

FACTORS INFLUENCING UTILIZATION
OF PHYSICAL THERAPY BY PERSONS WITH
MULTIPLE SCLEROSIS

THESIS

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By

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DEDICATION

To my husband, Mark Rosholt,
for providing emotional, financial, and
technical support throughout this journey.

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CHAPTER I

INTRODUCTION

Background

Multiple sclerosis (MS) is a chronic demyelinating disease of the central nervous system (CNS) that strikes young adults. The onset of the disease usually occurs between the ages of 15 and 45,^{1,2} with the majority of initial diagnoses made for individuals in their 30's.³ Although there are many theories as to the etiology of the disease, MS remains idiopathic and its course unpredictable, both in physical and emotional manifestations.^{1,2,4} Physical therapists can be utilized to assist MS patients in a variety of ways, including educating patients on how to perform more efficient functional activities, helping to control symptoms, and setting up a home exercise program, depending on the patient's level and type of disability. Patients with MS who are treated by physical therapists tend to be those with more severe forms of the disease, such as chronic progressive MS and, thus, those with a poor level of function.^{5,6} However, patients with benign or more slowly progressing forms of MS can also benefit from physical therapy (PT).^{2,4} This study seeks to examine which factors may influence whether or not a person with the diagnosis of MS receives physical therapy services.

Problem

There is adequate research documenting benefits of physical therapy for persons with MS, especially those with more chronic progressive forms of MS.^{5,6,7} However, those with this diagnosis also tend to be underserved by physical therapists.^{7,8,9} Lacking in the literature are studies regarding the descriptive and functional characteristics of those patients who are receiving physical therapy compared to those that are not. Therefore, a need exists to describe who, among MS patients, is receiving physical therapy for treatment of MS. In addition, it may be helpful to examine the relationships between receiving physical therapy and factors such as patients' illness, level of disability, physical activity, and socio-demographic characteristics in order to identify strategies to better meet the needs of all persons with MS.

Purpose

The purpose of this study is to investigate the characteristics of those persons diagnosed with MS who utilize physical therapy for treatment of their MS-related disabilities in order to increase awareness among health providers (physical therapists, physicians) and patients and to increase use of physical therapy by all persons with MS, regardless of disease course and severity, physical activity level, or socio-demographic traits.

Primary Research Question

- Among community-dwelling persons with multiple sclerosis, what are the factors that influence whether or not the individual receives physical therapy services?

Secondary Research Questions

- What is the difference in frequency of physical therapy use between men and women with multiple sclerosis?
- What is the difference in the frequency of physical therapy use between persons with MS living in urban areas versus those living in rural areas?
- Is there a difference between the disability status of persons with MS and their use of physical therapy?
- What is the difference in frequency of physical therapy use among persons with four clinical courses of multiple sclerosis: benign, relapsing-remitting, chronic progressive, and acute progressive?
- Is there a difference between length of time since diagnosis and use of physical therapy by persons with MS?
- What is the difference between economic resources and use of physical therapy by persons with MS?
- What is the difference between age and use of physical therapy by persons with MS?

- Is there a difference in the level of activity of those persons with MS who use PT and those who don't?
- Is there a difference in the amount of stretching done by those persons with MS who use PT and those who don't?

Definition of Terms

Multiple Sclerosis is a disease of the central nervous system characterized by inflammation and destruction of myelin in the brain and spinal cord. The disease process is usually characterized by relapses and remissions in disease-related symptom.¹⁰

Benign multiple sclerosis is a type of MS disease course which leads to little disability over time.⁴

Relapsing-remitting multiple sclerosis is characterized by periods of exacerbations and remissions with partial or full recovery. Some persons with this disease course experience complete remission of symptoms after each relapse. Others experience increasing disability with each attack.⁴

Chronic progressive MS is characterized by increased disability over time and lack of remission.⁴

Acute progressive MS is characterized by a fast progression to disability.⁴

Myelin is a lipid-rich substance produced by Schwann cells in peripheral nerves and oligodendrocytes in the central nervous system. The myelin sheath covers nerve fibers to increase the rate of electrical conduction by acting as an insulator.¹¹

Demyelination is the process of destruction of the myelin sheath surrounding nerve axons.³ Demyelination is associated with a decrease in efficiency of electrical conduction in the CNS.¹²

Physical Therapy is the examination, treatment, and instruction of persons in order to detect, assess, prevent, correct, alleviate, and limit physical disability, bodily malfunction, and pain from injury, disease, and any other bodily and mental conditions.¹³

Rehabilitation is the process of restoring a person's ability to live and work as normally as possible after a disabling injury or illness, in order to help the patient achieve maximum possible physical and psychological fitness and regain the ability to care for him/herself.¹³

Community-dwelling persons with MS are those persons with MS who are not living in institutions.¹²

Functional disability is the inability to perform usual tasks and activities due to a physical limitation.¹² In this study, functional disability was measured with the **Incapacity Status Scale**.¹⁴ The ISS is not included in this document due to copyright.

A **rural** area is defined as a non-metropolitan county, whereas **urban** is defined as a metropolitan county.¹⁵

Spasticity is increased tone and resistance to movement in the muscles due to a lesion in the central nervous system.²

Occupational Therapy is the art and science of restoring, reinforcing, and enhancing performance, facilitating learning skills and functions essential for adaptation and productivity, diminishing or correcting pathology and promoting and maintaining health.¹³

A **placebo** is a substance given as a medicine that has no inherent therapeutic value and lessens symptoms only because the patient is convinced that it will.¹³

Baclofen is an antispasticity drug that is thought to work by interfering with spinal cord activity that produces spasticity.²

The Ashworth Scale measures muscle tone using a 5-point scale ranging from 0 to 4; grade 0 indicates no increase in tone and grade 4 indicates that the affected part is rigid in either flexion or extension.⁴

Chapter Summary

This chapter presented a brief background for and purpose of this study. The primary research question and nine secondary research questions were given and significant terms were defined. The next chapter will present a review of the literature relevant to this study.

CHAPTER II

REVIEW OF THE LITERATURE

The literature review addresses multiple sclerosis (MS) and the significance of using physical therapy (PT) in the treatment of persons with this diagnosis. Literature available on MS pathophysiology, etiology, disease characteristics, and various clinical courses is reviewed. Along with the roles of physical therapy and rehabilitation services in treating persons with MS, physical activity and MS literature is also reviewed.

Multiple Sclerosis

Definition of MS

Multiple sclerosis is a chronic demyelinating disease of the central nervous system. The onset of the disease is generally between ages 15 and 50.⁴ The disease is characterized for the most part by periods of exacerbations and remissions of symptoms.¹⁰ Between 250,000 and 350,000 persons in the United States have a medical diagnosis of MS,¹⁶ making it the most common disease causing neurologic disability in young adults,¹⁷ and the third most common cause of disability in those persons between the ages of 20 and 50 years. The majority of those diagnosed, approximately two

thirds, are between the ages of 20 and 40 years.⁵ Females are affected more often with MS, with a ratio of approximately 2:1 when compared to males with the diagnosis.¹⁰

Pathophysiology of MS

In MS, myelin of nerve axons is destroyed leaving lesions called plaques in the white matter of the central nervous system (CNS). These plaques, which are scar tissue produced by glial cells, are found all over the CNS, but appear in greater numbers around the ventricles of the cerebrum, the cerebellar peduncles, the brainstem, and the dorsal columns of the spinal cord.¹ Historically, MS has been considered to be the hallmark demyelinating disease of the central nervous system. It has been assumed that although myelin is destroyed during periods of inflammation, the cell axons are spared.¹⁷ Recent research has now contradicted this assumption by showing axonal destruction as a result of demyelination in MS.¹⁷ This destruction may be the result of chronic demyelination, a direct immunological attack, or “insoluble inflammatory mediators.”¹¹ A relationship was discovered between inflammation and axonal death; therefore, if a way was created to reduce inflammation, it may also reduce injury and loss of axons. Infiltration of T cells and macrophages has been found around the acute lesions, indicating possible immune system involvement in the pathogenesis of the disease. This infiltration, along with the demyelination of the nerve cells, hinders nerve impulse conduction, causing nerves to fatigue quickly.¹ Because of the varied locations of plaques within the CNS, and the exacerbating/remitting nature

of the disease, the course and symptoms of persons with MS will differ greatly.

Epidemiology and Etiology of MS

The cause of MS is unknown, although its etiology appears to be multifactorial.^{4,17} Epidemiologic studies suggest environmental components may trigger the disease in those who are genetically susceptible.^{3,18}

A higher incidence of MS in geographic areas which are farther from the equator and outbreaks in particular regions, such as the Shetland and Orkney Islands near Scotland, and the Faroe Islands off the coast of Norway, suggest a strong environmental component.^{1,3,4} MS occurs more often in latitudes 40° above the equator than in areas closer to the equator worldwide.¹⁸ In the United States, the prevalence of MS above the 37th parallel is 110-140 per 100,000 as opposed to 57 - 78 cases per 100,000 below the 37th parallel. Additionally, the first fifteen years of life appears to be most important. An individual moving from an area with a lower risk to an area with a higher risk before the age of 15 can increase that individual's risk of developing MS. The opposite is also true: a person moving from a higher risk area to a lower risk area after the age of 15 continues to carry the risk of the original region.¹⁸ This information suggests a viral etiology, and although there have been several different viruses implicated, this theory remains unproven.⁴

Genetic predisposition also contributes to the development of the disease.^{4,17} Women are at a greater risk for MS by a ratio of about 2:1, and

whites, particularly descendants of Northern Europeans, are at a greater risk than other ethnic groups. About 15% of persons with MS have a close family member with MS, and 5% have a sibling with MS.³ However, MS is not directly inherited, as exhibited by the fact that an identical twin of a person with MS has a 1 in 3 chance of developing the disease, and 80% of people with MS do not have a close relative with MS.¹⁹ The five major factors found to contribute to an increased risk of developing MS are being female, being of European ancestry, having siblings with MS, being between the ages of 20 and 40, and living in a temperate climate before the age of 15.²⁰

The epidemiological trends above lend support to the theory that MS is probably caused by a combination of infectious agents, immunological factors, and genetic predisposition.^{1,10}

Symptoms of MS

Symptoms of MS are often fluctuating and unpredictable from day to day, making MS unique among neurological disorders. Primary symptoms of MS include numbness or other sensory disturbances such as paresthesias or pain, weakness, dizziness, visual disturbances, ataxia, bladder and bowel problems, spasticity, sexual dysfunction, and cognitive impairments.^{2,4,20} Fatigue, one of the more common symptoms of MS, can be frustrating for the patient in that it is invisible, but often very disabling.⁴ It can greatly affect a person's quality of life by intensifying symptoms and contributing to a feeling of losing control over the disease.²¹ Fragoso et al²² suggest MS fatigue may be related to deficiencies in the body's ability to

effectively utilize oxygen peripherally. Fatigue can often lead to the need for major changes in lifestyle and work for persons with MS.²³ Secondary symptoms occurring as a result of inactivity or other sequelae following the primary symptoms can include contractures, urinary tract infections, osteoporosis, decubitus ulcers, and greater weakness and fatigue due to deconditioning.^{3,4,24}

Types of MS

MS is categorized into four main disease courses: benign, relapsing-remitting, chronic progressive, and severe, or acute, progressive MS.^{1,12} Benign MS consists mainly of sensory symptoms, with little progression to functional disability. Relapsing-remitting MS can be either benign, in which symptoms fluctuate but little functional disability is suffered, or chronic relapsing, in which functional disability increases with each exacerbation. Chronic progressive MS is characterized by increasing disability without remissions, and severe progressive MS rapidly advances.⁴

Most people with MS have some form of progressive MS, though the course of the disease differs greatly among individuals.²⁰ Life expectancy of MS patients is good, however. Within the last 15 years, mean survival time has risen to approximately 40 years.^{6,9} About 75% of those diagnosed with MS will be alive 25 years after diagnosis.^{20,25} Of that percentage, 66% are still ambulatory after 25 years.²⁵ Consequently, most persons diagnosed with MS have the potential for living many productive years.²⁶

Physical Activity and MS

Several studies have examined physical activity and its effects on persons with MS. It is important to review the recommendations on physical activity for the general public before discussing its effects on the population of persons with MS.

Recommendations for adult physical activity from the Centers for Disease Control and Prevention and the American College of Sports Medicine include participation in 30 minutes of activity of a moderate intensity as many days as possible per week for United States adults.²⁷ These 30 minutes can be accumulated throughout the day; if lower level activities are performed, they can be done longer, more often, or both. Calorie expenditure and amount of time physical activity is performed are associated with decreased cardiovascular disease and mortality. People who maintain their muscle strength, coordination, balance, and flexibility are better able to perform activities of daily living and avoid disability.

Unfortunately, not everyone is as physically active as is recommended. Physical inactivity is especially prevalent in certain populations such as the socio-economically disadvantaged, the less educated, older adults, and the disabled. For persons with chronic disease or disabilities, interventions should emphasize the importance of performing daily activities with limited assistance to increase physiological capacity as well as to improve performance of the activities. Health

professionals, such as PTs, can play a large part in encouraging their patients to begin and maintain regular physical activity.²⁷

For multiple sclerosis patients, maintaining mobility is very important.^{28,29} Decreased movement, which often can occur after some motor function loss, can lead to atrophy of secondary muscles.²⁹ Strengthening exercises can serve to maximize remaining muscle, and stretching exercises reduce contractures and decrease spasticity.^{4,28 29} Walking improves cardiovascular status of the patient with MS.²⁸ Other benefits of exercise for persons with multiple sclerosis include increasing range of motion, decreasing muscle spasms, and regaining functional losses resulting from exacerbations. Exercise can also decrease general fatigue, as long as the activity is not performed to the point of exhaustion and increased body temperature.²⁹ Exercising in a temperature controlled environment with many fans, and wearing cooler clothing should ensure adequate heat loss in persons with MS.^{25,32} Maintaining mobility gives persons with MS a more positive outlook on life and increased self-esteem.^{28,29}

Swimming is an excellent all-around activity for persons with MS.²⁹ The buoyancy of water enables persons with MS to perform exercises they would not be able to do on land, giving these patients an increased sense of control over their bodies. Aquatic therapy can help to strengthen muscles and increase joint range of motion.³⁰

The research of Gehlsen et al³¹ on the effects of aquatic fitness programs on people with MS indicated that patients were able to improve muscular work without harming muscle strength and endurance.

Subjects ($n = 10$) participated in a 10-week program of freestyle swimming and shallow water calisthenics for 3 1-hour sessions each week, training at 60-75% of their estimated maximum heart rate. Results showed significant improvements ($p < .05$) in muscular work and significant decreases ($p < .05$) in fatigue.

Stuifbergen³³ examined relationships between physical activity and different aspects of health in 37 persons with MS. Subjects completed surveys, including the Human Activity Profile (HAP), the Medical Outcome Study (MOS) - Short-Form Health Status Survey (SF36), and questions about demographics. In addition, a small subset of 4 people completed a 6-week aquatic exercise program and were given surveys at the beginning, at 6 weeks, and at 6 months. As a whole, scores on the HAP were lower for the subjects in this study than those for a normative sample and those for persons with other chronic conditions. The average level of activity was less than what the subjects should have been able to maximally accomplish. Positive correlations ($p < .05$) were found between activity scores and scores for general health and physical functioning on the SF36. In addition, persons with MS who regularly exercised had higher physical functioning scores than those who never or rarely exercised. Physical function of the aquatics program participants ($n = 4$) increased at 6 weeks for 2 persons and at 6 months for 1 subject. This study highlights the importance of daily activity for persons with MS.³³

Petajan et al²⁴ studied the effects of aerobic exercise on fitness and quality of life in 46 patients with MS. The patients were divided into two groups, one that received exercise and one that did not. Subjects were

tested before and after 15 weeks of aerobic training for maximal aerobic capacity, isometric strength, blood lipids, and body composition. The Profile of Mood States (POMS), Sickness Impact Profile (SIP), Fatigue Severity Scale (FSS), and neurological exams were used to measure subjects daily activities, moods, level of fatigue, and disease status. The experimental “exercise” group performed aerobic exercise for 40 minutes, 3 sessions per week, including arm and leg ergometry. $\dot{V}O_2$ max increased in the exercise group over the 15 week period by 22% compared to 1% increase in the non-exercise group. Physical work capacity (PWC) increased in the exercise group by 48% compared to 12% in the non-exercise group. Isometric strength increased significantly in knee extension, shoulder extension, shoulder flexion, and elbow extension in the exercise group ($p < .05$). A significant decrease in skinfold thickness was found in the exercise group (70 ± 5 mm before training, 64 ± 4 mm after training; $p < .05$) and in serum triglyceride levels (before training, 114 ± 11 mg/dl, after training 95 ± 9 mg/dl; $p < .05$). Significant decreases in scores for depression and anger subscales were noted at 5 and 10 weeks ($p < .05$), but not by week 15. At week 10, scores for fatigue in the exercise group were significantly lower as well ($p < .05$).²⁴

In the SIP data, scores for all three dimensions (ambulation, mobility, and body care and movement), of the physical dimension subscale for the exercise group decreased, indicating improvement in all areas sometime during the intervention.²⁴ In addition, significant correlations were discovered between changes in $\dot{V}O_2$ max, or the total gains in aerobic capacity of the subjects, and some psychological variables. The subscales

tension ($r = -0.50$), vigor ($r = 0.39$), fatigue ($r = -0.68$), and confusion ($r = -0.40$) all had significant relationships with the individuals' changes in aerobic capacity.

Unfortunately, real or perceived barriers can impede physical activity for persons with chronic diseases such as MS. Stuifbergen¹⁵ examined barriers to health behaviors, such as physical activity, in 603 persons with MS in urban counties and 204 persons with MS in rural counties. Subjects completed 4 instruments designed to uncover attitudes, beliefs, and behaviors regarding how they took care of their health. Physical activity was reported significantly more often among urban dwellers with MS than those in the rural sample. This highlights the importance for health professionals, such as physical therapists, of considering environment when planning interventions for persons with chronic conditions like MS.¹⁵

Rehabilitation and MS

Rehabilitation, and physical therapy intervention in particular, is extremely important for persons with a diagnosis of MS in order to prevent secondary complications, maintain existing function, and improve general quality of life.³⁴ Unfortunately, little is known about long-term effects of rehabilitation on persons with MS due to the infrequent nature of the research, lack of controls, or incomplete follow-up.⁶ In addition, the research that exists on rehabilitation primarily addresses its effects on patients with more serious, progressive forms of MS.^{5,6} This research is

scarce, probably due to the belief that patients with this diagnosis would not benefit from rehabilitation.^{5,35} Because of this belief, this patient population tends to be underserved by physical therapists and other rehabilitation professionals.^{7,26} However, with rehabilitation, functional gains, as well as improved quality of life, can be gained.

Rehabilitation for the MS patient is unique due to the ever-changing disease process, so a therapist must be flexible.⁴ A rehabilitation program should begin as soon as possible to counteract further progression of complications.⁹ Even though symptoms may be “invisible” to others, in that they affect function but are not obvious to the casual observer, the program can still be used to educate the patient about disease management and to improve their general condition.⁴ Even mild forms of MS can benefit from education in conditioning, recreation, and other healthy lifestyle practices. Historically, patients with the diagnosis of MS were inactive and cautioned to rest, which led to social isolation and sequelae due to inactivity.⁹ Physical therapy treatment was passive as opposed to activity-driven. This inactivity served to impair function of remaining neurons and increased spasticity in the patient. Rehabilitation programs are not just for patients who have been institutionalized, but treatment should begin when the initial diagnosis has been made. Patients should be as active as possible as early as possible, not just to decrease development of complications, but to keep them both motivated and involved in their own rehabilitation. Kraft et al⁸ recommend “overrehabilitation”, or rehabilitating a person with MS for a level of disability greater than what is currently observed, to preserve function as the patient’s disability progresses.

Rehabilitation should be multidisciplinary. An interdisciplinary treatment, including health providers such as PTs, occupational therapists (OTs), speech therapists, physicians, and dietitians, centered around and managed by the patient, should be a way of life.⁹ Poser et al³⁶ reported that psychiatric assistance is necessary during all rehabilitation and disease stages to help patients cope with the disease and to relieve stress within the family.

Feigenson et al³⁷ showed that intense multidisciplinary rehabilitation at an inpatient rehabilitation setting proved to be beneficial for patients with progressive MS. Subjects with MS (n = 20) were given the 20-item MS Functional Profile at admission and at discharge. After treatment using an intensive multidisciplinary therapy approach, subjects showed statistically significant improvements in the following areas: balance, self-care, bladder control, bed mobility, wheelchair transfers, ambulatory transfers (if ambulatory), homemaking, and ability to perform “real-life” activities ($p < .05$). The rehabilitation served to teach patients to compensate for their functional losses and was a cost-effective model.³⁷

The research of DiFabio et al⁶ reported that patients with progressive MS can benefit from an outpatient rehabilitation program that is comprehensive, or multidisciplinary, and lacks time limits. This “maintenance” program stresses both physical and mental function, and includes team members from physical therapy, occupational therapy, recreational therapy, counseling, and social work. This type of rehabilitation program served to assist patients with maintaining rather than restoring function. Researchers studied 31 persons with chronic

progressive MS by administering an initial evaluation and one year follow-up evaluation. Subjects were divided into 2 groups on the basis of whether they were admitted to the Multiple Sclerosis Achievement Center (MSAC), a rehabilitation center in Minneapolis, Minnesota, or on a waiting list to be admitted. Instruments used included the SF-36 for 8 aspects of physical and emotional health, a modified Multiple Sclerosis Quality of Life questionnaire (MS-QOL-54), which contained questions regarding specific disease issues such as cognitive and sexual function, and the Rehabilitation Institute of Chicago Functional Assessment Scale (RIC-FAS, version 2) used for evaluating functions like bed mobility and ambulation. Interventions for the treatment group (n = 12) included physical therapy for skills such as balance, coordination, and endurance, while OT treatment was received for upper extremity function. Recreational activities, counseling from a chaplain, and social services were also provided. Patients spent one day per week at the center for a 5-hour period during the entire year of the investigation. The group receiving the interventions demonstrated improvements in all but three of the health-status categories, whereas the control group showed decreases in seven domains. The study discovered that rehabilitation with this multidisciplinary focus can decrease the rate of decline in physical function for persons with MS and increase their health-related quality of life.^{5,6}

In a study by Greenspun et al⁷, 33 admissions to a university rehabilitation center by persons with progressive forms of MS were examined. Patients completed an initial questionnaire, one at discharge, and another at approximately 90 days after discharge. Questionnaires

addressed two main areas: mobility, which included ambulation, transfers, and stair climbing, and activities of daily living (ADLs), which included dressing, bathing, eating, and toileting. Patients made the greatest improvements in stair-climbing and ambulation. At admission, 9% of the subjects could climb stairs without a person assisting them, and 18% could ambulate independently. Upon completion of the inpatient rehabilitation program with a mean length of stay of 28 days, 64% were able to climb stairs independently and the percentage of those able to ambulate independently rose to 76%. The follow-up studies at 90 days after discharge proved that the gains made were preserved, as 76% reported independence in ambulation and 70% in stair-climbing. Researchers reported that as needs of each patient evolved throughout the disease, long-term rehabilitation should be made to fit the patient's individual needs.⁷

Physical Therapy and MS

Physical therapy intervention is an important aspect of the rehabilitation process. Some of the ways in which physical therapists can make a difference in the lives of persons with a diagnosis of MS are to aid with spasticity reduction, improve balance and coordination, increase strength, improve ambulation and general physical fitness, and reduce occurrence of musculoskeletal problems.⁴ Improvements are needed in providing access to physical therapy for patients with MS.⁹ Little research has been reported on the most effective types of physical therapy interventions and benefits of regular long-term physical therapy

intervention. Physical therapists have knowledge of neurophysiological mechanisms that other health care specialists may not have. With this knowledge, PTs are in a unique position to provide for their patients with MS such techniques as Proprioceptive Neuromuscular Facilitation (PNF), effective for strengthening muscles and improving joint range of motion,¹ and Neurodevelopmental Treatment (NDT), to manage spasticity and to promote normal movement using key points to inhibit certain reflexes.³ PTs can provide gait training, joint mobilization and positioning to prevent joint deformity, and orthotic fitting.¹ Additionally, PTs can provide education on compensating for sensory losses, postural retraining, and energy conservation techniques for functional activities. In addition to supervised PT sessions, home exercise programs developed by therapists are vital to the success of the MS patient.⁹

Significant improvements were made in functional, balance, and daily living activities in 40 persons with MS after they attended treatment sessions utilizing a variety of physical therapy methods.³⁸ Patients were taught techniques such as reflex inhibitory positions to control muscle tone, relaxation techniques to decrease stress and fatigue, and pelvic floor muscle exercises to increase bladder control. Patients were given individualized home exercise programs, based on their achievements in therapy sessions, with emphasis on improving function in their every day activities.

PT and OT intervention is often necessary for patients with MS due to the unpredictable nature of symptoms in this disease. Roush³⁹ examined satisfaction of persons with MS with the services they received from PTs

and OTs. The Therapist Evaluation Form (TEF) was completed by 81 individuals. This evaluation included 14 Likert format items indicating degree of agreement or disagreement with the statements about their care from an OT or PT (81% of the professionals in the study were PTs). A high degree of satisfaction with PTs and OTs was reported by the subjects in this study. In response to the question of what was the “most positive” characteristic of the therapist, 69% related to good communication and good rapport between therapist and patient.³⁹

Due to the great number of persons with MS who remain ambulatory 20 years or more after their diagnosis, treatment emphasis should be on retaining as much independence in function as possible. This would include training in balance and coordination skills. Balance training for persons with multiple sclerosis was examined by Kasser and Clark⁴⁰ using four subjects with MS. After initial assessment, subjects then underwent 12 weeks of balance training. Training sessions were 30 - 45 minutes long and were completed twice a week. Training included static, quasi-static, and dynamic balance activities on different surfaces, and with varying sensory input. Subjects were reassessed at the end of the 12-week intervention, given a home program to perform, and assessed again after 3 months. All patients showed improvements in varying degrees in the Limits of Stability (LOS) tests and Sensory Organization Tests (SOT), both at the end of the intervention and after 3 months, indicating increased postural control and stability. In addition, all patients reported feeling greater confidence in performing daily activities that challenged their balance, and walking on uneven surfaces.⁴⁰

Pain is a symptom sometimes associated with MS.^{3,4} Physical therapists are trained to help with pain management of their patients. Techniques, such as Transcutaneous Electrical Stimulation (TENS) often can be used in reducing pain that occurs with MS. A case study report by Pert⁴¹ documented the success of using TENS for pain reduction in the right calf of a patient with MS. The patient reported not only a reduction of pain, but also demonstrated decreased tone, increased sensation and increased proprioception in that extremity.

Brar and Smith et al⁴² studied the effects of different treatment protocols on minimal to moderate spasticity of 30 persons with MS. The study was a 10-week, double-blind, placebo-controlled cross-over trial, in which each subject received each of the following treatments: baclofen alone, stretching exercises with a placebo, a combination of baclofen and stretching exercises, a placebo without stretching exercises. Testing was performed by a physical therapist at the same time and same day of the week for each subject. Subjects were given a maximum of 20 milligrams of baclofen daily. A PT taught the subjects stretching exercises for the following muscle groups: the hamstrings, the quadriceps, the adductors, and the plantarflexors. Stretches were performed daily, 1 1/2 minutes for each muscle group.

Assessment of quadricep hypertonicity was performed using Cybex flexion scores for objective measurement, the Ashworth scale for subjective measurement, and a self-rated questionnaire to evaluate functional activities.⁴² Objective measurements significantly improved ($p < .05$) after both the baclofen treatment and the combination treatment. No significant

difference was found between the combination treatment and the baclofen treatment, although the Cybex flexion scores were greater for the combination treatment. The Ashworth scale results showed a decrease in spasticity after both the combination and baclofen treatments as well, and a significant negative correlation ($r = -0.3$, $p < .05$) was noted between the Ashworth ratings and Cybex flexion; as Ashworth scores increased, flexion scores decreased, indicating greater spasticity of the quadricep muscle. Stretching exercises alone did not significantly decrease spasticity; however, subjects expressed great interest in continuing the stretching program, as it gave them a sense of control over their spasticity.⁴²

A study by Kraft et al⁸ reviewed services received and future services needed by patients with MS. Medical services, including physical therapy, were used by a greater percentage of the patients compared to community, psychologic and vocational services. All medical services correlated with mobility level; less mobile individuals were more likely to be receiving physical therapy. Additionally, the current mobility levels of individuals also correlated with their perception of needing PT services in the future. The use of PT, both for current and perceived future needs, was also positively correlated with disease duration. PT was one of the areas of greatest perceived need. This study also showed that early on, persons with MS are more motivated to become involved in the rehabilitation process if services are available and referrals are made in a timely manner.⁸

Health care providers, like PTs, are an important source of information for promoting health in persons with MS.⁴³ These

professionals need to be aware of the effects they can have on the lives of people with MS by encouraging health-promotion activities.

Chapter Summary

Multiple sclerosis is a central nervous system disease that produces fluctuating symptoms and disability, and is one of the most common causes of disability in young adults. The disease course can run from benign to severely progressive. Most of the research concerning MS and rehabilitation, including physical therapy, has been done with persons with more progressive forms of the disease. Though the literature cites benefits of exercise, including increasing strength and endurance, improving self-esteem, and reducing spasticity and fatigue for persons with MS of all abilities, there seems to be little research on effects of physical therapy for those individuals with less severe courses of MS.

CHAPTER III

METHODOLOGY

Data Collection Procedures

Data used in this research were collected from February through March, 1996, by researchers at The University of Texas at Austin School of Nursing as part of a study on health promotion and quality of life among persons with chronic disabling diseases and conditions (R29NRO3195, NIH, NINR, A. Stuifbergen, Principal Investigator). The subjects for the study were recruited with help from two chapters of the MS Society in the southwestern United States. A letter was sent to 2,772 people from combined mailing lists describing the study and asking for participation. The researchers received 936 responses from individuals indicating their interest by providing their names and addresses. These 936 were sent a packet of information including a cover letter, the survey instrument, and a preaddressed, stamped envelope to facilitate return of the survey. Research staff were on hand via a toll-free telephone number to answer questions or clarify instructions for the participants.¹²

Follow-up postcards were sent approximately 2 to 3 weeks after the initial survey was mailed, requesting a response from some participants

and thanking those who had returned the survey. A total of 834 (89%) of the surveys were returned, of which 807 were usable (86%).¹²

Instruments

A self-report survey was used to collect data for the original study. The survey in booklet form was sent to participants. This booklet included several instruments in large print and increased spacing to facilitate easy reading for the participant. The booklet contained questions regarding sociodemographic information, severity of illness measures, quality of life and health-promoting behaviors.¹²

For the purposes of this study, the instruments used from the original survey were questions from the Background Information sheet, the Incapacity Status Scale (ISS)¹⁴, and selected questions concerning physical activity from the Health Promoting Lifestyle Profile II (HLPL II).⁴⁴ The Background Information Sheet collected information on the participant-reported demographics, such as age, gender, education, and employment status. Information regarding adequacy of economic resources was also collected from the Background Information Sheet. The responses for adequacy of economic resources were divided into four categories, based on the survey response options to questions regarding how well the respondent's income met their needs. Options were "1 = not at all", "2 = less than adequately", "3 = adequately", and "4 = more than adequately". Information related to the participants' disease was gathered by asking them to respond to questions about the type of MS that best described their

course of the disease, what year they had received the diagnosis from a physician, what year they had begun experiencing symptoms, and what treatments they were currently using. To this last inquiry, one of the response choices for treatment used was physical therapy.

The Incapacity Status Scale (ISS) was used as an objective measure of functional disability due to MS for each participant.¹⁴ The ISS was adapted as a self-report questionnaire by which the participant self-assessed sixteen different aspects of function. Questions addressed personal functions such as vision, ambulation, bowel and bladder functioning. For each question, a five point scale was given, with “0” being completely normal function, and “4” being completely unable to perform the function. The ISS has been evaluated by experts and deemed to possess construct validity as a record for disability. Internal consistency reliability in this study was 0.86.¹²

The Health Promoting Lifestyle Profile II (HPLPII) is a revised version of the HPLP.⁴² Although the instrument has six subscales, only the subscale for Physical Activity was used for this study. The instrument assesses frequency with which the respondents performed an activity, again using a 4-point scale. Internal consistency reliability of the HPLPII subscales ranged from .74 -.86.¹²

To create the activity scale, survey questions which reported the respondents’ levels of activity were grouped together and tested for their internal consistency using Cronbach’s coefficient alpha. This scale proved to have an internal consistency reliability of 0.75. Respondents reported

whether they performed the following activities “never”, “sometimes”, “often”, or “routinely”:

- Exercise vigorously for 20 or more minutes at least 3 times a week (such as swimming, brisk walking, bicycling, aerobic dancing, using a stair climber)
- Take part in light to moderate physical activity (such as sustained walking 30-40 minutes 5 or more times a week)
- Take part in leisure-time (recreational) physical activities (such as swimming, dancing, bicycling)
- Get exercise during usual daily activities (such as walking during lunch, using stairs instead of elevators, parking car away from destination and walking)

One question in the HPLPII related to activity was analyzed separately due to its effect on the internal consistency of the activity scale. This question inquired how frequently the respondents perform stretching exercises at least three times per week.

Sample Characteristics

All participants in the study had been diagnosed with MS for at least one year, were community-dwellers, and were residents of Texas. Age of the participants ranged from 18 to 95 years. Ethnicity of the sample was delineated as follows: 750 white/Caucasian, 31 black/African American, 19 Hispanic/Mexican American, 1 Asian American, and 6 other for a total of 807 respondents.

Frequency statistics were performed on the variables to describe the population (table 1). The mean age of respondents was 48, with 50.4% being 47 or younger. Of the 807 respondents, 303 (37.5%) had a high school diploma and 372 (46%) respondents had a post-high school degree. The most frequent response to years of education was 12 years with 210 out of 805 respondents (26%). A majority of all respondents (58.6%) reported their income met their needs adequately or more than adequately, whereas 41.4% of all respondents reported their needs were met less than adequately or not at all. The greatest frequency was 174 of 805 respondents (21.6%) who reported that their needs were met “adequately” (3.00).

Of 806 respondents, 269 (33.4%) were unemployed due to disability, whereas the next highest frequency, 234 (29%) worked full-time for pay. There were 100 respondents (12.4%) reporting they were full-time homemakers. The next greatest frequency, 86 respondents (10.7%), were retired. The remainder of responses (14.5%) were made up of individuals who reported one of the following: work part-time; full-time homemaker while ranching or farming; full-time homemaker with part-time pay; unemployed due to age; laid off; fired; full-time student; working student; or no jobs available in the area. The response choice “unemployed due to age” may have been chosen by respondents instead of “retired” if they perceived themselves as being “too old” to work.

The highest score possible on the ISS in this survey was 65, with coding such that the higher the score, the greater the disability of the individual. Scores obtained ranged from 1 to 48 from the 766 respondents for the ISS. Of these, 221 (28.9%) individuals scored 12 or below. The

majority of respondents, 379 (49.5%), scored from 13 to 24, and 139 (18.1%) scored in the 25 to 36 range. The lowest frequency occurred from 37 to 48, with 20 respondents (2.6%). The mean score was 17.94 ($s = 8.7$).

The length of time since diagnosis of MS ranged from 0 (.4%) to 46 (.1%) years, with a mean of 10.87 years ($s = 7.9$). The greatest frequency was 5 years with a total of 62 respondents (7.8%). Length of time since symptoms of MS began ranged from 0 (.3%) to 57 (.1%) years. The mean number of years reported since symptoms began was 15.14 years ($s = 9.46$).

Marital status data of 807 respondents resulted in 49 (6.1%) never married, 567 (70.3%) married, 122 (15.1%) divorced, 27 (3.3%) widowed, 13 (1.6%) separated, and 29 (3.6%) living with someone. 603 (74.7%) of 807 respondents reported living in an urban area, whereas 204 (25.3%) lived in rural areas.

Data Analysis

Descriptive statistics were used to analyze the data from this study using SPSS 6.1 statistical software. All statistical tests were performed at the .05 alpha level of significance.

Descriptive tests were used on the variables to describe the population. The distribution of each variable was examined and found to have an approximate normal distribution. Below is a description of the data analysis performed for specific research questions.

The differences in frequency of physical therapy use between men and women, between persons living in rural versus urban areas, and

between persons with different clinical courses of MS were calculated using crosstabulation and chi-square tests. A t-test was used to test for significant differences between use of physical therapy and the following variables: disability status, length of time since diagnosis, economic resources, age, level of physical activity, and stretching habits of persons with MS.

Table 1: Demographic Characteristics of the Sample Population

	N	Mean	Median	Standard Deviation	Range
Age	807	48.00	47.00	10.64	18 - 95
Economic need	805	3.0	3.0	.685	1.00 - 4.63
Hours worked per week	318	36.83	40	12.98	0 - 80
Incapacity Status Scale	766	17.94	17.0	8.7	1.00 - 48.00
Years since Diagnosis	800	10.87	9.0	7.9	.00 - 46.00
Years since first symptoms	791	15.14	13.0	9.46	.00 - 57.00
Years of education	805	14.24	14.0	2.75	1 - 25

CHAPTER IV

RESULTS

This chapter describes the results obtained for each research question. Tests used to examine the research questions included descriptive statistics such as chi square, t-test, and tests for equality of variance. Below are results from the specific statistical analyses of each research question.

Research Question 1

What is the difference in frequency of physical therapy use between genders of those persons with multiple sclerosis?

A case processing summary was completed for this question to determine the number of persons surveyed who answered the question regarding whether or not they had used physical therapy for treatment of symptoms of their MS. Out of 807 total N, 805, or 99.8% responded to this question. A crosstabulation analysis of this question revealed 142 (20%) males and 573 (80%) females, or a total of 715 (89%) persons did not use physical therapy for treatment of their MS (Table 2). Of the 90 persons that answered “yes”, 20 (22%) were male, and 70 (78%) were female. A Pearson

Chi-Square test showed no significant difference between gender and frequency of physical therapy use ($X^2 = .277$, $df = 1$, $sig = .598$).

Table 2. Number of Persons with MS Utilizing Physical Therapy

Use of PT for treatment of MS?	Gender				
	Male	%	Female	%	Total
Yes	20	22	70	78	90
No	142	20	573	80	715
Total	162	20	643	80	805

Research Question 2

What is the difference in the frequency of physical therapy use between persons with MS living in urban areas and those living in rural areas?

These survey questions were answered by 805 out of 807 respondents, or 99.8%. Crosstabulation showed that of the 715 persons that did not report using physical therapy for their MS, 533 lived in urban areas, and 182 in rural areas (Table 3). Of the 90 persons who did receive PT, 68 lived in urban and 22 in rural areas. For both groups, those who did use PT and those who did not, 75% lived in urban areas. A Pearson Chi-Square test showed no significant difference between frequency of physical therapy use and geographic area ($X^2 = .043$, $df = 1$, $sig = .836$).

Table 3. Utilization of Physical Therapy by Persons with MS in Urban and Rural Areas

Geographic area	Physical therapy intervention response				
	No PT intervention	%	PT intervention	%	Total
Urban areas	533	89	68	11	601
Rural areas	182	89	22	11	205
All	715	89	90	11	805

Research Question 3

Is there a difference between the disability status of persons with MS and their use of physical therapy?

Of those respondents who completed the Incapacity Status Scale (ISS) portion of the survey, the group statistics were: the mean ISS total for those persons who did not receive PT (n = 682) was 17.2, whereas the mean for those who did receive PT (n = 83) was 23.7. A Levene's Test for Equality of Variances was applied for the ISS variable and equal variances were assumed. A t-test was performed for Equality of Means and a significant difference was found between the disability status of persons with MS and their use of physical therapy ($t = -6.607$, $df = 763$, $sig = <.001$).

Research Question 4

What is the difference in frequency of physical therapy use among persons with four clinical courses of multiple sclerosis: benign, relapsing-remitting, chronic progressive, and acute progressive?

This survey question was answered by 785, or 97.3% of the 807 respondents. The crosstabulation resulted in the 695 persons who did not use PT separated into clinical courses of MS as follows: 102 (14.7%) benign sensory, 328 (47.2%) relapsing remitting, 223 (32.1%) progressive, and 42 (6%) severe progressive (Table 4). Of those persons who did use PT, 3 (3.3%) were benign sensory, 25 (27.8%) relapsing-remitting, 54 (60%) progressive, and 8 (8.9%) severe progressive, for a total of 90 persons. A Chi-Square test found a significant difference between the clinical course of MS and the frequency of physical therapy use ($X^2 = 32.953$, $df = 3$, $sig = <.001$). The most significant standardized residual value for respondents was 3.9 for those with chronic progressive MS who utilized PT.

Table 4. Type of MS and Utilization of Physical Therapy

Use of PT	Type of MS								Total
	Benign	%	Relapsing-remitting	%	Chronic progressive	%	Acute progressive	%	
No PT	102	14.7	328	47.2	223	32.1	42	6	695
Standard Residual	0.9		0.9		-1.4		-0.3		
PT	3	3.3	25	27.8	54	60	8	8.9	90
Standard Residual	-2.6		-2.4		3.9		0.9		
Total	105	13	353	46	277	35	50	6	785

Research Question 5

Is there a difference between length of time since diagnosis and use of physical therapy by persons with MS?

The mean length of time since diagnosis for those persons with MS who did not use physical therapy was 10.6 years and 12.7 years for those who did use physical therapy. A t-test showed that there was a significant difference between the length of time since diagnosis of MS and use of physical therapy treatment intervention ($t = -2.388$, $df = 796$, $\text{sig}(2\text{-tailed}) = .017$).

Research Question 6

What is the difference between economic resources and use of physical therapy by persons with MS?

The mean score in this category of those persons who did not receive physical therapy was 3.00 while the mean score of those who did receive physical therapy was 2.98. The Levene's Test for equality of variances revealed that the assumption of homogeneity of variance was not violated. No significant difference was found after running a t-test comparing the two groups ($t = .348$, $df = 801$, $sig = .728$).

Research Question 7

What is the difference between age and use of physical therapy by persons with MS?

The mean age for the group of persons with MS who were not receiving physical therapy services was 47.57 years, whereas the mean age for those receiving PT was 51.47 years. A Levene's Test for equality of variances did not show a significant difference in variance between these two groups. Therefore, the assumption of homogeneity of variance was not violated. A t-test for equality of means showed a significant difference between the mean age of those persons receiving PT and those who did not ($t = -3.298$, $df = 803$, $sig = .001$).

Research Question 8

Is there a difference in the level of activity of those persons with MS who use PT and those who don't?

The reliability analysis performed on this 4-item activity scale revealed an alpha of 0.75, supporting the internal consistency of the scale. The mean score in response to level of activity for the group not using physical therapy was 7.65, and the mean for the group using physical therapy was 7.31. The Levene's Test for Equality of Variances did not show a significant difference in variance between the two groups, nor did the t-test for equality of means show a significant difference between the means ($t = .965$, $df = 803$, $sig = .335$).

Research Question 9

Is there a difference in the amount of stretching done by those persons with MS who use PT and those who don't?

Of those persons with MS who did not use PT ($n = 715$) the mean score for the item in the survey asking about the frequency with which the person performed stretching exercises at least three times per week was 2.16. The mean score for those who did use PT ($n = 90$) was 3.13. Levene's Test for equality of variance showed no significant difference in variance between the two groups. A t-test was then done to compare the equality of means and a significant difference was found between them ($t = -7.768$, $df = 803$, $sig < .001$).

Chapter Summary

This chapter has presented the statistical analysis and results of each of the nine secondary research questions. The following chapter will discuss the results of each secondary question, as well as attempt to answer the primary research question. Recommendations for further research, and limitations of the study will be presented.

CHAPTER V

DISCUSSION

Introduction

This chapter discusses the results reported in the last chapter for each research question and attempts to answer the primary research question. Recommendations for further study are made, limitations are discussed, and finally, conclusions drawn from the study are presented.

Research Question 1

Analysis of frequencies of PT use between gender of persons with MS produced no significant difference. Within the general population of persons with MS, women outnumber men with this diagnosis by approximately 2:1. The sample used for this question ($n = 805$) contains an even greater number of women (643) compare to men (162), or approximately a 3:1 ratio. Investigations and case studies in the literature documenting effects of rehabilitation and PT interventions on persons with MS reflect these ratios, primarily involving women.^{5-7,23,36,40,41} The results in

this study indicate that the likelihood of men receiving PT compared to women is no different proportionally.

Research Question 2

No significant difference was noted between frequency of physical therapy use of those persons with MS in rural areas and those in urban areas. This result is interesting in that it could be assumed persons with MS living in urban areas would have easier access to PT, whether admitted to a rehabilitation setting or on an outpatient basis, than those persons in a rural area. In contrast, Stuifbergen¹⁵ discovered that barriers to health practices were greater in persons with MS living in rural areas compared to those living in urban areas. Because no significant difference was found in use of PT by persons in the two regions in this study, both groups must have equal issues regarding access to PT, although barriers to utilization of PT may be different. A possible explanation could be that those persons who utilized PT had severe enough symptoms and disability that regardless of their location they would seek out help, most likely from their physicians, who could then refer them to a rehabilitation center. Moreover, a person reporting that they live in a rural area may have benefits of an urban area due to technology such as telecommuting, whereas individuals living in small towns may perceive themselves as living in a rural environment even if it is a metropolitan county.¹⁵

Research Question 3

A significant difference was discovered ($p < .001$) between the disability status of persons with MS and whether or not they utilized physical therapy for treatment. In general, the greater the disability the more likely a person with MS was to utilize PT interventions. This result is not surprising given that the majority of the literature on rehabilitation and physical therapy for persons with MS involves studying persons with more progressive forms of MS.^{5-7,37} If a person is admitted to a long term rehabilitation program that individual is likely to receive PT services as part of the interdisciplinary treatment.^{5,6} However, benefits also can be gained from physical therapy for persons with a more benign form of the disease.

Persons with MS but without disabilities that limit their function, or with very mild functional disabilities may not be receiving PT for a variety of reasons. They may not be aware that there may be benefits from PT for prevention of secondary conditions which may develop in the future or for strategies to help maintain current function. It is possible that fear of what the future holds with regard to the disease course may be a barrier to seeking treatment. Persons with mild cases of MS may believe their symptoms will not increase and therefore do not seek out preventative measures. Another factor limiting these persons access to PT may be a lack of knowledge on the part of physicians and other health providers. They, too, may be unaware of the benefits PT can provide for persons with benign or relapsing-remitting forms of MS.

Rehabilitation professionals need to learn more about benign and relapsing-remitting types of cases.³⁶ Preventative care for secondary complications, education on energy conservation techniques, balance and coordination training can all be addressed by physical therapists to aid persons with mild symptoms of MS to manage their disease. In some cases, the therapist's role may be simply as an educator, to encourage general conditioning and good health habits.⁴

Research Question 4

A significant difference was noted between the clinical course of MS and the frequency of PT utilization by persons with MS. Of those who did use PT, 54 persons (60%) reported they had chronic progressive MS, which is generally a more serious course with no remissions.⁴ A standardized residual value of 3.9 for chronic progressive MS indicates that this category had the greatest impact on the statistical outcome for this question. The proportion of those individuals who have this type of MS and utilized PT is greater than expected by chance. It would appear that those individuals with greater disability, due to a more severe course of MS, are more likely to receive PT services, especially if admitted to an inpatient rehabilitation program. This finding is supported by the work of DiFabio et al,^{5,6} whose studies included only individuals with a Kurtzke Expanded Disability Scale score of between 5 and 8. This indicates that, minimally, subjects were not able to walk 200 meters without assistance, nor could they work a full day without certain modifications.

In this study, results produced 3 individuals with benign MS and 25 with relapsing-remitting forms of MS who utilized physical therapy for their MS. Because of the small number ($n < 5$) in some cases, results must be interpreted carefully. Though these numbers are not significant, it does show that there are persons with less severe forms of the disease who are receiving PT treatment. The literature includes limited studies documenting benefits of PT intervention on an outpatient basis for functional deficits that may interfere with activities of daily living and quality of life, but don't necessarily require inpatient rehabilitation.^{40,41} Again, lack of knowledge on the part of the patient or physician on benefits of PT may be an explanation for the low numbers of persons receiving PT in the benign and relapsing/remitting groups. Also, the survey question asked respondents if they were "currently" receiving PT for treatment of their MS. Some individuals with less severe forms of MS may have seen a PT in the past, or may use PT intermittently when exacerbations occur, making it difficult to draw conclusions regarding use of PT for these groups.

Research Question 5

A significant difference was noted between the length of time since diagnosis for persons with MS and their use of physical therapy. A person with MS was found to be more likely to have used PT for treatment of their MS symptoms if they had been diagnosed for a longer period of time. Since MS is generally a progressive disease, this finding is not surprising.

Increasing levels of disability are correlated with longer disease duration.^{8,42} Therefore, the likelihood of utilizing PT for functional deficits may increase as length of time since diagnosis increases. In the population of persons with MS, 50 - 60% have some type of progressive course of the disease, whether it is a primary or secondary progression.^{2,26} Much of the research involving MS and rehabilitation involves subjects who have had the diagnosis with MS for many years on average.^{5-7,37} However, PT can be helpful to persons with MS even in the early stages of the disease.

Mertin⁹ suggests rehabilitation should begin with diagnosis, and that it become a way of life managed by the patient as much as possible, but with guidance from a neurologist with experience in MS. Physical therapists can create home exercise programs for patients with emphasis on preventing loss of function secondary to spasticity.⁹ Rehabilitation is important early on in the disease process even if symptoms are not readily visible to educate the individual about disease management, general conditioning, and to improve their outlook by helping them take charge of their lives.⁴

Research Question 6

No significant difference was noted between individuals' economic resources and whether or not they utilized PT for their MS symptoms. One might expect a difference between those who reported adequate or more than adequate resources and those that reported less than adequate resources, in that persons with less than adequate economic resources may

not have the insurance coverage or income necessary to receive PT services. An important point to note is that answers to questions regarding adequacy of economic resources were based on respondents' perceptions of their economic status, not specific reports of yearly income or type and amount of insurance coverage. Apparently, economic resources, as perceived by the respondents, are not a primary factor in determining whether or not a person with MS receives PT for treatment.

Research Question 7

A significant difference was present between age and whether or not a person with MS had used physical therapy intervention for treatment of symptoms related to MS. One of the correlates with disease severity in MS is age.⁴² Consequently, as severity of the disease increases with age, the likelihood of utilizing PT for symptoms of MS may also increase. Persons without a chronic disease such as MS tend to become less active while they age. When this happens with people with the diagnosis of MS, the results are even more dangerous. In addition to increased risk of cardiovascular disease, inactivity in persons with MS increases risk of respiratory and bladder infections, bowel dysfunction, contractures in the joints, and increased spasticity.³ Progressive forms of MS are seen more frequently in persons who are older at the onset of the disease.²⁶ Therefore, older persons with MS are probably more likely to have been treated by a physical therapist for their symptoms, probably in an inpatient rehabilitation setting.

Research Question 8

There was not a significant difference between the level of physical activity of persons with MS and whether or not they utilized physical therapy for treatment. Given the amount of research showing the benefits of physical activity on symptoms of MS for person with this diagnosis,^{24,25,31,33} this finding is surprising. Physical activity has been shown to produce many positive results in persons with MS, including minimizing deconditioning, increasing strength and aerobic capacity, decreasing depression and fatigue, improving mobility, and bettering quality of life.^{24,25,27,31-33} One might expect that a person receiving physical therapy would tend to be more physically active, due to education and home exercise programs prescribed by a PT, or that more physically active people with MS would require less PT. However, this may be influenced by the fact that increased severity of the disease probably leads to decreased activity.

Research Question 9

The question regarding amount of time spent stretching per week was separated from the activity scale due to its influence on the scale's reliability. Clearly, this question was very different from the other activity questions in the subjects' minds. A significant difference was noted between the frequency with which an individual performed stretching

exercises per week and whether or not they utilized physical therapy for treatment of their MS symptoms.

Reasons for this significance may be that those individuals with MS who utilized PT for treatment performed stretching exercises frequently in their physical therapy sessions, or at home as part of a home exercise program devised by a PT. Stretching exercises are often used by persons with MS for management of spasticity.^{2,4,42}

What is not clear from the results of this question, is whether persons who stretched more frequently did so because they were receiving PT, or if people who stretch more frequently to help relieve symptoms of MS are more likely to seek out PT as a treatment for functional changes occurring as symptoms of MS. Brar and Smith et al⁴² reported that stretching provided patients with a subjective increased sense of control over their spasticity.

Recommendations

For the most part, the findings of this study are what one might expect based on the existing literature. Persons with MS are more likely to receive physical therapy services for treatment of their MS if they are older, have had the disease longer, have a more severe course of the disease, and have greater disability. Other results were more difficult to explain. Adequacy of economic resources does not appear to increase the likelihood of receiving PT services for these patients, nor does living in an urban environment as opposed to a rural one. Men were as likely to receive PT

services for treatment of MS as women, despite the fact that the disease course for men with MS tends to be a chronic progressive one¹, and therefore more likely to require PT intervention.

Another somewhat surprising result was the lack of a significant difference between physical activity and whether or not a person utilized PT for treatment. Though it is impossible to draw conclusions from this finding, the best explanation may be that because so often persons with MS utilize PT treatment only during exacerbations or due to severe progression of the disease, their functional disabilities may be such that participation in regular physical activity is difficult. Because physical activity is so important in increasing physiological capacity, as well as maintaining or improving daily function, physical therapists can play a large part in encouraging persons with MS of all levels of severity to begin and maintain regular physical activity.

Future research is necessary to examine physicians' and other health professionals' knowledge of the benefits of PT for these patients. If, indeed, persons with mild or relapsing-remitting forms of MS are being underserved by PT, it may be due to a lack of awareness on the health-provider's part, of these benefits. In addition, persons with MS themselves need to become educated on what PT can do to alleviate their symptoms and prevent further complications and loss of function as much as possible.

Other recommendations include more research on effects of various PT interventions on individuals with mild cases of MS, including longitudinal studies beginning at diagnosis and following patients with and without PT interventions throughout the disease progression. Finally,

research is needed to discover if the activity level of those persons with MS who are physically active and utilizing PT for intervention, is a result of PT intervention, or an active routine established prior to the intervention.

An interesting addition to this study might be to research for what aspects of the disease these individuals are receiving PT intervention and whether or not they have benefited from the treatment.

Limitations

There are several limitations in this descriptive study which must be acknowledged. The sample used was a sample of convenience, obtained on a volunteer basis. In addition, the surveys were assumed to be completed honestly and accurately by the respondents. Therefore, one must use caution in interpreting the data. One can only make suggestions based on the data analysis regarding the factors which may influence whether or not persons with MS utilize PT interventions for treatment of symptoms. In addition, this study was a secondary analysis of preexisting data, and therefore limited in its scope. Lastly, the data in this study was collected from February through September of 1996. In the 4 years since then, changes in Medicare coverage and effects of managed care may have influenced the utilization of PT by persons with MS. Responses to the same survey questions may be quite different today. Another significant development has been the approval of new drugs by the FDA in treatment of MS. These drugs are aimed at slowing down disease progression and decreasing the number and severity of exacerbations. With the exception of

one, Betaseron, these drugs were unavailable in 1996. Data gathered today may yield significantly different results from those found in this study.

Conclusion

Persons with MS, especially those with benign and relapsing-remitting forms of the disease, appear to be underserved by rehabilitation professionals, physical therapists in particular. Although the literature includes research of the benefits of PT, most is aimed at serving those persons with progressive forms of MS. The findings from this study show that persons with MS are more likely to receive PT for treatment of their MS if they are older, have greater disability, have been diagnosed longer, and have more progressive courses of the disease. Physical therapy can provide many benefits for persons with mild forms of the disease as well and further research is needed to increase utilization of PT by these individuals.

Appendix A

Background Information

1. What is your age? _____
2. What is your gender?
 - 1 Male
 - 2 Female
3. Which of the following best describes your racial/ethnic group?
 - 1 White/Caucasian
 - 2 African American /Black
 - 3 Asian-American
 - 4 Hispanic/Mexican American
 - 5 Other (Please describe) _____
4. What is your present marital status?
 - 1 Never married
 - 2 Married
 - 3 Divorced
 - 4 Widowed
 - 5 Separated
 - 6 Living with a significant other
5. Do you have children?
 - 1 Yes
 - 2 No

If you have children, please list their ages below:

If you have children, are they living with you?

 - 1 Yes
 - 2 No
6. How many years of school have you completed? _____
7. What is the highest degree you have completed?
 - 1 No degree
 - 2 Vocational Training or Certificate
 - 3 GED
 - 4 High School Diploma
 - 5 Associate Degree
 - 6 Bachelors Degree
 - 7 Graduate Degree (Masters or Doctoral)

8. What is your employment status? (Please circle only one choice.)
- 1 I work full-time for pay (Includes farm/ranch work)
 - 2 I work part-time for pay (Includes farm/ranch work)
 - 3 I am a full-time homemaker
 - 4 I am a full-time homemaker and also help with farm/ranch work
 - 5 I am a full-time homemaker and also work part-time at another job
 - 6 I am unemployed due to age
 - 7 I am unemployed due to disability
 - 8 I am laid off
 - 9 I have been fired
 - 10 I am a full-time student
 - 11 I am a student (full or part time) and also work for pay
 - 12 I have been unable to find suitable work because of where I live
 - 13 I am retired
9. If you are employed, how many hours a week do you work? _____
Please describe what kind of business or industry you work in:

The following are general questions related to the economics of daily living.

1 = Not at all

2 = Less than Adequately

3 = Adequately

4 = More than Adequately

1. Does your family income allow you to meet your
need for daily living? 1 2 3 4
2. Does your family income allow you to meet your rent
or mortgage payment? 1 2 3 4
3. Does your family income allow you to meet your
food bills? 1 2 3 4
4. Does your family income allow you to meet
health care needs? 1 2 3 4
5. Does your family income allow you to participate
in recreation? 1 2 3 4
6. Does your family income allow you to meet child costs
or the costs of other dependents (skip if no children
or dependents)? 1 2 3 4
7. Does your family income allow you to meet
the special needs created by MS? 1 2 3 4
8. Does your family income allow you to meet
other financial needs you have? 1 2 3 4

Please specify these needs:

What is the name of the county in which you reside? _____

How many miles do you have to drive for emergency medical care? _____

The following questions are about your MS, your symptoms and treatment.

1. MS tends to take one of four clinical courses. Which type best describes your MS?
 - 1 Benign Sensory MS: attacks are characterized by sensory symptoms and/or optic neuritis, usually no long-term severe disability.
 - 2 Relapsing-Remitting MS: symptoms fluctuate (come and go) over time
 - 3 Progressive MS: symptoms and disability become more serious over time
 - 4 Severe Progressive MS: symptoms generally do not remit but progress in seriousness and disability from the beginning of the disease course

2. What year did you first start having symptoms of MS? _____

3. What year were you diagnosed with MS by a physician? _____

4. What treatments are you presently using for your MS? (circle all that apply)
 - 1 Steroids (e.g. Prednisone, SoluMedrol)
 - 2 Betaseron
 - 3 Other medications (Please list)_____
 - 4 Physical Therapy
 - 5 Other (Please describe)_____

5. Since you've been diagnosed with MS, how often have you taken steroids for treatment:
 - 0 I have not taken steroids at any time
 - 1 I have taken one course of steroid treatment
 - 2 I have taken several (2 - 5) courses of steroid treatment
 - 3 I have taken many courses (more than 5) of steroid treatment

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REFERENCES

1. O'Sullivan SB. Multiple sclerosis. In: O'Sullivan SB, Schmitz TJ. *Physical rehabilitation: assessment and treatment*. 3rd ed. Philadelphia: F.A. Davis Co.; 1994:451-467.
2. Lechtenberg R. *Multiple sclerosis fact book*. 2nd ed. Philadelphia: F.A. Davis Co.; 1995.
3. Frankel D. Multiple sclerosis. In: Umphred DA, ed. *Neurological Rehabilitation*. 3rd ed. St. Louis: Mosby-Year Book, Inc; 1995:588-605.
4. Schapiro RT. *Multiple Sclerosis: A rehabilitation approach to management..* New York: Demos publications; 1991.
5. Di Fabio RP, Soderberg J, Choi T, Hansen CR, Schapiro RT. Extended outpatient rehabilitation: its influence on symptom frequency, fatigue, and functional status for persons with progressive multiple sclerosis. *Arch Phys Med Rehabil* . 1998;79:141-6.
6. Di Fabio RP, Choi T, Soderberg J, Hansen CR. Health-related quality of life for patients with progressive multiple sclerosis: influence of rehabilitation. *Phys Ther*. 1997;77:1704-16.
7. Greenspun B, Stineman M, Agri R. Multiple sclerosis and rehabilitation outcome. *Arch Phys Med Rehabil* 1987;68:434-37.
8. Kraft GH, Freal JE, Coryell JK. Disability, disease duration, and rehabilitation service needs in multiple sclerosis: patient perspectives. *Arch Phys Med Rehabil* 1986;67:164-68.
9. Mertin J. Rehabilitation in multiple sclerosis. *Ann Neur* 1994;36 Suppl:S131-S133.
10. Perkin GD. Multiple sclerosis and other demyelinating disorders. In: *Mosby's Color Atlas and Text of Neurology*. London: Mosby-Wolfe; 1998:179-191.

11. Waxman SG. Demyelinating diseases - new pathological insights, new therapeutic targets. *N Engl J Med* 1998;338:323-25.
12. Stuifbergen AK, Roberts GJ. Health promotion practices of women with multiple sclerosis. *Arch Phys Med Rehabil* 1997;78 Suppl 5:S-3-S-9.
13. Miller BF, Keane CB. Encyclopedia and dictionary of medicine, nursing, and allied health. 3rd Ed. W.B. Saunders Co; 1983.
14. Kurtzke JF. A proposal for a uniform minimal record of disability in multiple sclerosis. *Acta Neurol Scand.* 1981;64 Suppl 87:110-29.
15. Stuifbergen AK. Barriers and health behaviors of rural and urban persons with MS. *American Journal of Health Behavior*. In press.
16. Anderson DW, Ellenberg JH, Leventhal CM, Reingold SC, Rodriguez M, Silberberg DH. Revised estimate of the prevalence of multiple sclerosis in the United States. *Ann Neur.* 1992;31:333-336.
17. Trapp BD, Peterson J, Ransohoff RM, Rudick R, Mörk S, Bö L. Axonal transection in the lesions of multiple sclerosis. *N Engl J Med.* 1998;338:278-85.
18. MS Information: Epidemiology. National Multiple Sclerosis Society Web site. Available at: <http://www.nmss.org/msinfo/cmsi/epidemiology>. Accessed March 7, 1999.
19. MS Information: Genetics. National Multiple Sclerosis Society Web site. Available at: <http://www.nmss.org/msinfo/cmsi/epidemiology>. Accessed March 7, 1999.
20. Lazar RB. *Principles of neurologic rehabilitation*. McGraw-Hill Co. Inc; 1998.
21. *Fatigue and multiple sclerosis: evidence-based management strategies for fatigue in multiple sclerosis*. Multiple Sclerosis Council for Clinical Practice Guidelines. Paralyzed Veterans of America; October 1998.
22. Fragoso C, Wirz D, Mashman J. Establishing a physiological basis to multiple sclerosis-related fatigue: a case report. *Arch Phys Med Rehabil.* 1995;76:583-586.
23. Stuifbergen AK, Rogers S. The experience of fatigue and strategies of self-care among persons with multiple sclerosis. *Applied Nursing Research* 1997;10:2-10.

24. Petajan JH, Gappmaier E, White AT, Spencer MK, Mino L, Hicks RW. Impact of aerobic training on fitness and quality of life in multiple sclerosis. *Ann Neur* 1996;39:432-41.
25. Ponichtera-Mulcare JA. Exercise and multiple sclerosis. *Med Sci Sports Exerc* 1993;25:451-65.
26. Kraft GH, Freal JE, Coryell JK, Hanan CL, Chitnis N. Multiple sclerosis: early prognostic guidelines. *Arch Phys Med Rehabil* 1981;62:54-58.
27. Pate RR, Pratt M, Blair SN et al. Physical activity and public health. *JAMA*. 1995;273:402-407.
28. Levine AM. Management of multiple sclerosis. *Postgraduate Medicine*. 1985;77:121-127.
29. Clark C. Nursing care for multiple sclerosis. *Orthopaedic Nursing*. 1991;10:21-32.
30. Lewis SM. Therapeutic swimming: a different kind of nursing. *J Nurs Educ*. 1985;24:125.
31. Gehlsen GM, Grigsby SA, Winant DM. Effects of an aquatic fitness program on the muscular strength and endurance of patients with multiple sclerosis. *Phys Ther* 1984;64:653-57.
32. Johnson KB. Exercise, drug treatment, and the optimal care of multiple sclerosis patients. *Ann Neur* 1996;39:422-23.
33. Stuijbergen AK. Physical activity and perceived health status in persons with multiple sclerosis. *Journal of Neuroscience Nursing*. 1997;29:238-243.
34. Rimmer JH. Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions. *Phys Ther*. 1999;79:495-502.
35. Brooks NA, Matson RR. Social-Psychological adjustment to multiple sclerosis. *Soc Sci Med*. 1982;16:2129-2135.
36. Poser S, Bauer HJ, Ritter G, Friedrich H, Beland H, Denecke P. Rehabilitation for patients with multiple sclerosis? *J Neurol* 1981;224:283-90.
37. Feigenson JS, Scheinberg L, Catalano M, Polkow L, Mantegazza PM, Feigenson WD, LaRocca NG. The cost-effectiveness of multiple sclerosis rehabilitation: a model. *Neurology* 1981;31:1316-22.

38. Roush SE. The satisfaction of patients with multiple sclerosis regarding services received from physical and occupational therapists. *International Journal of Rehabilitation and Health*. 1995;1:155-166.
39. DeSouza LH. A different approach to physiotherapy for multiple sclerosis patients. *Physiotherapy*. 1984;70:429-432.
40. Kasser SL, Rose DJ, Clark S. Balance training for adults with multiple sclerosis: multiple case studies. *Neurology Report*. 1999;23:5-12.
41. Pert V. TENS for pain in multiple sclerosis. *Physiotherapy*. 1991;77:227-28.
42. Brar SP, Smith MB, Nelson LM, Franklin GM, Cobble ND. Evaluation of treatment protocols on minimal to moderate spasticity in multiple sclerosis. *Arch Phys Med Rehabil*. 1991;72:186-189.
43. Stuifbergen AK, Rogers S. Health promotion: an essential component of rehabilitation for persons with chronic disabling conditions. *Adv Nurs Sci*. 1997;19:1-20.
44. Walker SN, Sechrist KR, Pender NJ. The health-promoting lifestyle profile: development and psychometric characteristics. *Nurs Res*. 1987;36:76-81.

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