THE RELATIONSHIP BETWEEN EXERCISE AND RESILIENCE
IN PEOPLE WITH MULTIPLE SCLEROSIS

by

Nyla Sue Chandler

A thesis submitted in partial fulfillment
of the requirements for the degree

of

Master

of

Nursing

MONTANA STATE UNIVERSITY
Bozeman, Montana

March 2014
# TABLE OF CONTENTS

1. INTRODUCTION .......................................................................................................... 1
   - Background and Significance of the Study.............................................................. 2
   - Statement of the Problem and Research Question .................................................. 6
   - Hypothesis ............................................................................................................... 6
   - Definition of Concepts ............................................................................................ 6
   - Limitations .............................................................................................................. 7

2. LITERATURE REVIEW ............................................................................................... 9
   - Resilience ............................................................................................................... 9
   - Exercise .................................................................................................................. 14
   - Conclusions from the Literature Review .............................................................. 19

3. METHODOLOGY ....................................................................................................... 21
   - Introduction ........................................................................................................... 21
   - Sample and Population ......................................................................................... 21
   - Procedure .............................................................................................................. 23
   - Design of the Study ............................................................................................... 24
   - Instrumentation ...................................................................................................... 24
   - Data Analysis ........................................................................................................ 27
   - Protection of Human Subjects ................................................................................ 28
   - Summary and Conclusion ..................................................................................... 29

4. PRESENTATION AND ANALYSIS OF DATA ........................................................ 30
   - Introduction ........................................................................................................... 30
   - Demographic Characteristics of the Sample ......................................................... 30
   - Analysis of Data/Descriptive Statistics .................................................................... 30
   - Hypothesis Testing ................................................................................................. 32

5. CONCLUSION ............................................................................................................. 34
   - Introduction ........................................................................................................... 34
   - Discussion .............................................................................................................. 34
   - Limitations ............................................................................................................. 36
   - Implications for Future Practice ............................................................................ 37
   - Areas for Future Study ......................................................................................... 39
   - Conclusion ............................................................................................................. 40
<table>
<thead>
<tr>
<th>REFERENCES</th>
<th>41</th>
</tr>
</thead>
<tbody>
<tr>
<td>APPENDICES</td>
<td>44</td>
</tr>
<tr>
<td>APPENDIX A: Subject Consent Form</td>
<td>45</td>
</tr>
<tr>
<td>APPENDIX B: Demographics</td>
<td>48</td>
</tr>
<tr>
<td>APPENDIX C: Godin Liesure Time Exercise Questionnaire</td>
<td>50</td>
</tr>
<tr>
<td>APPENDIX D: Resilience Scale</td>
<td>52</td>
</tr>
<tr>
<td>Table</td>
<td>Page</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>1. Summary Descriptive Statistics.</td>
<td>31</td>
</tr>
<tr>
<td>2. GLTEQ Scores</td>
<td>33</td>
</tr>
<tr>
<td>3. Resilience Scale Scores</td>
<td>33</td>
</tr>
<tr>
<td>Figure</td>
<td>Page</td>
</tr>
<tr>
<td>--------</td>
<td>------</td>
</tr>
<tr>
<td>1. Woodgate's Model Applied to MS</td>
<td>13</td>
</tr>
</tbody>
</table>
ABSTRACT

Multiple sclerosis (MS) is an autoimmune disease, in which a person’s own white blood cells to attack the fatty protective layer called myelin around nerves in the brain and spinal cord resulting in demyelinization and nerve damage. MS is typically diagnosed between the ages of 20 and 40 years old. The impact and damage is highly variable from one person to the next. Women are affected more often than men. Exercise is a pattern of physical activity and movement. Resilience is the ability to cope with change or misfortune, a fluid quality that acts to modify individual responses to risk.

The purpose of this study was to examine the relationship between exercise and resilience in people with MS. A correlational study was used to determine if a relationship exists between exercise and resilience in a convenience sample, consisting of 74 MS patients at a neuroscience center.

The hypothesis that there was a positive relationship between exercise and resilience in persons with MS was not borne out in this population. \( r = 0.094 \) indicating that there was no relationship between exercise and resilience in persons with MS.

Characteristics that may have contributed to the lower GLTEQ scores and the higher RS scores include that the sample was older, substantially unemployed, had suffered the impact of the disease for many years, and may have been living at a lower income level from those who more recently were diagnosed with MS. The convenience sample was somewhat homogeneous, and was missing younger persons who were in earlier stage of the disease. Recommended areas for future study and emphasis include; Targeting prevention from initial diagnosis instead of waiting until an MS patient has already suffered many negative outcomes. Studying a more active, fit subpopulation of MS patients may indicate a positive correlation between resilience and fitness, and therefore underscore the need for more structured, rigorous, aerobic exercise programs that would maintain and lead to fitness for those with MS.
CHAPTER 1

INTRODUCTION

Multiple Sclerosis (MS) is a disabling, chronic disease that affects an estimated 400,000 people in the United States (U.S.) (Bishop, Frain, Rumrill, & Raymond, 2009, p. 120). There are over 12,000 people with MS in the greater northwestern United States, and over 1,600 people in Montana (retrieved from www.MSsociety.org, National MS Society information, and resource center). According to the National MS Society website (retrieved 11/15/10 from www.MSsociety.org, brochure “Just the facts” pp. 2-5) this chronic neurological disease can result in gait disturbances, weakness, balance problems, fatigue, vision loss, cognitive disturbances, bowel, bladder and sexual difficulties, numbness, depression and even death. This disease is typically diagnosed among adults aged between 20 and 40 years old. Women are affected more often than men. Individuals differ in the way they respond to the challenges of this lifelong, chronic disease. Some are proactive, trying to maintain function and positivity, thriving in the face of this adversity, while others passively succumb to a negative downward spiral. The ability to thrive in the face of adversity has been termed “resilience” (Ehde & Bombardier, 2005). It is this author’s hypothesis that resilient individuals engage in more protective self-management activities such as exercise. The purpose of this study is to examine the relationship between exercise and resilience in people with MS. Focusing on promotion of protective self-management beliefs and behaviors such as exercise and
resilience may help nurses and clinicians find ways to mitigate the negative consequences of MS.

**Background and Significance of the Study**

Multiple Sclerosis is an autoimmune disease where a person’s own white blood cells attack the fatty protective layer called myelin around nerves in the brain and spinal cord which results in demyelinization and nerve damage. The course or form of this chronic disease can be relapsing-remitting (85% initially are diagnosed with this form), primary- progressive (10% of cases), secondary- progressive (in the past about 50% develop this form within 10 years of diagnosis-but treatment may reduce this percentage) or progressive-relapsing (5% of cases), and the impact and damage is highly variable from one person to the next. The diagnosis and monitoring of MS is made by evaluating a person’s medical history and neurological exam, and obtaining certain tests including magnetic resonance imaging (MRI) of the brain and possibly the spine, evoked potentials (EP) and spinal fluid analysis (MS Society brochure “Just the Facts”).

Disease modifying therapy (DMT) has the potential to reduce the percentage of people who progress from a relapsing-remitting form to more progressive forms of MS, as well as reduce the disease burden, however only 50-60% of patients are using DMTs (Bishop et al., 2009). Reasons for the lower rate of DMT use include that the therapies are very expensive, have side effects and the ongoing difficulty of maintaining and paying for insurance and co-pays is daunting.
Betaseron, a beta interferon, a self-administered injection, was approved for use for people with the most common forms of MS by the Food and Drug Administration in the early 1990’s. This DMT blocks certain white blood cells from attacking the myelin sheath that insulates nerves, and over time decreases the damage from MS. Prior to Betaseron approval there were no medications available to change the course of the disease. Over the next two decades, other DMTs were approved, including other beta interferon preparations (Avonex, Rebif, Extavia, and another self-injected medication called Copaxone (glatiramer acetate). The evidence suggested that use of these medications slowed and positively changed the natural course of MS.

The availability of magnetic resonance imagery (MRI) to detect disease activity and burden in the spine and brain was improving during this same decade. This resulted in the standard of care or cornerstone of treatment for people with most forms of MS to include advising the use of DMT, slowing the disease, reducing disease burden, and disability. These drugs were the recommended first line of treatment, reducing relapse rates and evidenced by fewer MRI changes and active lesions in the brain. In 2005, Tysabri, a monthly intravenous infusion, was approved as a second tier drug for patients whose disease was not adequately controlled, as evidenced by MRI results, by the first tier DMTs. Tysabri was also available for those people who did not tolerate the available first line DMTs. Due to the increased incidence of a fatal brain infection, the drug was taken off the market for part of 2005 and 2006 but was re-approved for use as long as patients used Tysabri as a monotherapy (not combined with another DMT), enrolled in a
monitoring program, and were aware of the risks of use. The Tysabri infusions take place once a month in clinical settings such as infusion centers.

The combination of the cost, hassle, potential risks/side effects, and time involved in pursuing DMT is substantial, but has obvious benefits for those who manage to obtain the therapies and decrease the neurological damage of MS (retrieved 7/12/12 from www.NationalMSsociety.org “Multiple Sclerosis Trend Report,” 2008). With patient education from health care givers, the MS Society, pharmaceutical company sponsored education programs, and patient assistance programs for those without financial or insurance access to DMTs, the awareness of the benefits and programs to enhance DMT use has been steadily increasing. In our fragmented health care system, MS patients must negotiate many hurdles to access DMT and then requires personal stamina to stay on the drugs.

There are many potential negative consequences and challenges that can come with MS that may compound the difficulties faced while trying to successfully manage this chronic disease. Bishop et al. (2009) state that the jobless rate among people with MS ranges between 25 to 80%, with 70 to 80% of people unemployed five years after diagnosis. Unemployment has obvious economic repercussions, impacts medical insurance coverage, and access to DMT.

Understanding the relationship between exercise and resilience will supplement the body of knowledge regarding the management of MS. Resilience and exercise have been identified as areas of future direction, to “improve our understanding of factors that will enhance emotional resilience in the face of this serious neurologic condition.” (Ehde
et al., 2005, p. 437). This day to day management does tie into employment and DMT use.

Bishop et al. (2009) compared employed versus unemployed people with MS in regard to DMT use and self-management. They state that

the central premise of self-management is that day to day management of chronic illness should rest in the hands of the patient, as opposed to medical providers, and self-management skills are a critical focus in mitigating disability and improving outcomes . . . however self-management has not received significant research attention among people with MS. p. 121.

Self-management was defined as “learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition” (p. 121). This included caring for oneself in terms of exercise and diet, and maintaining and engaging in one’s normal life activities, which included work and leisure activities. Self-management was assessed using the Multiple Sclerosis Self-management Scale (MSSM). The results, confirming a positive relationship between self-management and employment, were discussed in terms of rehabilitation intervention.

Successfully managing this disease requires many aspects of health. Exercise is a protective self-management activity that can positively impact people with MS; however, the lack of support and advice about exercise and mobility has been a notable gap in research (Hartley, 2009). It has been suggested that “exercise could lead to functional improvements in people with MS, with positive improvements reported in muscle strength, quality of life, physical functioning, mood and fatigue” (p. 35). However, advice regarding exercise and MS has been conflicted historically. Prior to around 2000,
MS patients were cautioned against exercise due to concerns about increasing fatigue and raising body temperature which potentially exacerbated symptoms.

**Statement of the Problem and Research Question**

“Protective self management beliefs and behaviors such as resilience and exercise can be a critical focus in mitigating disability and improving outcome in multiple sclerosis” (Bishop, et al, 2009, p. 121); however, the lack of research attention in this area of protective self-management beliefs and behaviors in people with MS have led to the following research question; “Is there a relationship between exercise and resilience in people with multiple sclerosis in northwestern United States?”

**Hypothesis**

There is a positive relationship between exercise and resilience in people with MS. The hypothesis is based on the idea that there may be a synergistic strengthening of each of these protective factors; i.e. exercise may be self-perpetuating, and increase levels of confidence, functioning, stamina and coping mechanisms, and thus increase resilience. Increasing resilience may increase the capacity for exercise leading to better function. Better functioning would result in increased quality of life and health.

**Definition of Concepts**

In this section operational and theoretical definitions will be provided for all of the variables and concepts of interest.
1) Exercise is a pattern of physical activity and movement, and will be measured with the Godin Leisure Time Exercise Questionnaire (GLTEG) (Godin & Shepherd, 1985).

2) Resilience is the ability to cope with change or misfortune, a fluid quality that acts to modify individual responses to risk, and will be measured by the Resilience Scale (RS) (Wagnild & Young, 1990).

Assumptions

The first assumption is that it is necessary to guide nursing practice and research using the models and theories produced by nurses who have established these frameworks in a studied, accepted fashion. The second assumption is that there are many theories that could be used in this type of research as long as these theories dealt with individuals at risk from certain health conditions and the protective factors that can lead this person to adapt in a healthy manner. The third assumption is that a researcher will choose a theorist based on assessment of how closely that theorist’s work fits with the problem being studied, and the choice will reflect the researcher’s own professional and private life experiences. The fourth assumption is that each project or thesis is limited in scope and breadth of study.

Limitations

This project will be limited by time. There are financial limitations, as no funding will be available for the project. Another limitation will be that the study will be
gathering information from subjects only once, not over a period of time. The sample size may be limited as well, as it is unknown how many MS patients will consent to be in the study and complete the questionnaires.
This chapter provides an in depth discussion of the concepts relevant to this study; namely resilience, exercise and MS. The midrange nursing theory of resilience of R. Woodgate (1999) will be introduced to provide a construct for resilience in people with MS.

Resilience

Wagnild and Young (1990) discuss and identify characteristics of older women who have successfully adjusted after a major loss in their lives. They described resilience as “a fluid quality that acts to modify individual responses to risk” (p.254). This quality was an emotional stamina that helped these women to survive their loss in a healthy, adaptive manner that allowed them to reconstruct their lives in a meaningful way.

The five characteristics constituting the “resilience core” (Wagnild, 2009) are:

1) A purposeful life (having a sense of meaning in one’s existence).
2) Perseverance (the ability to keep going despite difficulties),
3) Equanimity (ability to have a sense of flexibility or perspective, to not tend to define events as catastrophes),
4) Self-reliance (understanding one’s own talents or strengths, areas where one might need help, then seeking more skills/knowledge or assistance),
5) Existential aloneness/coming home to oneself (becoming comfortable with oneself, realizing and accepting who one is even if this is not popular—which is a liberating process).

Ahern, Keihl, Sole, and Byers (2006) described resilience as representing the interaction between risk factors (vulnerability) and protective resources (protection). Resilience moderated the negative effects of stress and promoted adaptation.

In Ehde and Bombadier’s literature review on depression in people with MS, biopsychosocial protective factors in people with MS who do not suffer from depression are researched as well as the risk factors for those with MS for developing a depressive disorder. The lifetime risk of major depressive disorder in persons with MS was reported to be between 22.85 and 54%. Resilience and exercise were identified as areas of future research and reported that this research will fill a gap in the knowledge of people with MS who are doing well and not suffering many of the mood disorders common in persons with MS. (Ehde et al., 2005). They went on to describe the process that many individuals experience during significant medical illnesses in which the individuals not only persevere but thrive. They term this process of adapting well in spite of these life challenges resilience. Achieving this adjustment, which is an ongoing challenge in chronic diseases like MS, “can result in feelings of increased personal strength, improved interpersonal relationships, finding new purpose and meaning in life.” “Research examining those people who do not become depressed, but who thrive while living with MS, is needed” (p.445). These researchers identified exercise as holding
promise as a means of treating major depression and recommend this as an area of future research.

Woodgate’s Model of Resilience

Woodgate developed a model of resilience to better explain coping in children with cancer. This model came to be called the Adolescent Resilience Model (ARM) (Woodgate, 1999). This model identified positive resources and patterns or strengths for successfully coping with adolescent cancer. Woodgate’s model has been applied to other conditions or stressors as well, including successful navigation of maternal adaptation among military wives (Schachman, Lee & Lederman, 2004). Excessive vulnerability factors or limited protective factors in this especially at risk population can influence whether a new military wife adapts successfully to her new role as a mother or maladapts.

With the challenges of the ongoing stressors of dealing with MS, the interacting parts of Woodgate’s model are fluid, with ongoing adjustments over time. The obvious desirable goal is that a person leans toward successful adaptation, rather than a downward spiral of maladaptation. The development and maintenance of the protective factors will hopefully result in increased resilience. Increased resilience will hopefully lead to adaptation, not maladaptation. There is a circular nature to both the negative and positive pattern (a self-fulfilling pattern), with resilience being a central determinant, or building block, or “glue” in the direction of flow.

The following figure (Figure 1), applying Woodgate’s model to MS, reveals the relationship between the stressor of MS, the vulnerability and protective factors that may
influence outcomes and coping, and the maladaptive and adaptive outcomes that may occur. Stressors of MS include the diagnosis process (MRI’s, spinal taps, evaluations by neurologists), the financial/insurance issues, decisions regarding treatment, and the physical/emotional impacts of having flare ups of disease. Vulnerability factors include the particular impact that the MS has on a person physically and cognitively, with potential secondary financial impacts such as unemployment, lack of insurance coverage, lower socioeconomic status, impact on self-esteem and family structure. Protective factors include such things as a person’s sense of self-esteem, self-reliance, discipline, personal health habits (exercise and dietary practices), resources in local community-physical or occupational therapy, family support, church or clergy support, wealth, adequate health insurance, and access to DMT. Vulnerability and protective factors can interact and influence each other, and play into a person’s resilience. Resilience can determine whether a person adapts in a negative way (Maladaptation) or positive way (Adaptation).
Stressors: Multiple Sclerosis medical diagnosis, evaluation, treatment, financial/insurance issues.

**Vulnerability Factors**
- MS severity and disease progression, loss of employment,
- Lack of insurance/Medicaid/Medicare or ability to afford DMT
- Unable to access patient assistance programs, poverty
- Lack of family or social support/low self-esteem

**Protective Factors**
- Internal resources; self-esteem, self-reliance and discipline
- External resources; family and community support
- Exercise, diet, supplements, occupational therapy, physical therapy
- Possessing wealth or having adequate insurance, access to DMT

**Maladaptation**
- Unemployment, poverty, loss of physical and cognitive function, isolation, depression, inactivity, downward spiral of disease progression and disability.

**Adaptation**
- Maintaining physical and cognitive function, employment and fulfilling roles in family and community.
- Coping with the disease in the most positive manner as possible.
- Successful navigation of US health care system in maintaining access to DMT, occupational and physical therapy.
- Maintaining a reasonable standard of living/income.

**Resilience**

Figure 1. Woodgate's Model Applied to MS.
Casperon et al. (1985), proposed definitions of physical activity and exercise and physical fitness. Physical activity was defined as bodily movement produced by skeletal muscles, thus burning calories. Exercise is a subset of physical activity, more planned, with an objective of achieving fitness. Fitness is defined as a set of health or skill attributes that are measured with specific tests, pp 130-131.

Prior to 1999, MS patients were advised to avoid exercise because of excessive fatigue and thermosensitivity (Petejan & White, 1999). However, there was some anecdotal evidence that people with MS who were actively participating in exercise were reporting that they felt long-term benefits.

Hartley (2009) developed an interdisciplinary self-management and exercise model for people with MS. Hartley went on to report that MS subjects are less active than their healthy counterparts and thus, more likely to develop cardiovascular disease and obesity. Since 1999, a number of studies suggested that regular exercise and physical activity could lead to functional improvements in people with MS, and improved muscle strength, quality of life, physical functioning, mood, and fatigue. Hartley described responses from a questionnaire of individuals with MS who had undergone a 14 week exercise program of yoga and exercise. “Feeling empowered,” and “more able to make lifestyle choices” were among the responses noted when asked regarding the results of the program (pp 39-40). It was noted that there were gaps in education on the benefits of exercise for people with MS, and availability of exercise programs for people with MS.
He stated that it “is imperative to identify the reasons people with MS choose not to participate in exercise programs,” p 42.

Garrett and Coote (2009) conducted a systematic review of the literature regarding MS and exercise into people with minimal gait impairment. Nineteen studies were categorized to four exercise parameters, aerobic, progressive resistance exercise (PRE), combined aerobic and PRE and “Other” which included yoga and aquatic exercises. The outcomes areas were; effect on body structure and function, effect on activity, and effect on participation. The exercise group results suggested positive effects in all these areas, including a decrease in fatigue and improved quality of life, as well as providing some rationale for neuroprotection, though this was not conclusive in the studies. There were no harmful effects, p.179.

Oken et al. (2004) studied yoga and exercise in persons with MS. They reported improved energy and less fatigue after a six month yoga and exercise program (compared to a control group). There was no clear improvement in cognitive function or mood in the intervention groups.

Litchfield and Thomas (2010), p.36, described NICE guidelines on MS (NICE 2003) ; an initial physiotherapy assessment followed by promotion of an individualized program “exercise on prescription” courses, or utilization of MS Therapy Centers (available in the United Kingdom) for MS specific exercise classes. They recommended integrated care for people diagnosed with MS, starting with the onset of their disease, integrating teaching and problem solving in self-care, exercise, drug therapy and checking into their health benefits and what they are entitled to (the journal article written
in the United Kingdom where the health care is a single payer system and is generally universally available).

Further studies by Motl and McAuley (2009), on pathways between physical activity and quality of life (QOL) in adults with MS, determined that people with MS are generally less active than people without MS. They were studying the negative effects (i.e. depression and decreased quality of life) that may occur with decreased activity levels with people having MS. They suggested future studies considering the positive effects as a pathway in the association between physical activity and QOL. They listed development of self-efficacy as a possible option in encouraging physical activity, as well as focusing on an enjoyable exercise experience, establishing an environment in which people feel comfortable, and developing social support both in and out of the physical activity environment. They also mentioned that this should be done early on in the course of the disease, in conjunction with the use of disease modifying therapies. They went on to “recognize the possibility of alternative models for explaining the associations among physical activity and quality of life”, p.17, and suggested future studies to explore this.

Beckerman et al. (2010) did a cross-sectional study of 106 people with MS to determine levels of activity and factors related to physical activity behavior. The authors wrote about physical activity of people with MS and understanding how they can become more physically active. Using the Person with a Disability (PAD) model as a framework, the authors encouraged interventions that promote “variables such as cognition, self-efficacy, knowledge, skills, current behavior, social support, balance between pros and
cons in decision making perceived barriers and benefits, and enjoyment,” p. 1002. They encouraged patients to find ways to keep their jobs and continue to perform work related activities, slow down the disease progression, and find support to care for their children. They recommended that individual barriers to exercise needed to be addressed and a yearly plan be developed and updated utilizing a fitness professional. They advised that this be implemented early on in the course of the disease, as people with MS were less active if their disease was more severe.

Motl et al. (2011) studied the efficacy of exercise training in regard to cognitive function in people with MS. Cognitive impairment (slowed mental processing speed and memory problems) in those with MS was reported to be between 43% and 65%. The researchers found that in older adults, cognitive function is better in those with more aerobic fitness, exercise training, and physical activity. Exercise training was found to have comparable effects on quality of life and mobility in those with MS, but that future research should examine exercise training and cognition, as this research is in its infancy. They underscored the need for this research, as cognitive impairment is implicated in life-altering aspects such as unemployment and lowered quality of life.

Measurement of physical activity must take into account the particular impact that MS has on people, including gait impairment and autonomic nervous system changes. Motl, McAuley, Snook, and Scott (2006), and Weikert and Motl (2009) looked at the validity of different measurements of physical activity in people with MS. Motl et al. (2006), studied self-report methods such as the Godin Leisure Time Exercise Questionnaire (GLTEQ) and a seven day activity recall of physical activity (the 7dPAR),
and objective methods such as pedometers and accelerometers. The authors only included ambulatory patients in their sample. The median Expanded Disability Status Scale (EDSS) score in the population studied was 2.5 (range 0-10). An EDSS score of 2.5 indicates mild disability in one functional system or minimal disability in two systems, but fully ambulatory. A score of 7 or above indicates inability to ambulate even with the help of a cane or walker. They eliminated the question on the GLTEQ that involved the sweat index, due to autonomic nervous system disturbances that can disturb sweating in those with MS. They concluded that after their study, there was stronger evidence to show that scores from the above four measures could be validly interpreted among people with MS. There is also a strong correlation between the self-report methods and the physical objective measures, and a weaker but still moderate to strong and statistically significant correlation between scores from the objective and self-report measures. Weikert et al. (2009, p. 5) measured physical activity in people with MS with the GLTEQ (using only the first part as this was consistent with previous research done on people with MS) and the short form of the International Physical Activity Questionnaire (IPAQ). They did not include the duration component of the seven day recall based on previous studies that determined problems with accuracy of memory in people with MS. Their sample had a mean Patient Determined Disease Steps scale (PDDS) disability score of 2 (range 0-6). They defended this scale as an inexpensive surrogate for the EDDS. They found the two self-report measures (the GLTEQ and the IPAQ) were strongly correlated and provided for evidence for the validity as well. They also studied an accelerometer. They discovered problems with measuring of physical
activity with an Actigraph accelerometer in people with MS (it was not accurate due to probable gait impairment) and discouraged its further use until the problem can be resolved. They concluded that previous studies and their study provided evidence of the validity of using GLTEQ and IPAQ as measures of physical activity in people with MS.

In summary, the following has been established regarding exercise and people with MS;

1) Historically, people with MS were told to not exercise until relatively recently.

2) People with MS are generally less active than their healthy counterparts, especially as the disease progresses.

3) It is generally accepted that in most cases ongoing exercise is beneficial for people with MS.

4) Autonomic nervous system changes (in regard to sweating) and memory issues potentially complicate using the available various objective and self-report measurements of physical activity/exercise in people with MS.

Conclusions from the Literature Review

Resilience and exercise are possible factors in the mediation of the course of multiple sclerosis, but the specific relationship between these two factors has not been studied or developed. These factors are measurable and modifiable and might have a positive and synergistic effect on each other. There has been little research on studying positive, protective pathways for changing health activities, habits, attitudes in the course
of MS, and little promotion or support for self-management or self-efficacy strategies in the area of exercise and coping/resilience. Given the significance of the problems that may occur for people with multiple sclerosis (see Chapter 1) and the costs to themselves and society, it is imperative that we study these protective factors. The potential benefits of understanding these factors will fill a gap in the current knowledge of MS and may improve future care of MS patients.
CHAPTER 3

METHODOLOGY

Introduction

A correlational design was chosen for this study as the researcher felt that it would reflect the direction and strength of any discovered relationship. In an effort to identify ways to mitigate the possible negative consequences of multiple sclerosis, identification of a relationship between exercise and resilience in this population could be used in developing nursing and medical practice and theory regarding these two protective factors.

This chapter will be divided into major sections including: the sample and population, sampling procedure and time frame, study design, instrumentation utilized during the study including descriptions of the instruments and data collection, discussion of how human subjects were protected, IRB approval obtained, and finally a summary and conclusion.

Sample and Population

There are approximately 2.5 million people in the world with MS (retrieved 11/15/10 from www.MSSociety.org). This is the overall study population. There are an estimated 12,000 people with MS in northwestern U.S., and 1,600 people with MS in Montana (retrieved 11/15/10 from www.MSsociety.org). This is the target population. A convenience sample of people diagnosed with MS is available by working with the
population served by a neuroscience center in Montana. The sample frame was from this population. Based on conversations with personnel at the center, it is estimated that 1000 people with MS visit the center each year for care. The clients mostly come from Montana, North Dakota, and Wyoming. The target population is mostly from rural areas. The neuroscience center itself is a magnet or funnel for attracting the population of interest, as the area is rural, and other specialty clinics for people with the diagnosis of MS are not readily available in this geographic region, and patients often travel up to 300 miles one way to obtain care (Loge, P., personal communication, Fall 2010).

The inclusion criteria included; a diagnosis of multiple sclerosis, ambulatory status (with at most the aid of a cane), being relapse free at the time of the data collection and in the preceding 30 days prior to the collection, and being able to complete the two questionnaires and demographic data. Subjects had to be over age eighteen. The criteria designating that only ambulatory subjects be included was justified by two reasons. First, people who are not ambulatory are less able to engage in exercise. Second, many of the studies on exercise and MS only used ambulatory subjects, which easily allows for possible replication of the study in the future. The definition of an MS relapse is having new or recurrent neurological symptoms that persist for at least 24 hours and is separated from the previous attack by 30 days (retrieved 11/16/10 from www.NationalMSSociety.org). It was expected that the sample size would be at least 70 individuals. Estimation of sample size for this Pearson correlation was determined by conducting a power analysis, which showed that 68 subjects were needed for an alpha of
0.05 and power of 80%, with medium effect size (retrieved 11/18/10 from http://www.changbioscience.com/stst/ssize.html).

**Procedure**

This researcher enlisted the help of the nurse and nurse practitioner at the neuroscience center to present a packet of documents to patients at the neuroscience center who have an established diagnosis of MS. The nurse or nurse practitioner only presented the packet to ambulatory MS patients. To instruct the nurse and nurse practitioner on the study and procedures, an on-site training (by this researcher) occurred before the data collection began. The packets included a description of the project, consent form, a form eliciting demographic data, and two questionnaires (see Appendices A-D). The questionnaires were completed in the clinic, then the client sealed the packet contents in an envelope and handed this back to the nurse or nurse practitioner. The instructions included the option of not initialing the consent or completing the questionnaires/demographic form, sealing the unused or incomplete packet in the envelope, and returning the packet to the nurse or nurse practitioner. This alleviated any potential coercion that could have been felt if the client had to verbally decline to be in the study. These envelopes were sealed in a prepared stamped envelope and stored at the neuroscience center in a locked file (provided by this researcher) and mailed to this researcher once a month. These documents were stored in a locked file cabinet in this researcher’s home during data analysis and will be destroyed after completion.
Design of the Study

This researcher used a correlational design for this study. The study used a convenience sample of subjects with MS to measure exercise and resilience to determine if a relationship exists between these two variables.

Instrumentation

Three instruments were used in this study. Demographic data was collected using a researcher developed questionnaire including: years the person has lived with the diagnosis of MS, gender, age, race, use of disease modifying drugs (DMT), employment and income (see Appendix B). This information was used in determining the distribution of the demographic characteristics of the sample after the data was collected. No individual demographic data was linked to the data from the two questionnaires, but only used to describe the convenience sample as a whole.

Physical activity/exercise was measured with a self-report measure called the Godin Leisure Time Exercise Questionnaire (GLTEQ) (Godin & Shephard, 1985). The GLTEQ consists of two parts. The first part asks the subject to measure the frequency of three general levels of activity in their typical week. The general levels are strenuous (e.g. running or road biking), moderate (e.g. fast walking or playing tennis) or mild (e.g. easy walking or beginning yoga). Examples of the levels are provided. The frequency of how many times in a week a person engages in each of these three levels for more than 15 minutes at a time is determined. There is no duration component beyond the initial 15 minutes. The weekly frequencies of each level (strenuous, moderate and mild) are
multiplied by 9, 5, and 3 metabolic equivalents (meqs), respectively. The numbers are summed to denote an objective score or measure of total leisure activity in an average week. The second part of the GLTEQ asks about frequencies of engaging in activities that produce sweating. This part was not used in most of the studies measuring exercise in people with MS, due to autonomic changes (people with MS may not sweat as easily as unaffected people). The correlation co-efficients were consistent between objective measures of activity such as pedometers and the GLTEQ in studies of people with MS. This is an important point, lending a stronger basis for using the GLTEQ in studies measuring exercise in people with MS. Gosney, Scott, Snook, and Motl (2007) described the GLTEQ as: “a simple and straightforward measure of physical activity that can be administered by researchers, practitioners, and clinicians within a variety of setting for measuring the activity behavior of individuals with MS” (Gosney et al., 2007, p. 149).

The range of scores for the GLTEQ are zero to an undetermined number (since the scores are measuring frequencies of discrete exercise sessions longer than 15 minutes but do not measure duration beyond 15 minutes). For example, a professional athlete in serious training might engage in seven hour long sessions of discrete strenuous activities in a typical day then have two more twenty minute sessions of stretching and yoga, then take the dog for a fast thirty minute walk after dinner, and walk (not a fast walk) to and from the gym (twenty minutes each way) on a typical day. Assuming that this athlete took one day to rest, this person would score:

- Seven episodes times 9 metabolic equivalents (meqs)=63 times 6 days =378 points strenuous activity
- One episode times 5 meqs=5 times 6 days=30 points moderate activity
• Four episodes times 3meqs=12 times 6 days=72 points mild activity for 
378+30+72=480.

• Total GLTEQ=480 for a serious athlete in training.

This researcher will be using only the first part of the GLTEQ, as supported by 
previous research (see Chapter 2, Review of the Literature) due to autonomic nervous 
system changes in sweating that can occur in people with MS.

Resilience was measured using the Resilience Scale (RS) developed by Wagnild 
and Young (1990).

The initial qualitative studies from which the RS was derived involved interviews 
of women who had successfully dealt with having a spouse with Alzheimer’s disease. 
Through a review of the literature on coping and adapting, more definition and getting to 
the specifics were added to these five characteristics, with a resulting 25 item objective 
scale. The 25 scores are added up for a total RS score. This possible range is 25 (all 
“1”s) to 175 (all “7”s).

Scoring the RS (Wagnild, 2009):

• Very low (25-100). People in this range have reported more depression, a 
lack of energy, more difficulty finding meaning, and often feel isolated.

• Low (101-115). People who score in this range are often somewhat depressed 
and anxious, may feel dissatisfied with their life, and may feel out of control 
of their lives.

• Medium low (116-130). People can see the “light at the end of the tunnel” 
even though they may be somewhat depressed and anxious. These people are 
employing some effort to resolve some identified problems in their lives.

• Moderate (131-144). People in this group are satisfied in general, but many 
aspects of their lives are not satisfactory. May be experiencing emotional 
fatigue.
• Moderately high (145-160). People who score in this range are finding meaning in general and doing well, but feel that they could do better. These people are rarely depressed, but still recognize areas where they might want to change things.

• High (161-175). These people are doing well in all areas of resilience. Like all people, life is not perfect, and they experience painful events like death or impending death or illness of people in their lives or themselves or other challenging situations. They view life as an adventure with many ways to look at things, with confidence that they will deal with what comes their way.

Ahern et al. (2006) report a reliability coefficient alpha of .91 and item to item correlations ranging from .37 to .75 (majority between .50 and .70, p<.001) (p. 113).

Ahern et al. (2006) report advantages of the RS instrument as “multiple applications of the sexes, multiple ages, and ethnic groups with good reliability and validity are available” (p. 115). A priori content validity was established “during construction of scale, items were selected that reflected generally accepted definitions of resilience from interviews with resilient individuals and with an expert panel” (p.114). Ahern et al. says “The study supports the internal consistency reliability and concurrent validity of the RS as an instrument to measure resilience” (p. 115).

Both tools selected to measure the two factors have withstood the test of time and academic scrutiny and seemed like appropriate choices to use in the sample of MS subjects for this study.

Data Analysis

The data was analyzed using Microsoft Excel© statistical analysis. Specific demographic data was analyzed for frequencies and central tendencies. For hypothesis testing, this researcher used statistical analysis of the numerical results of two well
established tools/scales, measuring resilience and physical activity in people with MS. Pearson product-moment correlation coefficient was used in data analysis. The Pearson correlation coefficient for these two factors was reported as an “r” value which ranges from minus one to plus one—describing the strength and direction of the relationship.

Protection of Human Subjects

Data collection approval was obtained from the university and hospital/neuroscience institutional review boards (IRBs). There was not any harm (physical, discomfort or psychological stress) or benefit (beyond that of possible contribution to science) to the participants in this study. There was no treatment involved in this study. The human subjects received the packet from trained personnel at the neuroscience center as described, with no coercion from personnel to read about, consent to, participate in, or complete the questionnaires. It was requested that the nurse and nurse practitioner at the neuroscience center present the packets (without coercion and exclusion for any reason other than the exclusion criteria) describing the project to every client who came to the center who had a diagnosis of multiple sclerosis and was ambulatory. The packets were not part of patient medical records, so as to keep neuroscience clientele medical care confidential and private. The patient used only his or her initials in signing the consent form. This was to ensure anonymity. The completed packets were stored in a locked file at the center, with mailings once a month via certified United States Post Service until the sample size was achieved. Once the packets arrived at this researcher’s home, the data was examined. Communication between this
researcher and her chair at the university was on password protected computers, files were maintained in a locked file cabinet, and will be destroyed after the study is completed.

Summary and Conclusion

In this chapter, the sample selected and rationale, the sample procedure, the study design, the instrumentation used to measure the variables and demographic data, the protection of human subjects have been stated.
CHAPTER 4

PRESENTATION AND ANALYSIS OF DATA

Introduction

This correlational study intended to investigate what the relationship of exercise and resilience is for people with MS. The hypothesis was that there is a positive relationship between exercise and resilience in people with MS in the Northwestern United States. This chapter presents the results of the data analysis pertaining to demographic characteristics of the sample and the hypothesis.

Demographic Characteristics of the Sample

A total of eighty packets were presented to clients. A total of seventy-five clients met the criteria and consented and completed the questionnaires. Five subjects sealed the packet contents in the envelopes totally unanswered and blank and this was determined by this researcher to mean that these subjects were declining to participate, but nonetheless, the packets were mailed to this researcher. One packet was partially completed but discarded by this researcher as incomplete. A total of seventy four were used for data analysis for a response rate of 92.5%.

Analysis of Data/Descriptive Statistics

The data was analyzed using Microsoft Excel© statistical analysis. Of the 74 individuals with MS, 52 (70%) were female and 22 (30%) were male. Ninety-seven
percent were Caucasian and 3% were Native American or a mix of Caucasian/Native American. The age range was 26 to 73 years of age, with a median and mean of 48 years old. Forty-three percent were unemployed, 14% employed part time, and 43% employed full time. Income ranges were broken down into ranges of $25,000 increments. Twenty-two percent of subjects reported incomes of 0-$25,000. Forty-nine percent made less than $50,000. The subjects had been diagnosed from 0.5-44 years, with a mean number of years since diagnosis of 13 years, median 11 years. Ninety seven per cent of the sample reported being on disease modifying medications (DMT), with 47% indicating that they were specifically receiving Tysabri infusions. The total number of years on DMT was a range of 22 years, mean of 9 years, median of 10 years. Table 1 shows the demographic characteristics of the full sample and are based on the use of DMTs.

Table 1. Summary Descriptive Statistics.

<table>
<thead>
<tr>
<th></th>
<th>Full Sample</th>
<th>On Tysabri</th>
<th>Unspecified DMT</th>
<th>No DMT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;40</td>
<td>15 (20%)</td>
<td>6 (8%)</td>
<td>7 (9%)</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>40-50</td>
<td>31 (42%)</td>
<td>12 (16%)</td>
<td>19 (26%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>50-60</td>
<td>22 (30%)</td>
<td>14 (19%)</td>
<td>8 (10%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>&gt;60</td>
<td>6 (8%)</td>
<td>3 (4%)</td>
<td>3 (4%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Gender (M,F)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>22 (30%)</td>
<td>10 (14%)</td>
<td>11 (15%)</td>
<td>1 (&lt;1%)</td>
</tr>
<tr>
<td>Female</td>
<td>52 (70%)</td>
<td>25 (34%)</td>
<td>26 (35%)</td>
<td>1 (&lt;1%)</td>
</tr>
<tr>
<td>Employment (F,P,U)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>32 (43%)</td>
<td>15 (20%)</td>
<td>16 (22%)</td>
<td>1 (&lt;1%)</td>
</tr>
<tr>
<td>Part time</td>
<td>9 (12%)</td>
<td>3 (4%)</td>
<td>6 (8%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td></td>
<td>33 (45%)</td>
<td>16 (22%)</td>
<td>16 (22%)</td>
<td>1 (&lt;1%)</td>
</tr>
</tbody>
</table>
Table 1. Summary Descriptive Statistics (continued).

<table>
<thead>
<tr>
<th></th>
<th>Full Sample</th>
<th>On Tysabri</th>
<th>Unspecified DMT</th>
<th>No DMT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-25K</td>
<td>15 (20%)</td>
<td>9 (12%)</td>
<td>6 (8%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>25-50K</td>
<td>20 (27%)</td>
<td>8 (10%)</td>
<td>10 (14%)</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>50-75K</td>
<td>14 (19%)</td>
<td>8 (10%)</td>
<td>6 (8%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>75-100K</td>
<td>4 (5%)</td>
<td>1 (&lt;1%)</td>
<td>5 (7%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>100-125K</td>
<td>3 (4%)</td>
<td>0 (0%)</td>
<td>3 (4%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>&gt;125K</td>
<td>4 (5%)</td>
<td>0 (0%)</td>
<td>4 (5%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Years Dx’d with MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 5</td>
<td>18 (24%)</td>
<td>7 (9%)</td>
<td>9 (12%)</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>5-10</td>
<td>25 (34%)</td>
<td>15 (20%)</td>
<td>10 (14%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>11-15</td>
<td>23 (32%)</td>
<td>10 (14%)</td>
<td>13 (18%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>16-20</td>
<td>5 (7%)</td>
<td>2 (3%)</td>
<td>3 (4%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>&gt;20</td>
<td>1 (&lt;1%)</td>
<td>0 (0%)</td>
<td>1 (&lt;1%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

Hypothesis Testing

GLTEQ results ranged from zero to 287. The median was 24.5, the mean 39, indicating that the isolated high score of 287 was an outlier. There were eight subjects (11%) who had a score of zero on the GLTEQ, indicating that these people did not exercise at all. Another seventeen (23%) scored from 3 to 15 which would be equivalent to only one fifteen minute exercise episode of at least fifteen minutes of bowling, or three moderate (not strenuous) walks in a week. Only 15 individuals (or twenty percent) had scores over 50 which would be equivalent to six exercise episodes of strenuous activity such as jogging or Nordic skiing or ten moderate walks in a week. Table 2 shows the low, moderate, and higher GLTEQ scores in the sample population.
Table 2. GLTEQ Scores.

<table>
<thead>
<tr>
<th>GLTEQ range</th>
<th>GLTEQ scores</th>
<th>Number of subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low scores</td>
<td>Zero-15 (none to very low amounts of activity)</td>
<td>25 (34%)</td>
</tr>
<tr>
<td>Moderate scores</td>
<td>16-50</td>
<td>34 (46%)</td>
</tr>
<tr>
<td>Higher scores</td>
<td>&gt;50 (i.e. six Nordic ski episodes over 15 minutes or ten moderate walks in a week)</td>
<td>15 (20%)</td>
</tr>
</tbody>
</table>

The RS scores were from 56-171, with a mean of 138 and median of 139. A score between 131 and 144 indicates a moderate level of resilience. Scores above 145 indicates moderate to high resilience. Thirty subjects (40%) scored these higher than average scores. Table 3 shows the low, moderate, and high scores RS scores in the sample population.

Table 3. Resilience Scale Scores.

<table>
<thead>
<tr>
<th>RS score</th>
<th>RS range</th>
<th>Number of subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;131</td>
<td>Low scores</td>
<td>25 (34%)</td>
</tr>
<tr>
<td>132-144</td>
<td>Mod scores</td>
<td>19 ((26%)</td>
</tr>
<tr>
<td>&gt;145</td>
<td>Mod-High scores</td>
<td>30 (40%)</td>
</tr>
</tbody>
</table>

The hypothesis that there is a positive relationship between exercise and resilience in people with multiple sclerosis was not supported. Pearson’s correlation can range from -1 to +1, with -1 being a negative relationship, and +1 being a positive relationship. As the score approaches zero there is no relationship, positive or negative between the two variables. The Pearson’s correlation between the GLTEQ and the RS was 0.094, indicating no relationship between exercise and resilience in this population of people with MS.
CHAPTER 5

CONCLUSION

Introduction

In this chapter, the findings in relation to the demographics of the sample will be analyzed and limitations of the tools will be discussed, explaining possible reasons why the hypothesis was not supported. Implications for future practice and possible areas of future study will be explored.

Discussion

There are a number of characteristics of the sample that may have influenced the findings. First of all, the median age of the group was older, substantially unemployed, had suffered the impact of the disease for many years, and may be living at a lower income level from those who more recently were diagnosed with MS. These characteristics may have contributed to the lower GLTEQ scores and the higher RS scores. Older age may have contributed to higher RS scores, having had more years to respond to potential adversity. These people may have had to negotiate the economic process required to qualify for patient assistance programs, or Medicaid or Medicare disability programs in order to obtain these very expensive medications. As supported by the resilience models, successful negotiation of the obstacles can bolster resilience and result in higher resilience scores.
Secondly, ninety-seven percent (n=72) indicated that they were on DMT, while not everyone indicated which specific drug they were using. This unusually high percentage of respondents on DMT may have been because they were a “captive audience” at the neuroscience center, spending three hours a month getting their Tysabri infusions, a monthly intravenous infusion. Forty-seven percent (n=35) specifically identified that they receiving Tysabri. Actual Tysabri use may have been even higher among those who did not identify a specific drug. Since the neuroscience center also serves as an infusion center, this makes sense. The respondents may have felt compelled to participate because of their comfort level at the center, and their desire to advance MS research. This over representation may have biased the findings. In order to qualify for Tysabri one must have previously used the other available, less risky medications and either did not tolerate them, or their disease was progressing clinically or subclinically with MRI changes with an unacceptable rate of decline. Tysabri carries significant risk, and the FDA has issued a “black box warning,” due to a possible fatal brain infection.

This over representation of subjects on Tysabri may also explain why the sample had a low median score on the GLTEQ exercise questionnaire, as the group as a whole may have included a large number of individuals with more advanced aggressive MS, making exercise more difficult due to such things as fatigue, spasticity, and more neurological impairment.

The convenience sample is possibly missing the younger working middle or upper class group with private or group insurance, whose disease may be at an earlier stage when exercise might be easier to accomplish or tolerate. Also missing might be under or
uninsured clients who have not qualified for Medicaid/Medicare or patient assistance programs. As discussed in Chapter 2, Literature Review, until the mid to late 1990s, person with MS were discouraged from exercising and had no access to DMT, as none had been developed or approved for use. This may explain why the cohort of people in the sample who are on Tysabri (generally older and have had MS longer) may resemble the subjects in earlier studies (Hartley, 2009; Petajan & White, 1999; Motl & McAuley, 2009; Beckerman, deGroot, Scholten, Kempen, J.C.E. and Lankhorst, 2010) which confirmed that people with MS were generally less active than their healthy counterparts, and became less active as their disease progressed.

Limitations

The GLTEQ, while it is a reasonable choice for measuring exercise activity, has no duration component. This may be a limitation. For example, one who engages in a four hour cross country ski trip would score the same as one who spent 20 minutes jogging.

The RS uses Likert scales, which may result in some variations in results as well, as individuals may inherently give themselves top scores, or hesitate to give themselves anything other than scores in the middle, regardless of the quality being measured. This may represent an additional limitation of the tools used to measure the variables.

The convenience sample may have been somewhat homogeneous, with very little racial variation, and geographically limited as well. The sample demographics reflected a predominantly white and rural population, which is typical in this region. The
geographic area in which the neuroscience center serves is cold, windy, and isolated for up to nine months a year. Engaging in leisure time physical exercise might be harder to accomplish in this setting.

**Implications for Future Practice**

The finding that over 30% of the sample did not engage in any exercise or a very low level of physical activity is a concern to nurses. Targeting prevention from initial diagnosis instead of waiting until an MS patient has already suffered many negative outcomes by having a comprehensive health care team approach would be a much needed paradigm shift. Nurses are in a good position to spearhead this team approach. Actively promoting exercise and resilience early on after initial diagnosis of MS may have significant impacts on positively dealing with this chronic disease.

This change or shift in health behavior could occur in a similar way that DMTs have gradually been successfully promoted after it became obvious that MS patients were not being started on DMTs or staying on their medications. The National MS Society and pharmaceutical companies have developed educational materials and programs that the health care providers who care for those with MS have actively disseminated and encouraged. They have used the media (magazines/radio/internet/television/billboards/stationary/pens and coffee mugs with promotional logos), and employed “patient advocates”- MS patients who are already on the DMTs to come and share their experiences at fancy presentations by neurologists in nice motel conference rooms serving gourmet food and wine to promote DMTs, and have developed patient assistance
programs and telephone and internet “help lines” with registered nurses with special training in caring for those with MS. A similar strategy could be employed (and is starting to be employed) to promote more exercise in those recently diagnosed with MS, as well as in those in later stages of the disease.

Getting gymnasiums and health clubs with physical therapists specially trained in caring for those with MS involved in programs and media events, perhaps with financial help from university hospitals or grants from the National MS Society would help make exercise more available and appealing. If medical schools or continuing education entities training neurologists, primary care physicians and physician assistants, and nursing schools training nurses and nurse practitioners included curriculums on how to actively promote more exercise in those with MS, perhaps prevention of disease progression could occur. Embracing meaningful health care reform would help refocus our efforts toward disease prevention in addition to illness care. This paradigm shift would hopefully reduce disease progression. Prevention care could include allowing more time for care provider’s to counsel and refer to programs and those practitioners involved with exercise therapy/activities and campaigns. By utilizing more support, electronic medical records could be employed to create networks of those with chronic diseases. Those with MS could become more educated about their health and opportunities to become involved with more prevention of morbidity from this disease.
Areas for Future Study

Replicating this study in a different population of MS patients which included those with fewer years of disease burden might result in a positive correlation between exercise and resilience. Not using an infusion center for Tysabri would possibly eliminate the selection bias which occurred in this study. Using a more urban setting may increase access to gymnasiums or opportunities for physical therapy/exercise programs. Studying a more racially diverse population may result in a more representative sample. Developing and using an MS specific tool other than the GLTEQ, which may more accurately measure exercise levels for MS patients, may establish a different correlation between exercise and resilience. Studying a more active, fit subpopulation of MS patients may indicate a positive correlation between resilience and fitness, and therefore underscore the need for more structured, rigorous, aerobic exercise programs that would lead to fitness for those with MS. As discussed in the literature review (Motl et al. 2011), research on cognition and exercise in those with MS is very much needed, as loss of cognition has such serious deleterious effects. Studying the relationship between resilience and cognition may also elucidate indirect variables that influence adherence to exercise programs. R Woodgate’s theory on resilience and pathways of adaptation could serve as a valuable framework for these future studies.

Needless to say, encouraging exercise and resilience in people with MS is a laudable goal which could result in prevention of some of the negative consequences of this disease. In our current health care system in the United States, prevention is not a focus as much as “illness care” with pharmaceuticals and diagnostic tests. Encouraging
and paying for physical and occupational therapy and media promotion of exercise programs/avenues for people with MS would probably represent significant cost savings over time, as well as better preservation of physical and cognitive skills in those with MS.

Conclusion

While this correlational study did not support the hypothesis that there is a positive relationship between exercise and resilience in people with MS, the examination of the data did bring up where future study and emphasis might be helpful. A paradigm shift in our health care system of illness care to including prevention care is one area. Identifying and promoting protective mechanisms in the course of MS could alter the impact of the disease, resulting in more desirable long term outcomes. To gain more health preservation and quality of life, the utilization of exercise and resilience should be initiated and promoted early on in the course of the disease.


National MS Society brochure “Just the facts” extracted from www.NationalMSsociety.org

NARCOMS information extracted from www.mscare.org/cmsc/


Sonja Slikfa Study and demographic information extracted from www.nationalmultiplesclerosisociety.org and www.MSsociety.org and the National MS Society information and resource hotline, 1-800-344-4867.


APPENDICES
APPENDIX A

SUBJECT CONSENT FORM
Title: The relationship between exercise and resilience in persons with multiple sclerosis

What am I being asked to do? You are being asked to participate in a research project conducted by Nyla Chandler, a women’s health nurse practitioner, MSU student. The research will study exercise and resilience in persons with multiple sclerosis (MS). MS patients at this neuroscience center are being invited to complete three questionnaires.

Rationale of research: The purpose of this study is to better understand the role of exercise and resilience in persons with MS, and in the future to help nurses and clinicians develop management options that are accessible and effective.

What procedures are involved? Participation is voluntary. If you agree to participate you will be asked to complete three questionnaires in the clinic today, which will take about 30 minutes. A consent form and the three questionnaires are enclosed in this packet. You will be able to complete them in privacy, while you are in the exam room. When you are done, you will place the consent form and questionnaires in the enclosed envelope, seal the envelope, and return to the nurse. Please only participate once in this study, if choosing to participate, to avoid data duplication.

What are the potential risks and discomforts? There are no known risks of participation in this study unless you find it uncomfortable to complete the questionnaires. You may be inconvenienced due to the time required to complete the questionnaires (approximately 30 minutes).

What are the potential benefits to taking part in this research? There are no direct benefits to participating in this research.

What other options are there? You may choose to not participate, or decide to not complete the questionnaires by simply putting all the paperwork back into the packet envelope unfinished, sealing the envelope and handing the packet back to the nurse. Your decision whether or not to participate in this research will not affect your current or future care at the neuroscience center, or future relations with Montana State University or this researcher. If you volunteer for this study, you may withdraw at any time without consequence.

What are the costs for participating in this study? None.
What about privacy and confidentiality? All efforts will be utilized to protect your identity, as the information you provide if you volunteer will be anonymous, with only initials of your name on the consent form, with no identifying information on the questionnaires. This packet will not be a part of your medical records at the neuroscience center. Packets will be kept in a secure locked file at the neuroscience center and mailed through certified US Postal Service to Nyla Chandler. She will keep these packets in a secure locked file in her home, then shredded after completion of her study at MSU. Any communication between this researcher and her professor at MSU regarding this project will be on computers accessible only to her and her MSU professor, and will be password protected. The information that will be produced and reported from this project will not contain any personal information from individuals, but only general data regarding exercise and resilience in persons with MS.

Will I be paid for my participation in this research? No, there will not be any monetary compensation, or material compensation. There is no funding for this researcher, MSU, or the neuroscience center for this study.

Who should I contact if I have questions? The nurse researcher conducting this study is Nyla Chandler, WHNP-BC. If you have questions regarding this research please contact Nyla at (406)585-9836 nylasteve@msn.com. If you have additional questions, comments or concerns regarding your rights as a research participant, or this study, please contact the head of the Montana State University Institutional Review Board (IRB), Mark Quinn, (406) 994-4707 mquinn@montana.edu and/or the Institutional Review Board of Billings, (406) 238-5657, which is a volunteer group that acts as a research subject advocate. Both IRBs have reviewed this consent form for clarity of information.
APPENDIX B

DEMOGRAPHICS
Thank you for participating in this study. This page is the first of three questionnaires to be completed. Please return all three to the envelope with the consent form, seal it, and give it to ___________ (the nurse).

Age_________

Gender (circle) Male  Female

Race (circle all that apply) Caucasian, American Indian, Black, Hispanic, Asian, Other or mixed

Employed (circle)   Part time     Full time    Not currently

Estimated total household income per year   (circle)   0 to 25,000 dollars,  25-50,000 dollars,  50-75,000 dollars,  75-100,000 dollars,  100-125,000 dollars,  125-150,000 dollars,  over 150,000 dollars

Year diagnosed with MS________

Currently taking disease modifying drugs ( Betaseron, Avonex, Novantrone, Copaxone, pulse steroids, Tysabri or Gilenia for example) for MS (circle) Yes   No

Total years on disease modifying drugs for MS_____________
APPENDIX C

GODIN LEISURE TIME EXERCISE QUESTIONNAIRE
1. Considering a **7-Day period** (a week), how many times on the average do you do the following kinds of exercise for **more than 15 minutes** during your **free time** (write on each line the appropriate number).

<table>
<thead>
<tr>
<th>Times Per Week</th>
<th></th>
</tr>
</thead>
</table>
| **STRENUOUS EXERCISE**  
(i.e., running, jogging, hockey, football, soccer, squash, basketball, cross country skiing, judo, roller skating, vigorous swimming, vigorous long distance bicycling) |   |
| **MODERATE EXERCISE**  
(i.e., fast walking, baseball, tennis, easy bicycling, volleyball, badminton, alpine skiing, easy swimming, popular and folk dancing) |   |
| **MILD EXERCISE**  
(i.e., yoga, archery, fishing from river bank, bowling, horseshoes, golf, snow-mobiling, easy walking) |   |
APPENDIX D

RESILIENCE SCALE
<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>When I make plans I follow through with them.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I usually manage one way or another.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I am able to depend on myself more than anyone else.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Keeping interested in things is important to me.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I can be on my own if I have to.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I feel proud that I have accomplished things in my life.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I usually take things in stride.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>I am friends with myself.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I feel that I can handle many things at a time.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I am determined.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>I seldom wonder what the point of it all is.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>I take things one day at a time.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>I can get through difficult times because I've experienced difficulty before.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>I have self-discipline.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>I keep interested in things.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>I can usually find something to laugh about.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>My belief in myself gets me through hard times.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>In an emergency, I'm someone people generally can rely on.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>I can usually look at a situation in a number of ways:</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>Sometimes I make myself do things whether I want to or not.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>My life has meaning.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>I do not dwell on things that I can't do anything about.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>When I'm in a difficult situation, I can usually find my way out of it.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>I have enough energy to do what I have to do.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>It's okay if there are people who don't like me.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>

© 1987 Wagnild and Young.