

Rehabilitation in Multiple Sclerosis

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Multiple Sclerosis, a highly prevalent neurologic condition of young adults, can cause progressive impairment over the individual's lifespan. This results in restrictions in participation in multiple areas of mobility, daily activities, and life roles. Research has demonstrated the value of rehabilitation in reducing disablement and improving health-related quality of life.



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Introduction. Multiple Sclerosis (MS) is a leading cause of significant disability of young to middle aged adults and the most common disabling neurologic diagnosis. While immunomodulating therapies are now available that can alter or slow the progression, the course and symptomatology for each person is highly variable and uncertain. Most people with MS experience increasing impairment and functional limitations over time. The philosophy of rehabilitation which addresses the needs of the whole patient and emphasizes patient education and self-management is ideally suited to the needs of patients with the complexities of a progressive neurological disorder such as MS. Clearly rehabilitation cannot alter the underlying neurological damage or disease course. However, there is increasing evidence that rehabilitation can reduce disablement by minimizing impact of impairments on daily activities and enhancing the ability of the individual to participate in his or her usual life roles. In addition, there is evidence to suggest that rehabilitation can prevent secondary complications, improve quality of life and reduce health care utilization. However many people with chronic disabilities have trouble accessing appropriate rehabilitation services due to inadequate resources and limited knowledge of referring healthcare providers.

Evidence for Rehabilitation in MS. Recently the Medical Advisory Board of the

National Multiple Sclerosis Society published an Expert Opinion Paper on rehabilitation recommendations for persons with MS.¹ The following definition for MS Rehabilitation was submitted:

Definition:

Rehabilitation in MS is a process that helps a person achieve and maintain maximal physical, psychological, social and vocational potential, and quality of life consistent with physiologic impairment, environment, and life goals. Achievement and maintenance of optimal function are essential in a progressive disease such as MS.

By definition, rehabilitation should be individualized to match the specific needs of each patient. Multiple sclerosis, with its broad range of symptoms and associated disability, creates added variability that poses significant difficulties for quality rehabilitation research. Studies of in-patient rehabilitation for people with MS date back to 1981. The early studies were either retrospective or prospective single group pre and post study designs all demonstrating progress or reductions in disability and handicap with in-patient rehabilitation. More recent studies have attempted randomization with controls. Freeman, et.al. demonstrated the effects of inpatient rehabilitation.² Benefits included reduction in disability and handicap as well as improvement in emotional well-being and health related quality of life (HRQL). Solarie, et. al. also

established positive effects of a 3-week rehabilitation program for an ambulatory group of patients with MS including reduction in disability and improvement in HRQL.³ Two studies of patients with relapsing remitting MS demonstrated greater improvement with rehabilitation. Craig, et. al. found greater improvement in functional status, mobility, and quality of life when patients received multidisciplinary rehabilitation in addition to IV steroids over those who received steroids alone.⁴ Liu et al suggested that in-patient rehabilitation is useful for patients with incomplete recovery from relapses.⁵ Rehabilitation can also be of benefit in multiple settings as demonstrated by Wiles et al.⁶ A physical therapy program conducted either at home or in a hospital outpatient clinic resulted in improvements in mobility, well being, and mood.

Physical activity or exercise programs have also been shown to be of benefit to people with MS. Historically, people with MS were discouraged from increasing their activity because it was felt that the stress of physical exertion may enhance disease activity. This myth has been dispelled over the years by experience. Decreased activity can actually lead to deconditioning leading to further physical limitations followed by lower activity levels etc. In addition, it is known that inactivity can increase risk for secondary complications such as restrictions in joint range of motion, pressure sores, and depression. Petijan et al. found that 15 week exercise training resulted in improved fitness and HRLQ.⁷

Based on these and other studies, the advisory board submitted a list of recommendations to guide practitioners regarding use of rehabilitation services. Some of them are summarized here.

Further research is needed to determine

NMSS Rehabilitation: Recommendations for Persons with MS

- Consider referral for rehabilitation assessment with abrupt or gradual worsening function or increased impairment
- Consider referral early in the disease course when behavior and life-style changes may be easier to implement
- The complex interaction of symptoms and impairments in an unpredictable progressive disease requires periodic reassessment and rehabilitative interventions
- The frequency, intensity and setting of rehabilitation must be based on individual needs
- Appropriate assessments and outcomes measures must be applied periodically to establish and revise goals, identify need for treatment modifications, and measure the results of the intervention.
- Known complications of MS may be reduced or prevented by specific rehabilitative interventions.
- A thorough assessment for wheelchairs, positioning devices, other durable medical equipment and environmental modification by rehabilitation professionals is recommended.

the relative efficacy of different lengths of inpatient rehabilitation stay, and the relative benefits of inpatient vs. home therapy programs vs. supervised outpatient rehabilitation programs. Future research in MS rehabilitation will also attempt to identify new types of treatment protocols, including therapies that actually enhance the nervous systems ability for reorganization and recovery.

Challenges in MS Rehabilitation.

There are important concepts for rehabilitation that apply to all individuals.

- 1) Goal setting is required to measure effectiveness of rehabilitation;
- 2) Rehabilitation should be interdisciplinary;
- and 3) Rehabilitation is restorative, adaptive, preventative and patient centered. However

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5. Liu C, Playford ED, Thompson AJ. Does neurorehabilitation have a role in relapsing remitting multiple sclerosis? *J Neurol* 2003; 250(10): 1214-1218.

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there are specific challenges in applying these concepts to the person with MS.

1. Goal Setting. Goal setting is necessary to the development of appropriate treatment plan and measurement of outcome. To be most effective these goals must be realistic and attainable. There are unique barriers in individuals with MS affecting ability to set and achieve appropriate goals.

Barriers to Goal Setting

- MS is chronic, variable, and unpredictable
- MS symptoms are multiple, complex and interactive
- “Silent” symptoms of MS
 - Fatigue in MS is a common symptom that may affect sustained function
 - Cognitive dysfunction occurs in varying degrees in more than 50%
 - Depression is more prevalent in MS than equally disabling chronic diseases

Variability and Unpredictability.

Most care providers are trained and accustomed to treating acute illness where the model is to diagnose the illness, prescribe treatment and the individual gets well or at a minimum reaches a stable state. With a chronic progressive condition such as MS, treatment provided on one day may not be appropriate at the next visit due to greater impairment, necessitating ongoing re-evaluation. The variability can also affect adherence and commitment to a plan of treatment or prescribed exercise program. Goals therefore must be flexible and alterable in response to the changes in the disease.

Multiple Symptoms and Interaction.

Symptoms and signs are a representation of impairment of affected CNS structure and function. Research and experience support

rehabilitation in concert with medical interventions for many of these symptoms. However, these symptoms cannot be considered in isolation because of the interaction of symptoms on function and because medical treatments of one symptom may adversely affect another symptom. For example, fatigue may be increased by medication to treat spasticity or by poor sleep from frequent awakenings due to urinary frequency and urgency. Alternatively, spasticity may be worsened by constipation or urinary retention. Secondary complications such as infection may worsen all symptoms and may be associated with significant functional decline.

Silent Symptoms of MS.

Fatigue is the most common symptom reported by people with MS and can be very limiting despite little measurable impairment on neurologic examination. It is often experienced as an unexplained lassitude or inability for sustained physical function. It

Common MS Symptoms

- Movement dysfunction
 - Weakness
 - Spasticity
 - Tremor and Ataxia
- Sensory dysfunction
 - Pain
 - Numbness
 - Paresthesias
- Visual deficits
- Bladder dysfunction
- Bowel dysfunction
- Sexual dysfunction
- Cognitive dysfunction
- Depression
- Emotional lability
- Fatigability
- Heat intolerance

can be exacerbated by, deconditioning, increased energy consumption due to the demands of disability, sleep disturbance, medications and depression. Many find that fatigue limits a full day's function and therefore feel that therapy visits and exercise programs only create extra burden. The key to this challenge is to identify the causes and factors that worsen fatigue followed by education in effective fatigue management often in combination with medications. Effective strategies may include, pacing, work simplification, structured graded exercise programs, sleep hygiene, assistive devices with possibly earlier use of durable medical equipment (DME) such as wheelchairs.

Cognitive Dysfunction is estimated to occur in about 50 percent of people with MS over the course of the disease. Most limitations are fairly mild and are amenable to use of compensation strategies. However, about 10 percent of individuals may have severe problems that affect daily functioning. Difficulties can be experienced in areas of memory, attention, slowed information processing, executive functions (planning, organizing, problem-solving), word-finding, visual-spatial orientation and communication. The individual's ability to recognize problems, and actively participate in the rehabilitation process may depend on these cognitive limitations. Assumptions about cognitive functioning cannot be made based on physical symptoms or time since diagnosis. Careful assessment can help identify areas of difficulty that might not only be amenable to treatment but also help to identify appropriate strategies to facilitate goal setting and attainment.

Depression in people with MS is more prevalent compared to other chronic disabling conditions. This is believed due not only to the stresses of the disease but also due to biochemical changes in the brain. A person

who is depressed often lacks the ability to set goals and be an active participant in the rehabilitative process. Adequate diagnosis and treatment of depressive or other emotional symptoms are essential to success of rehabilitation.

2. Interdisciplinary Team — Framework of MS Management. Multiple Sclerosis often has its impact at the formative time of career and family. Because it can affect so many different physical and psychological functions, the collaborative efforts of a team of professionals is key. Members of the interdisciplinary team often include neurologist, physiatrist, physical therapists, occupational therapists, speech/language pathologists, social workers and psychologists. Other team participants can include the Primary Care Physician, Consultants, Dieticians, Orthotist, Vocational counselors, and clergy. These members can be present in a single setting making communication more efficient or by individual practitioners communicating through a designated coordinator such as the physiatrist, neurologist or primary care physician.

Each member of the team works with the person with MS to improve or preserve function in their given area of expertise however the goal setting is enhanced by information shared by other team members. Rehabilitation defined as an interdisciplinary effort, rather than being an isolated treatment in time, becomes the framework of ongoing management of MS.

3. Rehabilitation is restorative, adaptive, preventative, and patient centered. People with MS can experience a range of symptoms that contribute to loss of mobility and participation in daily activities such as weakness, spasticity, imbalance, ataxia and

fatigue. Mobility limitations not only affect function in the home but cause altered ability for work and social connection. Restorative goals are designed to help the person reach his or her highest functional level. When the course of MS is more progressive, goals become more adaptive to help maintain abilities as well as prevent the injuries and secondary complications that may result from increasing mobility limitations.

Accommodation in the form of adaptive devices or durable medical equipment (DME) and their appropriate timing may not be straightforward and depend on several variables. The person's physical function within the context of their unique symptom profile, potential for progression, the environment in which the individual must function, available supports and resources and lifestyle preferences all play a factor in choice and prescription of DME. For example, in the timing of manual versus powered wheelchairs, symptoms to consider include the strength and movement of extremities and core, fatigue factors and cognitive limitations along with the associated risk of secondary complications such as skin breakdown. A prescription written by a physician for a wheelchair is simply insufficient. Wheeled mobility devices vary widely. The type of base, support surface, upholstery, height, width, and capability for position change are a few considerations. The ability for a particular type of chair to be modified later for changing physical requirements is another consideration. Wheeled mobility devices also vary in many features including size, weight, maneuverability and transportability. The nature of activities the person needs and wants to perform in various environments when seated as well as the social acceptability of the device must be identified and matched with these features. Identifying the appropriate DME at

the appropriate time is a team effort that includes the patient, rehabilitation provider(s) (physiatrist, physical or occupational therapist) and the DME vendor.

Conclusion. The individual with MS has changing and ongoing needs for a variety of physicians, therapists, nurses, social, and community support services. Treatments and solutions to problems do not focus only on symptoms but must be adapted to functional status, requirements of living and the support system. Goal setting is key to defining the plan of treatment and assessing the effectiveness.

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