level II, randomized controlled study, Adamczyk, Flis, Zyarycha and Rejszel (2002) evaluated the effectiveness of health education in patients with neurological issues of stroke and MS. The study provided three weeks inpatient education and showed a 26 percent increase in knowledge following the first stage of the project and 64 percent increase after the second stage, concluding a “radical increase in the level of health-promoting knowledge among patients in a controlled environment” (p. 67).

In other countries, a program has been introduced which provides patients with a comprehensive education aimed at providing patients and their caregivers realistic expectations as MS progresses. The program, known as Therapeutic Patient Education (TPE) has been implemented in Europe and has been shown to be quite beneficial in reducing the number of hospital visits related to MS symptoms (Demaille-Wlodyka et al., 2011). Due to the varied nature of the numerous symptoms that are associated with the disease, development of specialized training programs addressing specific MS symptoms would be beneficial to patients. Additionally, education regarding treatment interventions should be adaptable in order to account for possible side effects of medications that are frequently used to treat some of the symptoms associated with MS, which, depending on drug class and dosing, can slow or hinder cognitive or physical abilities of an individual.

A review of self-management interventions revealed that the use of such programs targeted at improving the self-efficacy of individuals with MS has yielded promising results. When designing educational interventions for neurological disorders, it is important to tailor each program to the specific needs of both the individual disease as well as the patient who will be receiving the information (Rae-Grant et al., 2011). Programs addressing neurological disorders should bear in mind the unique challenges that are associated with a chronic disorder such as MS, which consists of period of remission and acute exacerbation and disease progression over time, to the point of physical and potentially mental incapacitation. Research into MS specific education interventions suggest positive outcomes are associated when the focus is on overall health behaviors and self-efficacy skills such as exercise programs, goal setting, and healthy coping strategies to effectively address the debilitating fatigue, stress, and pain that often accompanies the disease (Rae-Grant et al., 2011). At the current time, however, it

appears that a uniform program that delivers such options does not exist, at least not on a large scale or national level.

When studying educational interventions that have been shown to be beneficial for other neurological conditions, the inclusion of improving self-efficacy along with disease education has proven to be central to a successful outcome. Patients with MS report that self-care skills are among the most important in allowing them to maintain a sense of autonomy, thus potentially contributing to a better outlook and improved quality of life (O'Hara, de Souza, & Ide, 2000). Some aspects of self-care that have been reported as being essential include following a specific dietary regimen, healthy and positive stress coping skills, complementary therapy such as yoga, and activities that are associated with living independently (O'Hara et al., 2000). By including the aspects that patients have identified as being important, the proposed educational intervention can have a higher likelihood of addressing the needs of the patient, rather than basing the guidelines on textbook and diagnostic criteria.

Other educational programs aimed at patients with MS have shown great benefits when the information is presented in close proximity to receiving the diagnosis. Newly diagnosed patients may not be aware of the various symptoms that are associated with MS, or the progressive nature of the disease. One study evaluated the use of a specifically designed educational intervention for individuals who had recently received a diagnosis of MS, which consisted of an interview with a physician, an informative CD, and a take-home booklet, significantly increased the likelihood of a positive outcome, which was defined as a high level of attainment of disease knowledge with a high satisfaction with the care they had received (Solari et al., 2010). When the information is presented within two weeks of diagnosis, the retention of the information was greater, even when follow-up assessments were conducted at six months

after the initial educational intervention. While the information about the disease may be viewed as overwhelming for some patients, research suggests that anxiety was not markedly increased among patients who received the educational intervention used by Solari et al. (2010). The specific intervention has not been tested, however, on patients who have had a history of substance abuse, psychiatric conditions, or impaired cognitive ability.

Education on symptom management has been shown to be associated with a higher quality of life, as it can allow the patient to be better prepared for the potential effects of MS as well as providing an opportunity to learn about treatment options, thus leading to a more realistic understanding of the disease. Most educational interventions used for patients who have received a diagnosis of MS focus on two main aspects: disease modifying therapy choices and therapeutic options to address the symptoms of the disease (Ben-Zacharia, 2011). While focusing on the aspects of disease and symptom management have been shown to be beneficial, such an approach may not sufficiently increase the level of self-efficacy.

Measuring the quality of life can be difficult, as there are many facets which are deemed important, and the ranking of the variables can differ depending on both the individual and the disease. According to research regarding the quality of life, the severity of illness, antecedent variables, and health promoting behaviors have been identified as primary factors that contribute to either a higher or lower quality of life experienced by the individual (Stuifbergen, Seraphine, & Roberts, 2000). Designing an educational intervention for patients with MS can be extremely challenging due to the frequently unpredictable nature of the disease. Nevertheless, by focusing on increasing self-efficacy, which has been associated with a higher quality of life, the program can allow for the patient to navigate through the various symptoms which can include weakness, numbness, pain, bowel and bladder problems, and changes in sexual functioning (Stuifbergen et

al., 2000). The diverse symptoms that accompany MS can make the development of a specifically tailored program focusing on nurturing self-efficacy rather than solely on the symptoms, a beneficial approach.

With healthcare transitioning to a system that will expect the patient to effectively assume primary responsibility for managing chronic conditions, Battersby, Von Korff, Schaefer, Davis, Ludman, Greene, Parkerton and Wagner (2010) conducted a meta-analysis of 83 articles related to self-management. The conclusion supported the positive role of education within a medical practice enabling patients to successfully care for their chronic conditions. The authors recommended the use of a Care Manager responsible for patient education.

Project Plan and Evaluation

Strengths, Weaknesses, Opportunities, and Threats

Given that identifying strengths, weaknesses, opportunities, and threats (SWOT) assists in projecting a path for a project, an analysis was completed to determine the feasibility of an educational curriculum for MS patients. A SWOT analysis is a framework for identifying and analyzing the internal and external factors that can have an impact on the viability of a project, product, place, or person. The SWOT analysis was used to determine how internal strengths could be used to take advantage of opportunities and avoid threats, as well as how weaknesses could be overcome by taking advantages of opportunities.

Strengths of the project include strong support from key stakeholders, location of the project within a specialty MS practice, and the convenience sampling is accustomed to meeting regularly. Weaknesses of the project include time constraints, travel distance to the clinic, and

the utilization of a convenience sampling within one practice. The possibility of not reaching power is another real weakness.

Opportunities of the project include increased self-care efforts of patients following an educational program and the potential for the curriculum to be used by other practices. Threats to the project include the short duration of the education module, lack of continued reinforcement of new concepts, high potential for project dropout due to health or travel reasons, and the timing of the project.

Table 1. SWOT Analysis

INTERNAL	<u>STRENGTHS</u> Strong support from key stakeholders Project located within MS specialty practice Participants accustomed to meeting regularly	<u>WEAKNESSES</u> Convenience sampling within one practice Time constraints Potential travel distance
EXTERNAL	<u>OPPORTUNITIES</u> Increased patient education may result in better outcomes Potential for use by other practices	<u>THREATS</u> Short duration of study High potential for dropout Project timing (weather impacting travel)

While it is not possible to remove all threats to validity and reliability in most studies, certain precautions can be taken in order to reduce such risks. For this capstone project, precautions were taken to ensure that the data gathered and analyzed was an accurate representation of the pre- and post-educational curriculum intervention scores. The DNP capstone lead administering and scoring the MSKQ received specialized training to ensure that the instructions were understood. The questionnaire used has been shown to be effective in

measuring knowledge of MS and the associated symptoms when used in diverse populations, with varied educational levels (Giordano et al., 2010). Additionally, the same DNP capstone lead who administered the pre-educational curriculum intervention also administered the post-test questionnaire, thus reducing the instrumentation threats to internal validity.

Driving and Restraining Forces

Another element similar to SWOT was the identification of driving, restraining, and sustaining forces. According to Zaccagnini and White (2014), the capstone project should focus on an identified practice problem and the application of evidence to the problem, thus leading to change. In order to accomplish change, Kurt Lewin's Force Field Analysis was used as a strategic tool to understand how change should occur. Driving forces for consistent implementation of a MS education program included the prevalence of MS, the mean lifetime cost per patient, and the possibility of decreased healthcare costs resulting from effective education. Restraining forces consisted of delayed diagnosis, lack of adequate education on the part of primary care physicians and the lack of disease education programs offered. The sustaining force will attempt to guarantee that adequate reinforcement of the change will be provided to ensure the desired change is accepted and maintained into the future. Without this type of sustainability, patients tend to return to previous norms (Change Management Coach, n.d.).

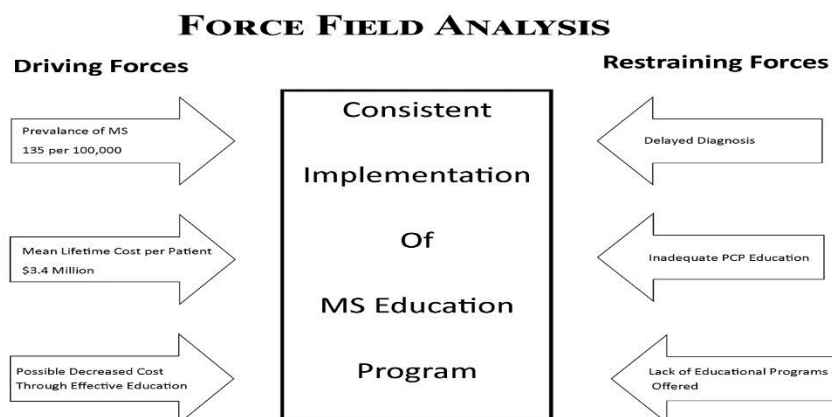


Figure 2. Force Field Analysis

Feasibility, Risks, Unintended Consequences

The proposed MS education policy is legally, administratively, and politically feasible. This program can be easily initiated via the National MS Society's Knowledge is Power series (NMSS, n.d.) at no additional cost to the society, hospital, or patient. The program can be taught by current health system staff, which would not require additional personnel or salary for specialists or educators. In addition, patients can be referred within the hospital network for the educational program, at no extra cost.

Risk to participants was minimal. In the event the measurement tool produced anxiety, debriefing, emotional support or counseling was available by a certified MS nurse. There were no unintended consequences.

Stakeholders and Project Team

Zaccagnini and White (2014) define stakeholders as key individuals who will be affected by a project. In the capstone project, stakeholders are identified as the various entities that will have a stake in the development and effectiveness of a MS educational program. The capstone

project team included Tamara Miller, M.D., medical director of Advanced Neurology, Dr. Miller's clinical studies nurse, Lillie Denny, RN, Colleen McCallum, DNP, RN, FNP-C, Capstone Chair, and Anna Parton, MSN, RN FNP-C, the DNP capstone project lead. Expected stakeholders include patients, families, primary care providers, neurologists, health networks, and the insurers, both public and private. Patients, families, and caregivers will benefit from the outcome of introducing the MS educational program by gaining an increased knowledge about the projected course of the disease, as well as benefitting from the increased self-efficacy and improved quality of life that have been shown to accompany the use of various educational interventions.

Primary care providers and neurologists can benefit from the development of an MS educational program given they will be dealing with a more educated patient, as well as possibly reducing the workload by more effective patient self-care. Given the reduced reliance upon primary care and specialists observed when such programs are employed, insurance companies, as well as the healthcare system in which the programs are utilized, should find the program financially feasible.

Cost-Benefit Analysis

Since it has been estimated that the cost of care for MS patients in the United States is near \$30 billion annually (NMSS, n.d.), the lack of effective educational interventions ultimately cost hospitals and insurance companies. These costs are in terms of not only finances, but also diverted resources, including healthcare providers, from tending to other health issues. In other terms, the knowledge deficit costs valuable time and money, for the patients, healthcare providers, and the insurance companies.

The cost of treating the symptoms associated with MS has been estimated at \$39,000 annually in just healthcare costs, with a total of \$69,000 for both the direct and indirect costs (NMSS, n.d.). While the costs are quite high, studies suggest that the cost of not treating the symptoms of MS may be higher (Rocky Mountain Multiple Sclerosis Center, 2015). The use of targeted educational programs can aid in reducing the costs associated with care and treatment for individuals with MS. The projected health care cost savings associated with the introduction of an education program should prove to be quite lucrative for the patients, healthcare providers, hospitals, insurance companies, and other stakeholders. For example, the baseline costs for health care for MS patients who do not receive the training are estimated to be \$39,000. After the first year of introducing the educational program (which will be offered free of charge to the patient), the cost savings are \$3,042 per year; after five years, the projected cost savings are estimated at \$13,015, the cost of one exacerbation (RMMSC, 2015), reducing the healthcare cost from \$39,000 to \$25,985 per year. If every MS patient in the United States were to receive an educational training program, increasing patient activation and efficacy, the estimated savings could be \$5,206,000,000 after five years, which is quite sizable.

On a global scale, the prevalence of MS is not exactly known, as there is currently no mandatory registry for MS. It is estimated, however, that approximately 2.5 million individuals live with the symptoms of MS. Outside of the United States, which has an estimated 400,000 cases total, or 200 new cases each week, equating to a prevalence of 140 cases per 100,000 (NMSS, n.d.). Other countries are experiencing similarly high rates; the United Kingdom, Norway, Sweden, Germany, the Czech Republic, Hungary, and Cyprus all have rates that fall between 149 and 189 per 100,000, but Canada and San Marino have a prevalence of 291 and 250 per 100,000 respectively (Pietrangelo & Higuera, 2015).

The countries that have the highest prevalence of MS obviously experience the greatest total costs, per patient, on an annual basis. According to a review of the medical costs, Sweden, which has one of the highest rates of MS (189 per 100,000), also has one of the highest documented total medical costs per patient, estimated to be \$54,465 annually, while the weighted average of MS care is \$41,335 per year (Trisolini, Honeycutt, Wiener, & Lesesne, 2010). It is probable, due to the age of the review from which the figures were obtained, that the current cost is much higher. Additionally, these estimates of care for MS patients only factor in the direct and indirect medical costs, such as loss of income due to early retirement, informal care, professional home care, hospitalizations, prescriptions, and disease-modifying drugs. The true cost is much higher, as the direct and indirect costs do not include intangible costs, such as the quality of life, utility measures, and the impact on family and friends (Trisolini et al., 2010). More severe, debilitating cases of MS take an enormous toll on the healthcare system as well as an association with severely reduced quality of life for not only the patient, but also the family and other care or support systems.

It has been speculated that over 400,000 people are currently living with the symptoms of MS in the United States, with the actual number estimated to be much higher due to the invisible symptoms that often accompany the disease, as well as the lack of a national registry (NMSS, n.d.). The cost of medications alone for the management of symptoms is estimated to be between \$20,000 and \$30,000 annually, with the cost for treating an exacerbation at just under \$13,000 per episode (RMMSC, 2015); however, since MS typically occurs during what is considered to be the most productive years (between 16 and 45 years of age), the cost is much higher when the loss of future wages due to inability to work outside of the house is factored in,

which increases the annual cost for the treatment of the disease in the United States to over \$50,000, or \$2.2 million to cover the lifetime costs associated with MS (RMMSC, 2015).

A study of the personal and social impact MS has on the patients in Europe revealed that the burden, both financially and in terms of the quality of life experienced are quite high. It is thought that the burden increases as the disease progresses, as the majority (80%) of individuals who have received a diagnosis experience impaired mobility within 10-15 years (Pike, Jones, Rajagopalan, Piercy, & Anderson, 2012), which is frequently associated with low employment rates (Jennum, Wanscher, Frederiksen, & Kjellberg, 2012). The low employment rates place a higher toll on the caregivers and MS patient, leading to significant socioeconomic impact.

Reduced mobility, often associated with MS, has been found to be strongly related to a decreased quality of life in regards to health-related disorders, not only for the patient, but in terms of the financial, emotional, and physical burden placed on the caregivers, both formal and informal (Pike et al., 2012). Such burdens can be considerable, with caregivers experiencing a decreased quality of life as well. Reduced mobility has also been shown to have an influence on the development of psychosocial issues, such as the development of clinical depression and anxiety, sexual dysfunction, changes in cognitive ability, and an increase in the amount of demoralization and grief experienced by MS patients (Kirzinger, Jones, Siegwald, & Crush, 2013). The combination of psychosocial and socioeconomic impact that has been observed to occur in patients with MS and their caretakers can have a severe effect on the quality of life.

The amount of health care resource utilization also increases when an individual with MS experiences mobility problems, with increases most often witnessed in primary care visits, urology consultations, therapy appointments, and the use of expensive long-term drug use outside of disease modifying therapies (Pike et al., 2012). The utilization of these services,

however, has been observed to decrease when educational programs and interventions specifically aimed at improving the ability of the individual to increase his or her mobility, leading to a positive socioeconomic impact (Pike et al., 2012).

While some individuals with MS may experience fewer symptoms and not become debilitated by the disease, others are not as fortunate. Early detection of potential symptoms of MS can help to prompt the use of the educational program, which, according to various studies can help to improve the outcome, while reducing the number of visits to physicians and hospitals for MS-related symptoms (Demaille-Wlodyka et al., 2011). It is hoped that the introduction of an MS educational program will:

- Reduce the number of hospital visits/admissions
- Decrease the overall cost associated with treating MS
- Increase the self-efficacy of patients
- Reduce the disease burden on the family and caregivers
- Increase the quality of life experienced by the patients, family, caregivers, and support system
- Increase adherence to treatment protocols
- Increase symptom management by patients

Considering the enormous cost of MS to the healthcare system, patient education is a relatively inexpensive solution to decrease total as well as individual cost of the disease process. Costs included approximately 80 hours of advance practice nurse (APN) labor, printing, and universal serial bus (USB) thumb drives for patients.

Table 2: *Actual cost of project*

Conference room and audiovisual equipment	Provided by practice
APN labor for prep (design of education modules, teaching, data collection and analysis)	80 hours @ \$50/hr = \$4000
Printing	\$35
USB drives	20 @ \$9/each = \$180
Gift cards for participants	20 @ \$15/each = \$300
Total	\$4515

Mission, Vision, Goals

The mission of the MS education project focused on providing education to newly diagnosed MS patients, families, and caregivers with the ultimate goal of determining the impact of education on patient activation and self-efficacy. By expanding the information to others outside of patients, families and caregivers can learn what to expect as well as understand how to identify symptom progression. Additionally, the education presented can help to enhance knowledge and facilitate self-management through having a better understanding of the disease process (Lillyman & Farquharson, 2013). Other goals of the MS educational project include:

- Realistic expectations, which will result in less fear
- Improved self-care and symptom management
- Decreased quantity and severity of exacerbations
- Decreased hospitalizations due to MS symptoms
- Increased quality of life for both the patients and their caregivers

The MS education program fits well with the established vision and goal of the MS Society. Through providing a structured MS education training session to each newly diagnosed MS patient and their families, offering it as a standard practice measure can enhance knowledge and facilitate a better understanding of the disease process (Lillyman & Farquharson, 2013).

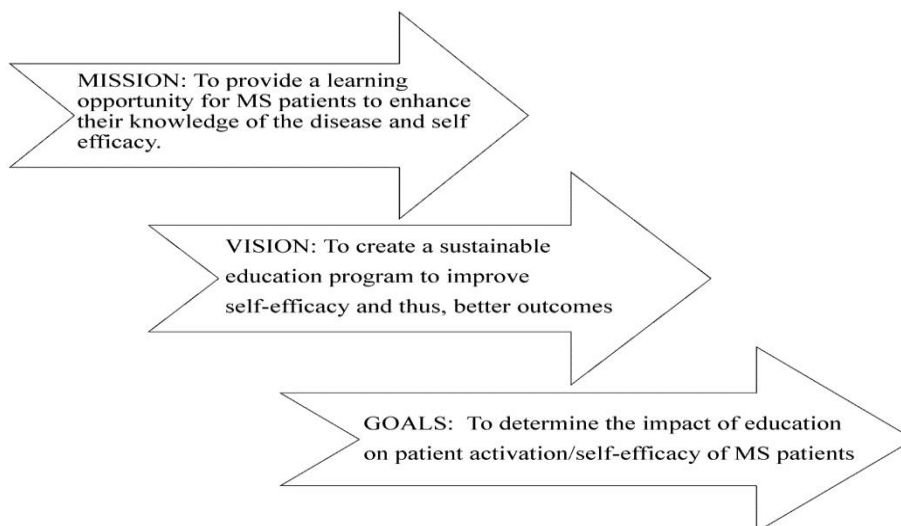


Figure 3. Mission, Vision, Goals

Primary Outcome Objectives and Measures

In this capstone project, the primary outcome measure is the ability of the patients to assume increased responsibility of their disease process and become more independent in their care as a result of increased knowledge. Terry (2012, p. 1) states, “In the broadest sense, outcomes in health care are the result of interventions based on the use of clinical judgment, scientific knowledge, skills, and experience.” Increased knowledge will be determined by the pre- and post-educational intervention levels attained by the patients during the intervention. Subjective evaluation of independent symptom(s) management and appropriate utilization of health care resources could be considered as well. These markers were selected as primary outcome measures for the potential contribution to future patients and healthcare professionals who work with MS patients.

Logic Model

The proposed conceptual model of MS education, as seen in Table 2, addresses the community assets that will be needed to implement a structured curriculum as well as the strategies to reach the goal and the assumptions behind both the how and why the educational program will work in the community. The intended location of the educational program is a neurological office in the southern United States. The goal of the proposed program is to create a uniform program that can provide patients with enhanced knowledge of MS and increased confidence related to self-care activities. In order to measure the usefulness of the program, the Multiple Sclerosis Knowledge Questionnaire (MSKQ) will be implemented to test the knowledge prior to the educational intervention, and then upon completion of the program (See Appendix A for logic model).

Table 3: *Conceptual Model of Multiple Sclerosis Education*

Problem or Issue	Patients who have been diagnosed with MS can often feel defeated after receiving their diagnosis. In some instances, doctors and other healthcare professionals may inform the patient of the diagnosis without providing education. In turn, the patient may experience stress associated with the diagnosis.
Community Needs/Assets	A formal, structured, reproducible educational curriculum which will include pathophysiology, symptom expectations, treatment options, and prognosis is needed for newly diagnosed MS patients.. The program will require the participation from patients, providers, and technical assistance for program implementation.
Desired Results (outputs, outcomes, and impact)	An increase in knowledge resulting in a decrease of unrealistic expectations of patients related to their disease. An increase in patient education leading to an increase in patient enrollment in treatment options.

	<p>More effective symptom management.</p> <p>Comprehensive program that can provide education to both healthcare professionals and patients.</p> <p>A more informed community.</p> <p>A healthier patient population with greater quality of life.</p>
Influential Factors	<p>Time available to develop the program.</p> <p>Money to fund the research and implementation of the program.</p> <p>The facilities available to hold the training for the clinicians and healthcare professionals, as well as the patients who have been diagnosed with MS.</p>
Strategies	<p>Through the creation and distribution of promotional materials and educational curricula, more patients can benefit from a specialized program that can be designed for use nationwide.</p> <p>Providing health screenings and training for hospital settings which can help to identify patients that would benefit from the intended intervention and educational program.</p> <p>Include patients and providers in the decision making process for program implementation.</p>
Assumptions	<p>The more information a patient has, the better informed he or she will be about the reality of the disease progression, as well as the treatment options that are available.</p> <p>Education about health issues can increase the quality of life for people who are affected by MS.</p> <p>Communities can influence public policy if they are informed of the potential benefits the intended changes can contribute to public health.</p> <p>Information fuels decision making ability.</p>

Population and Sampling

Sample sizes are critical to the overall outcome of a study, as a small sample size may not have enough power to detect a change, resulting in a type II error (Polit, 2010) and may not capture an accurate representation of the larger population. When working with a homogenous population, as in the case of patients who have been diagnosed with MS, purposive sampling was deemed an appropriate method (Terry, 2012). Due to the confines of the parameters (patients diagnosed with MS in one clinic in the United States), the sample was relatively small, but still representative of the target demographic.

To secure the convenience sample, flyers announcing the program were placed in strategic locations where MS patients frequent such as the physician's clinic, a neurological rehabilitation unit, and two MS Society branch offices. Enrollment was open to MS patient age 18 and older who could read and write English and their caregivers as well as interested staff persons. Non-English speaking patients and patients under the age of 16 were excluded. Participation could cease at any time, as participation was voluntary.

A power analysis with an alpha of 0.05 suggested a sample size of 50 participants for a medium power of 80 percent (Polit, 2010). The relatively small sample size of 11 used in the study proved to be a challenge when attempting a power analysis. When using a larger sample size, the power is also larger. The larger the power, the more likely the results will be accurate (Polit, 2010). In order to assess the effect size, it will be necessary to calculate the mean of the pre-intervention minus the mean of the post-intervention, divided by the common error variance, resulting in a d value; a d value of 0.2 would suggest a small effect size and a d value of 0.8 would indicate a large effect size (Polit, 2010). Using a paired t-test has much more statistical

power when the difference between the groups is small relative to the variation within groups (McDonald, 2014).

Protection of Human Rights

The proposed research will involve the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior. This information, along with the fact that the study will not involve members of vulnerable populations, meets exempt status as defined by the Department of Health and Human Services Code of Federal Regulations (DHS, 2009), and will allow for an exempt status request of the Regis University IRB (See Appendix B for IRB approval). The identified MS specialty practice does not possess an IRB, therefore outside approval will not be required (See Appendix C for letter of support). Participation will be voluntary, and patients may withdraw from the study at any time, without penalty or loss of benefits, and their responses will remain confidential.

The study posed minimal risk to participants, there was, however, a possibility of the measurement tools causing anxiety for patients. Debriefing, emotional support, or counseling services were available by a certified MS nurse and qualified mental health provider if needed. Information obtained was not be recorded in such a manner that patients can be identified, directly or through identifiers linked to the patients; and no disclosure of the human participants' responses outside the research could reasonably place the patients at risk for criminal or civil liability or be damaging to the patient's' financial standing, employability, or reputation, keeping in line with the code set forth by the U.S. Department of Health and Human Services (2009).

Anonymity and confidentiality was protected by the use of numbers rather than names, and data was aggregated to further protect confidentiality. Furthermore, the information will be

kept confidential, as the investigator will be the sole user of the data, which will be stored on a password-encrypted computer. According to the guidelines, the de-identified data will be kept in locked storage for three years. In addition, the primary investigator completed the Collaborative Institutional Training Initiative (CITI) as part of the human research curriculum as requested by faculty. (See Appendix D for CITI certificate).

Reliability/Validity of Instruments

This study utilized a single group, quasi-experimental design with a pre-test and post-test approach. The sample population was chosen through convenience sampling of patients with a confirmed diagnosis of MS. The difference in the amount of knowledge and self-efficacy gained due to the educational intervention was measured using the Multiple Sclerosis Knowledge Questionnaire (MSKQ) (See Appendix E for permission for use and instrument). The MSKQ is highly reliable with a reported Cronbach's alpha of 0.76 reliability (Ghojazadeh, Taghizadeh, Abdi, Azami-Andalib, & Farhouni, 2014) by means of the Kuder-Richardson method. Additionally, the MSKQ was developed with the concept in mind that a structured and targeted educational intervention is one of the main predictors in regards to knowledge about MS symptomatology, treatment options, and prognosis (Giordano et al., 2010), which made the MSKQ ideal for the current study.

The Patient Activation Measure (PAM) scale was administered in conjunction with the MSKQ to ascertain the level of knowledge, skills, and confidence the patients had managing their own health and healthcare (See Appendix F for permission for use and instrument). The PAM is a valid, highly reliable, unidimensional, probabilistic Guttman-like scale that reflects a developmental model of activation. The Rausch method of reliability for the 13-item PAM was 0.85 and Cronbach's alpha was 0.87 (Hibbard, Stockard, Mahoney, & Tusler, 2004).

Treatment Procedure and Data Collection

The treatment/intervention education project consisted of four, two-hour sessions held every other week at a multiple sclerosis specialty center in a southwestern state. Informed consent was not required per the Department of Health and Human Services Code of Federal Regulations (DHS, 2009); however, an information sheet was provided at the first education session. The information sheet included contact information for the investigator, capstone chair and Regis IRB (See Appendix G for information sheet).

The PAM and MSKQ pre-tests were completed during the first session. Each sessions included a 35-slide power point presentation with numerous pictures, diagrams, and information appropriate for the identified topics including references. Topics included anatomy and pathophysiology, diagnosis and treatment options, MS clinical features and symptom management, alternative therapies, the Affordable Care Act and self-efficacy and cost containment (see Appendix H for module outline).

A PAM and MSKQ post-test were completed following the conclusion of the fourth session. All participants were provided with a thumb drive containing all module content, six volumes of the National Multiple Sclerosis program *Knowledge is Power*, other public information from the National MS Society as well as additional MS patient education and reference materials collected by the investigator during the past two years of private practice. There were 58 documents included on the drive.

Project Findings and Results

In order to assess the effectiveness of the educational intervention utilized in this Capstone project, a quantitative approach was used. Through comparing the pre- and post-

intervention scores that were achieved on the Multiple Sclerosis Knowledge Questionnaire (MSKQ) and the Patient Activation Measure (PAM), the effect of the educational intervention was identified. Because the same participants completed the PAM and MSKQ before the educational intervention as well as after completion, a paired samples t-test was used to analyze the statistical significance of the data (Polit, 2010).

Statistical Package for the Social Sciences (SPSS), version 23 was used to examine the data that was gathered from both the MSKQ and PAM patient scores, with the raw data recorded on a Microsoft Excel spreadsheet. A spreadsheet was selected due to the small sample size and the ability to observe the difference in MSKQ and PAM scores easily. The data sets for the MSKQ and PAM scores, both before and after the educational intervention were normal, with skewness and kurtosis within acceptable ranges, which supported the use of the paired samples t-test statistical analysis. Kolmogorov-Smirnov and Shapiro-Wilk tests confirmed normality.

Results

Due to participant dropout, there were only 10 individuals who completed both pre- and post-test conditions of the PAM assessment; the scores obtained from participants two, five, and ten were excluded from analysis due to the individuals being unable to complete one of the pre- or post-test conditions. Eleven individuals completed both pre- and post-test conditions of the MSKQ assessment, with all 11 scores factored into the final statistical analysis of the MSKQ.

Scores for the pre-test condition of the PAM ranged from 45 to 91 (out of a possible 100), with a mean of 64 and a standard deviation of 13 for the 10 participants who completed both the pre- and post-test conditions. The difference between the two conditions was found to not be statistically significant ($p = 0.22$) and the result size is *not* significant at $p < 0.05$. For the post-test condition of the PAM, the scores ranged from 47 to 100, with a mean of 72 and a standard

deviation of 17. The scores on the MSKQ during the pre-test condition ranged from 44 to 100 (out of a possible 100), with a mean of 75 and a standard deviation of 16. The difference between the two conditions was found to be statistically significant ($p = 0.002$), making the result significant at $p < 0.05$.

Table 4

Pre and Post means \pm SD for the PAM outcome measures with an estimate of effect size using Cohen's D

	<u>Pre \pm SD</u>	<u>Post \pm SD</u>	<u>p</u>	<u>Cohen's D</u>
<u>PAM</u>	64.0 \pm 13.0	71.8 \pm 17.4	0.22	0.49
<u>MSKQ</u>	74.55 \pm 16.42	92.36 \pm 8.29	0.01	1.37

Table 5

Pre and Post means \pm SD for the MSKQ outcome measures with ITT analysis with an estimate of effect size using Cohen's D

	<u>Pre \pm SD</u>	<u>Post \pm SD</u>	<u>p</u>	<u>Cohen's D</u>
<u>PAM</u>	64.4 \pm 13.2	71.9 \pm 16.41	0.11	-0.50
<u>MSKQ</u>	74.15 \pm 17.09	89.23 \pm 13.50	0.01	-0.98

Based on the data obtained, the effect size between the pre- and post-test conditions in regards to the PAM, the Cohen's d was 0.49, which is considered to be a medium effect size (Polit, 2010). The difference between the pre- and post-test conditions in regards to the MSKQ scores provided a Cohen's d of 1.37, which is considered to be a relatively large effect size. Such a result would suggest that the educational intervention program used in the current study

was effective in expanding the knowledge base of the participants in regards to MS. Since the MSKQ has been observed to be both a reliable and a valid method of measuring MS knowledge, it can be ascertained that the results obtained in the current study regarding the MSKQ are also valid (Giordano et al., 2010).

Because intention-to-treat (ITT) is a cornerstone principle in the interpretation of randomized clinical trials (Detry & Lewis, 2014), the data was analyzed using this statistical test in addition to regular analysis. ITT includes every subject and ignores noncompliance, protocol deviations, withdrawal, and anything that happens after randomization. ITT avoids overoptimistic estimates of the efficacy of an intervention resulting from the removal of non-compliers by accepting that noncompliance and protocol deviations are likely to occur in actual clinical practice. The ITT outcomes provided similar data to regular analysis (See Table 4).

Discussion

The results from the current study suggest the educational intervention was effective at increasing the amount of knowledge for participants with respect to their disease and symptoms. Previous research has supported the claim that an educational intervention can help to increase the self-management practices as well as the health of those who complete such programs (Lorig et al., 2001). The results from the current study help to support this claim, as the scores on the MSKQ in the current study showed a statistically significant difference between the pre- and post-test points, with the majority of the participants experiencing an increase from their pre-test condition scores.

The hypotheses for the current study were supported by the results presented, as there was a difference between the mean values in the pre- and post-test conditions, following the introduction of the educational intervention. The use of targeted and structured educational

interventions for providing disease education to patients diagnosed with MS has been shown to be effective in providing a realistic picture of a progressive disorder such as MS (Giordano et al., 2010). Again, the results of the current study supported the previous research claims on the topic of educational interventions, specifically in regards to MS.

Limitations and Recommendations

Although the sample size was small and homogenous in regards to ethnicity (all participants were Caucasian), each participant served as his or her own control (pre-test condition), thus reducing the potential threat to internal validity. While the lack of diversity in the current study did not appear to have an influence on the effectiveness of the educational intervention, future studies could benefit from including individuals from a variety of cultural backgrounds, as some studies suggest that there may be a difference due to skin tones in regards to the development of MS (Langer-Gould, Brara, Beaber, & Zhang, 2013). If a difference exists, this difference could help to shape the course materials used in educational interventions for a more tailored experience.

Going forward, a longitudinal study with a larger sample size consisting of a diverse patient population would be recommended. Including a variety of ages and ethnicities could lead to a greater understanding of the effect of an educational intervention across a diverse population. While there are a variety of educational programs in place across the country for MS patients and their caretakers, development of a universal program providing the most current information and advances in research would be suggested. Such programs should incorporate a variety of topics, including the importance of exercise, the role stress management plays in effective symptom management, in addition to disease education and treatment options.

While the idea of mandatory education may seem improbable, other countries have surpassed the United States in regards to the educational programs that are devoted to MS patients and their caregivers, often with much higher rates of MS than currently found in the United States. Through the implementation of a mandatory disease education program for newly diagnosed MS patients, the quality of life for MS patients and their caregivers can be improved, in addition to reducing the burdensome cost associated with care. The development of a national as well as a global registry for MS can also help to gain a better grasp of the severity of MS on a national and global scale, which can assist further research endeavors.

Conclusion

Currently, there is no requirement for patient education for newly diagnosed MS patients. As our health system is not nationalized, there is no way to mandate such a requirement; however, the literature and the results of this capstone project clearly show the benefit of patient education. Newly diagnosed MS patients lack an adequate understanding of their disease process, leading to fear, anxiety, and poor coping skills, which often cause poor self-care, resulting in a diminished quality of life. With utilization of an effective educational program, costs associated with treating MS may decrease, while allowing patients to enjoy a greater sense of autonomy and self-efficacy.

References

- Adamczyk, K., Flis, D, Zaraycka, D., & Rejszel, E. (2002). Level of health education among neurological patients. *Patient Education and Counseling, 47*, 63-68.
- Bandura, A. (1993). Perceived self-efficacy in cognitive development and functioning. *Educational Psychologist, 28*(2), 117-148.
- Bandura, A. (1994). Self-efficacy. In V. S. Ramachandran (Ed.), *Encyclopedia of human behavior* (4th ed., pp. 71-81). New York, NY: Academic Press.
- Battersby, M., Von Korff, M., Schaefer, J., Davis, C., Ludman, E., Greene, M., Parkerton, M., & Wagner, E. (2010). Twelve evidence-based principles for implementing self-management support in primary care. *The Joint Commission Journal on Quality and Patient Safety, 36*(12), 561-570.
- Ben-Zacharia, A. B. (2011). Therapeutics for multiple sclerosis symptoms. *Mount Sinai Journal of Medicine, 78*(2), 176-191.
- Change Management. (n.d.). The Kurt Lewin change management model. Retrieved from http://www.change-management-coach.com/kurt_lewin.html
- Coulter, A., Entwistle, V., & Gilbert, D. (199). Sharing decision with patients: Is the information good enough? *British Medical Journal, 318*(7179), 318-322.
- Demaille-Wlodyka, S., Donze, C., Givron, P., & Gallien, P. (2011). Self care programs and multiple sclerosis: Physical therapeutics treatment - literature review. *Annals of Physical and Rehabilitation Medicine, 54*, 109-128.

- Detry, M., & Lewis, R. J. (2014). The intention-to-treat principle: How to assess the true effect of choosing a medical treatment. *JAMA Guide to Statistics and Methods*, 312(1), 85-86. doi:10.1001/jama.2014.7523
- Ennis, M., Thain, J., Bogglid, M., Baker, G. A., & Young, C. A. (2006). A randomized controlled trial of health promotion education programme for people with multiple sclerosis. *Clinical Rehabilitation*, 20(9), 783-792.
- Ghojzadeh, M., Taghizadeh, M., Abdi, S., Azami-Aghdash, S., Andalib, S., & Farhoudi, M. (2014). Fear of disease progression in patients with multiple sclerosis: Associations of anxiety, depression, quality of life, social support and knowledge. *Journal of Clinical Research & Governance*, 3(2), 141-146. doi:10.13183/jcrq.v3i2.105
- Giordano, A., Uccelli, M. M., Pucci, E., Martinelli, V., Borreani, C., Lugaresi, A., & Solari, A. (2010). The Multiple Sclerosis Knowledge Questionnaire: A self-administered instrument for recently diagnosed patients. *Multiple Sclerosis*, 16(1), 100-111.
- Greene, J., & Hibbard, J. H. (2012). Why does patient activation matter? An examination between the relationship between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 27(5), 520-526. doi:10.1007/S11606-011-1931-2
- Hessen, C., Kasper, J., Kopke, S., Richter, T., Segal, J., & Muhlhauser, I. (2007). Informed shared decision making in multiple sclerosis: Inevitable or impossible? *Journal of Neurological Science*, 259(1-2), 109-117.
- Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research*, 39(4), 1005-1026.

Houser, J., & Oman, K. S. (2011). *Evidence-based practice: An implementation guide for healthcare organizations*. Sudbury, MA: Jones & Bartlett Learning.

Jennum, P., Wanscher, B., Frederiksen, J., & Kjellberg, J. (2012). The socioeconomic consequences of multiple sclerosis: A controlled national study. *Journal of the European College of Neuropsychopharmacology*, 22(1), 36-43. doi: 10.1016/j.euroneuro.2011.05.001

Kasper, J., Kopke, S., Muhlhauser, I., & Heesen, C. (2006). Evidence-based patient information about treatment of multiple sclerosis: A phase one study on comprehension and emotional responses. *Patient Education and Counseling*, 62(1), 56-63.

Kirzinger, S. S., Jones, J., Siegwald, A., & Crush, A. B. (2013). Relationship between disease-modifying therapy and depression in multiple sclerosis. *International Journal of MS Care*, 15(3), 107-112. doi: 10.7224/1537-2073.2012-036

Kopke, S., Richter, T., Kasper, J., Muhlhauser, I., Flachenecker, P., & Heesen, C. (2012). Implementation of the patient education program on multiple sclerosis relapse management. *Patient Education and Counseling*, 86,91-97.

Langer-Gould, A., Brara, S. M., Beaber, B. E., & Zhang, J. L. (2013). Incidence of multiple sclerosis in multiple racial and ethnic groups. *Neurology*, 80(19), 1734-1739. doi:10.1212/WLN.0b013e3182918cc2

Lillyman, S., & Farquharson, N. (2013). Self-care management education models in primary care. *British Journal of Community Nursing*, 18(11), 556-560.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Bandura, A., Ritter, P., . . . Holman, H. R. (2001). Evidence suggesting that a chronic disease self-management

program can improve health status while reducing hospitalization: A randomized trial. *Medical Care*, 37(1), 5-14.

Melnyk, B. M., & Fineout-Overholt, E. (2011). Evidence-based practice in nursing and healthcare: A guide to best practice. 2nd ed. Philadelphia, PA: Wolters Kluwer/Lippincott Williams & Wilkins.

McDonald, J. H. (2014). Paired t-test. Retrieved from <http://www.biostathandbook.com/pairedttest.html>

Motl, R. W., & Snook, E. M. (2008). Physical activity, self-efficacy, and quality of life in multiple sclerosis. *Annals of Behavioral Medicine*, 35(1), 111-115.

National Multiple Sclerosis Society. (n.d.). Wellness for people with MS: The National MS Society responds. Retrieved from <http://www.nationalmssociety.org/About-the-Society/News/Wellness-for-People-with-MS---the-National-MS-Soci>

O'Hara, L., De Souza, L. H., & Ide, L. (2000). A Delphi study of self-care in a community population of people with multiple sclerosis. *Clinical Rehabilitation*, 14(1), 62-71.

Pearson, M. L., Mattke, S., Shaw, R., Ridgely, M. S., & Wiseman, S. H. (2007). Patient self-management support programs: An evaluation. Retrieved from <http://www.ahrq.gov/research/findings/final-reports/ptmgmt/ptmgmt.pdf>

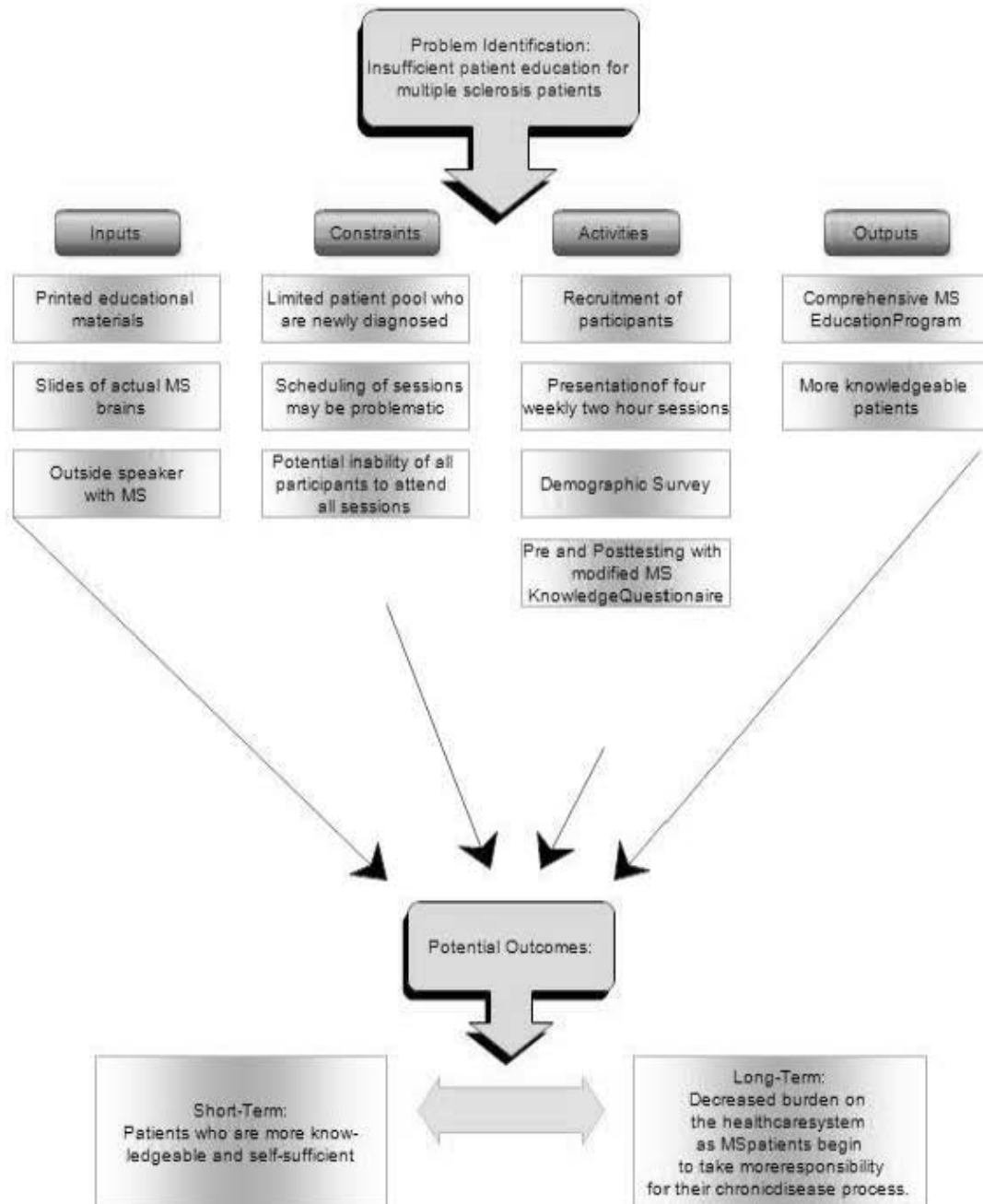
Pike, J., Jones, E., Rajagopalan, K., Piercy, J., & Anderson P. (2012). Social and economic burden of walking and mobility problems in multiple sclerosis. *BMC Neurology*, 12, 94-102.

- Pietrangelo, A., & Higuera, V. (2015). Multiple sclerosis by the numbers: Facts, statistics, and you. Retrieved from <http://www.healthline.com/health/multiple-sclerosis/facts-statistics-infographic>
- Polit, D. F. (2010). *Statistics and data analysis for nursing research* (2nd ed.). Upper Saddle River, NJ: Pearson Education, Inc.
- Rae-Grant, A. D., Turner, A. P., Sloan, A., Miller, D., Hunzinker, J., & Haselkorn, J. K. (2011). Self-management in neurological disorders: Systematic review of the literature and potential interventions in multiple sclerosis care. *Journal of Rehabilitation Research & Development*, 48(9), 1087-1100.
- Rigby, S. A., Domenech, C., Thornton, E. W., Tedman, S., & Young, C. A. (2003). Developmental and validation of a self-efficacy measure for people with multiple sclerosis: The multiple sclerosis self-efficacy scale. *Multiple Sclerosis*, 9(1), 73-81.
doi:10.1191/1352458503m870oa
- Rocky Mountain Multiple Sclerosis Center. (n.d.). MS: The basics. Retrieved from <http://www.mscenter.org/education/ms-the-basics>
- Shaw, M. K., Davis, S. A., Fleischer, A. B., & Feldman, S. R. (2014). The duration of office visits in the United States, 1993-2010. *The American Journal of Managed Care*. Retrieved from <http://www.ajmc.com/publications/issue/2014/2014-vol20-n10/The-Duration-of-Office-Visits-in-the-United-States-1993-to-2010>
- Solari, A., Martinelli, V., Trojano, M., Lugaresi, A., Granella, F., Giordano, A., & Borreani, C. (2010). An information aid for newly diagnosed multiple sclerosis patients improves disease knowledge and satisfaction. *Multiple Sclerosis*, 16(11), 1393-1405.

- Stuifbergen, A. K., Seraphine, A., & Roberts, G. (2000). An explanatory model of health promotion and quality of life in chronic disabling conditions. *Nursing Research, 49*(3), 122-129.
- Taraghi, Z., & Ilali E. (2010). Quality of life among multiple sclerosis patients. *Journal of Applied Science, 10*(14), 1485-1488.
- Terry, A. J. (2012). *Clinical research for the doctor of nursing practice*. Sudbury, MA: Jones & Bartlett Learning.
- Trisolini, M., Honeycutt, A., Wiener, J., & Lesesne, S. (2010). Global economic impact of multiple sclerosis. Retrieved from http://www.msif.org/wp-content/uploads/2014/09/Global_economic_impact_of_MS.pdf
- U.S. Department of Health & Human Services. (2009). IRBs and assurances. Retrieved from <http://www.hhs.gov/ohrp/assurances/index.html>
- Zaccagnini, M. E., & White, K. W. (2014). *The doctor of nursing practice essentials: A new model for advanced practice nursing*. Sudbury, MA: Jones and Bartlett Publishers.

Appendix A

Multiple Sclerosis Logic Model



Appendix B



Academic Grants

3333 Regis Boulevard, H-4
Denver, CO 80221-1099303-458-4206
303-964-5528 fax
www.regis.edu

IRB – REGIS UNIVERSITY

February 3, 2015

Anna Parton
8116 Golden Eagle Road
Ft. Collins, CO 80528**RE: IRB #: 15-057**

Dear Ms. Parton:

Your application to the Regis IRB for your project, “A Multiple Sclerosis Education Module to Promote Patient Activation and Efficacy”, was approved as an exempt study on February 2, 2015. This study was approved per exempt study category of research 45CFR46.101.b(#2).

The designation of “exempt” means no further IRB review of this project, as it is currently designed, is needed.

If changes are made in the research plan that significantly alter the involvement of human subjects from that which was approved in the named application, the new research plan must be resubmitted to the Regis IRB for approval.

Sincerely,

Patsy McGuire Cullen, PhD, PNP-BC
Chair, Institutional Review Board
Professor & Director
Doctor of Nursing Practice & Nurse Practitioner Programs
Loretto Heights School of Nursing
Regis University

cc: Patsy Cullen, PhD

Appendix C

**ADVANCED
NEUROLOGY
OF COLORADO,
LLC**

*Diplomate American Board
of Psychiatry and Neurology*

2121 East Harmony
Suite 180
Fort Collins, Colorado 80528

PHONE: (970)226-6111
FAX: (970) 226-6707

TAMARA A. MILLER, M.D.
PATRICIA FODOR, M.D.
JILL OLSON, M.D.
LILLIE L. DENNY R.N.
TARA BERNHARDT R.N.

October 30, 2014

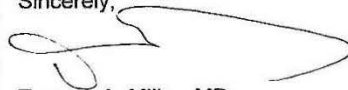
Regis University Institutional Review Board
Denver, Colorado

To Whom it may concern:

Anna Parton is a Regis University Doctoral candidate who will be conducting research and education at Advanced Neurology of Colorado in Fort Collins, Colorado for our patients with Multiple Sclerosis who currently participate in a support group. We do not have an Institutional Review Board.

This letter serves as approval for Anna Parton to conduct training and Research with the staff employed at Advanced Neurology of Colorado.

Sincerely,



Tamara A. Miller, MD
Medical Director

Appendix D

**COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)
HUMAN RESEARCH CURRICULUM COMPLETION REPORT**

Printed on 05/31/2014

LEARNER	Anna Parton (ID: 4186527)
DEPARTMENT	nursing
EMAIL	parto406@regis.edu
INSTITUTION	Regis University
EXPIRATION DATE	05/30/2017

SOCIAL BEHAVIORAL RESEARCH INVESTIGATORS AND KEY PERSONNEL

COURSE/STAGE:	Basic Course/1
PASSED ON:	05/31/2014
REFERENCE ID:	13116869

REQUIRED MODULES	DATE COMPLETED
Introduction	05/31/14
History and Ethical Principles - SBE	05/31/14
The Regulations - SBE	05/31/14
Assessing Risk - SBE	05/31/14
Informed Consent - SBE	05/31/14
Privacy and Confidentiality - SBE	05/31/14
Regis University	05/31/14

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Program course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator

Appendix E

Solari

Nov 17 (13 days ago)

Alessandra <Alessandra.Solari@istituto-besta.it>

to me

Dear Ms. Panton:

Enclosed you find the MSKQ and correct answers. Please note that this is an UK English translation (not a linguistic validation), the item on MS prevalence should be adapted. You should cite the MSKQ publication in any research product, as follows: Giordano A, Uccelli MM, Pucci E, Martinelli V, Borreani C, Lugaresi A, Trojano M, Granella F, Confalonieri P, Radice D, Solari A; SIMS-Trial group. The Multiple Sclerosis Knowledge Questionnaire: a self-administered instrument for recently diagnosed patients. *Mult Scler.* 2010; 16(1):100-111.

Sincerely,

AS

Dr. Alessandra Solari | MD Neurologist
Acting Head, Unit of Neuroepidemiology
Fondazione IRCCS Istituto Neurologico C. Besta
Via Celoria 11 | 20133 Milan Italy
tel: +39 02 2394 2391 | fax: +39 02 7060 6233
Skype: Alessandra.Solari1 | e-mail: Alessandra.Solari@istituto-besta.it
 Before printing, think about environmental responsibility

Da: Anna Parton [mailto:apartonnp@gmail.com]**Inviato:** lunedì 17 novembre 2014 03:36**A:** Solari Alessandra**Oggetto:** MSKQ

MULTIPLE SCLEROSIS KNOWLEDGE QUESTIONNAIRE

This questionnaire assesses your knowledge of multiple sclerosis. Please read each statement and tick the letter that corresponds to the answer you consider correct.

Please answer all statements, and tick only one answer for each statement.

1. Multiple sclerosis is a disease of:
 - a) The central nervous system
 - b) All body organs
 - c) Don't know

2. The central nervous system consists of:
 - a) Brain
 - b) Brain and spinal cord
 - c) Brain, spinal cord and optic nerves
 - d) Brain and peripheral nerves
 - e) Don't know

3. In the United States, multiple sclerosis affects:
 - a) About 5,000 people
 - b) About 50,000 people
 - c) About 575,000 people
 - d) Don't know

4. Multiple sclerosis significantly shortens lifespan:
 - a) True
 - b) False
 - c) Don't know

5. Multiple sclerosis is a disease of the immune system:
 - a) True
 - b) False
 - c) Don't know

6. Multiple sclerosis is a contagious disease:
 - a) True
 - b) False
 - c) Don't know

7. The causes of multiple sclerosis are still not completely clear. The most important causes seem to be:
 - a) Environmental (diet and smoking)
 - b) Environmental (alcohol consumption and infections)
 - c) Environmental (infection and smoking) and genetic (a number of genes)
 - d) Don't know

8. Multiple sclerosis is a monogenic genetic disease. It occurs as a direct consequence of a single defective gene which a parent with multiple sclerosis passes on to his/her children:
- a) True
 - b) False
 - c) Don't know
9. The likelihood of a relative of a patient with multiple sclerosis having the disease is:
- a) The same as a person with no MS in the family
 - b) Slightly higher (less than 5%) than a person with no MS in the family
 - c) Much higher (greater than 30%) than a person with no MS in the family
 - d) Don't know
10. Multiple sclerosis injures:
- a) The myelin
 - b) The axon (nerve fiber)
 - c) Both myelin and axon
 - d) Don't know
11. Multiple sclerosis can manifest at any age, but typically occurs:
- a) Before 20 years
 - b) Between 20–40 years
 - c) Between 40–60 years
 - d) Don't know
12. Multiple sclerosis occurs in:
- a) Women and men about equally
 - b) Men more than twice as often as women
 - c) Women more than twice as often as men
 - d) Don't know
13. Like the insulation of an electric wire, myelin facilitates and speeds up the transmission of nervous impulses:
- a) True
 - b) False
 - c) Don't know
14. At present there is no single test/examination that can diagnose multiple sclerosis with certainty:
- a) True
 - b) False
 - c) Don't know

15. Magnetic resonance imaging (MRI) is the examination most commonly used to confirm the multiple sclerosis diagnosis:
- a) True
 - b) False
 - c) Don't know
16. Intra-venous injection of contrast (gadolinium) during MRI reveals lesions that are:
- a) Old
 - b) Recent
 - c) Both old and recent
 - d) Don't know
17. MRI is repeated at intervals to better follow disease course over time:
- a) True
 - b) False
 - c) Don't know
18. Lumbar puncture is performed to assess the cerebrospinal fluid for antibodies (oligoclonal bands) that indicate an immune reaction typical of multiple sclerosis:
- a) True
 - b) False
 - c) Don't know
19. Lumbar puncture is repeated at intervals to better follow disease course over time:
- a) True
 - b) False
 - c) Don't know
20. A definite diagnosis of multiple sclerosis:
- a) Can require repetition of MRI
 - b) Is always possible at first disease attack
 - c) Don't know
21. "Relapsing–remitting" multiple sclerosis is characterized by:
- a) Slow and progressive deterioration in functioning (increase in disability) followed, after months or years, by attacks (relapses)
 - b) Repeated attacks (relapses) at more or less frequent intervals
 - c) Don't know
22. A person diagnosed with "clinically isolated syndrome", or "CIS":

- a) Has a disease which has nothing to do with multiple sclerosis
- b) In the event of a second attack (relapse) has confirmed multiple sclerosis
- c) Has multiple sclerosis ("CIS" is a synonym for multiple sclerosis)
- d) Don't know

23. Pregnancy worsens multiple sclerosis:

- a) True
- b) False
- c) Don't know

24. At present there is no treatment that can cure multiple sclerosis:

- a) True
- b) False
- c) Don't know

25. Disease modifying drugs are effective in:

- a) "Relapsing–remitting" multiple sclerosis
- b) "Primary progressive" multiple sclerosis
- c) Both "relapsing–remitting" and "primary progressive" multiple sclerosis
- d) Don't know

Giordano, A., Messmer Uccelli, M., Pucci, E., Martinelli, V., Borreani, C., Lugaresi, A., Trojano, M., Granella, F., Confalonieri, P., Radice, D. & Solari, A. (2010). The multiple sclerosis knowledge questionnaire: a self-administered instrument for recently diagnosed patients. *Multiple Sclerosis*, 16(1), 100-111.

Appendix F

Craig

Nov 2

Swanson <cswanson@insigniahealth.com>

to me

Anna:

Thank you for the information you provided below as well as your interest in and online order of PAM. Per the terms of your online order for your studies (PhD license category, sharing your data), I have attached the documents you need for your work:

- PAM survey and coaching guidance
- Excel sheet for entering, scoring and tracking PAM survey responses. This sheet automatically calculates PAM scores and levels.

Let me know if you have any questions. We look forward to seeing your final paper as well as the outcome data of your research.

Best regards,

Craig Swanson

(612) 998 6216

cswanson@insigniahealth.com

PAM 13 Question

Level 1	When all is said and done, I am the person who is responsible for taking care of my health
	Taking an active role in my own health care is the most important thing that affects my health
Level 2	I am confident I can help prevent or reduce problems associated with my health
	I know what each of my prescribed medications do
	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.
	I am confident that I can tell a doctor concerns I have even when he or she does not ask.
Level 3	I am confident that I can follow through on medical treatments I may need to do at home
	I understand my health problems and what causes them.
	I know what treatments are available for my health problems
Level 4	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising
	I know how to prevent problems with my health
	I am confident I can figure out solutions when new problems arise with my health.
	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.

* Related instruments: PAM 10, PAM 2, Clinician PAM



Appendix G

My name is Anna Parton. I am a doctoral student in the Loretto Heights School of Nursing at Regis University, Denver, Colorado. My contact information is: 8116 Golden Eagle Road, Ft. Collins, Colorado; 972-922-7123. I am conducting a research study entitled "A Multiple Sclerosis Education Module to Improve Patient Activation and Self-Efficacy" which seeks to determine the value of education on MS patients' ability to care for their chronic disease.

I am asking you to participate in this study because you have previously participated in other activities which have enhanced your knowledge of MS or your ability to care for your disease process. Your participation is voluntary. Choosing not to participate will not affect your access to any goods or services. There are no direct benefits to participating in the study.

I will be conducting the study by asking you to answer multiple choice question regarding your knowledge of multiple sclerosis and your involvement in your care. Participation in this study will take approximately 8 hours of your time, 2 hours on four separate dates. There will be no cost to participants.

I will not be collecting any data that can link you to the answers you provide. Your anonymity and the confidentiality of your responses will be protected as much as possible. If you are uncomfortable answering any question, you may choose to not answer that question or to stop your participation and have any notes, recordings, or hard copy answers destroyed. To further protect the confidentiality of your responses, I will not be collecting a signed consent form but will instead consider your participation in the study as consent permitting me to collect the data you provide.

Should you have any questions or concerns about participation in this study, you may contact me using the information in the first paragraph. My faculty Advisor is Dr. Colleen McCallum, email: cmccallum@regis.edu; phone: 303-964-6498.) You may also contact the Chair of the Regis University Institutional Review Board for human subjects participation by telephone at 303-346-4206; by mail at Regis University, Office of Academic Grants, 447 Main, Mail Code H-4, 3333 Regis Blvd., Denver, CO, 80221; or by e-mail at irb@regis.edu with questions or concerns, or if you feel that participation in this study has resulted in some harm.

Sincerely,



Anna C. Parton, RN, NP-C

Appendix H

A Multiple Sclerosis Education Module to Promote Patient Activation and Efficacy

I. **Session One**

- A. Introduction and brief overview of DNP research protocol
- B. Pre-test (Patient Activation Measure (PAM) and Multiple Sclerosis Knowledge Questionnaire (MSKQ))
- C. Definition of MS
 - 1. Immune system
 - 2. Inflammatory process
 - 3. Demyelination
- D. What Causes MS (epidemiology)
 - 1. Genetics
 - 2. Environmental Risk Factors
 - 3. Geography
- E. What Happens in MS
 - 1. Immune system/Blood Brain Barrier
 - 2. Inflammatory process
 - 3. B cells and T cells
 - 4. Demyelination
- F. How is MS Diagnosed
 - 1. Clinical event
 - 2. MRI
 - 3. Lumbar puncture
 - 4. Evoked potential
 - 5. McDonald Criteria
- G. Clinical Overview (symptoms as related to location of lesions)
 - 1. Sensory
 - 2. Visual and hearing
 - 3. Fatigue
 - 4. Impaired mobility (spasticity, ataxia, vertigo)
 - 5. Bowel and bladder
 - 6. Dysphagia
 - 7. Cognitive dysfunction
 - 8. Mood dysregulation

II. Session Two:

- A. Early diagnosis/Early treatment
 - 1. Decrease exacerbation
 - 2. Delay disability
- B. Treatment choices (informed decision)
 - 1. Avonex/Plegridy
 - 2. Betaseron/Extavia
 - 3. Copaxone
 - 4. Rebif
 - 5. Tysabri
 - 6. Novantrone
 - 7. Gilenya
 - 8. Aubagio
 - 9. Tecfidera
 - 10. Lemtrada

III. Session Three

- A. Clinical Features and Symptom Management
 - 1. Sensory
 - 2. Visual and hearing
 - 3. Fatigue
 - 4. Impaired mobility (spasticity, ataxia, vertigo)
 - 5. Bowel and bladder
 - 6. Dysphagia
 - 7. Cognitive dysfunction
 - 8. Mood dysregulation
- B. Alternative treatment thoughts
- C. Disclosure
 - 1. Family
 - 2. Friends
 - 3. Employer

IV. Session Four

- A. Self-Efficacy and Patient Activation
- B. Patient Responsibility
- C. Working with Your Doctor
- D. Cost Containment for Chronic Disease
- E. Affordable Care Act