

Rehabilitation of multiple sclerosis patients in India

Nirmal Surya

Director, Surya Neuro Centre, Mumbai, Maharashtra, India

Abstract

Multiple sclerosis (MS) is a chronic progressive disease which is one of the leading causes of handicap in young subjects. The large range of symptoms associated with MS lead to continuing decline in neurologic status and quality of life. The coexistence of physical and cognitive impairments, together with the imprevisible evolution of the disease makes MS rehabilitation very challenging. The main objective of rehabilitation is, therefore, to ease the burden of symptoms by improving self-performance and independence. Inpatient, outpatient and Home rehabilitation with multidisciplinary team has been shown to be beneficial in improving disability. Individualized programs elaborated by a multidisciplinary team of experts are the key to success of rehabilitation. Family plays a big role and Family Based Rehabilitation will be important in long term rehab program in MS.

Key Words

Disability, family based rehabilitation, multi-disciplinary team, multiple sclerosis, MS, neurorehabilitation

For correspondence:

Dr. Nirmal Surya, Surya Neuro Centre, 310 Lotus House, 33/A New Marine Lines, Next to Liberty Cinema, Mumbai - 400 020, Maharashtra, India.
E-mail: nirmal_surya@yahoo.com

Ann Indian Acad Neurol 2015;18 (Supplement 1):S43-S47

Introduction

Multiple sclerosis (MS) is an immune-mediated inflammatory disease of the central nervous system (CNS) that affects an estimated 2.5 million adults worldwide.^[1] The wide range of symptoms encountered in MS includes visual impairment, diplopia, muscle weakness, extreme fatigue, imbalance of gait, sensory disturbance, impaired speech, bulbar symptoms, sphincter incontinence and cognitive dysfunction. These symptoms often lead to a poor health-related quality of life (HRQOL),^[2-4] neurologic disability, and high health care costs (about \$1.7 billion annually in Canada, for example).^[5]

With the advent of MRI and an increasing number of neurologists, the number of MS cases worldwide has risen substantially. The newer disease modifying drugs have only been partially effective in reducing relapse rates and limiting disease progression. They are accessible to only a few due to their high cost. As a result, a large number of patients are left behind with significant impairment in daily living. Thus, ever increasing cohort of severely disabled patients will largely

depend on appropriate rehabilitation to improve their quality of life.

MS in India

Various studies from India have reported low prevalence rates of MS cases (1-2/100,000 population).^[6] The only exceptions are the studies in the small Parsi community by Bharucha *et al.* and Wadia *et al.* which reported a high MS prevalence of 21-26/100,000.^[7,8]

In the developing countries like India, as elsewhere, MS affects the young (average age of onset around 25-30 years) and is seen more commonly in women than in men. In Asia, two forms of clinical presentations have been described:

1. Clinical features restricted to optic nerve and spinal cord (designated as optico spinal MS (OS MS) or Asian MS).^[9]

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

How to cite this article: Surya N. Rehabilitation of multiple sclerosis patients in India. *Ann Indian Acad Neurol* 2015;18:43-7.

Received: 07-07-15, **Revised:** 01-08-15, **Accepted:** 05-08-15

Access this article online

Quick Response Code:



Website:

www.annalsofian.org

DOI:

10.4103/0972-2327.164828

2. Manifestations involving cerebellum, brainstem, cerebral white matter, optic nerve, and spinal cord (Western MS).

Neuromyelitis Optica (NMO) is reported to be more frequent in Asia and Africa than in the West. It occurs both as a monophasic and a relapsing illness.^[10]

Rehabilitation Challenges in India

Developing countries like India, Pakistan, Bangladesh and Sri Lanka all face the same problem- a huge population with a woefully inadequate number of skilled and trained neurorehabilitation specialists.^[11] About 70% of India's 1.3 billion population stays in rural areas and 30% live below the poverty line, with no access to any kind of rehabilitation facility. Even in urban areas with access to private medical services, the number of skilled and trained professionals is too small to cater to the population. Rehabilitation is now widely recognised as an essential requirement for the masses. Sadly, the current gap between the need and supply of rehabilitation services is astoundingly high.^[12] There are at present only a handful of well-equipped modern rehabilitation centres and qualified individual therapists trying to bridge this wide gap. These individuals try to impart the simple home care skills to close relatives and other caregivers of patients.

MS Rehabilitation in India

Rehabilitation in MS must address the issues of impairments, disabilities and handicaps:

- Impairments refer to those symptoms and limitations caused directly by CNS damage (e.g., decreased vision, decreased strength, spasticity, tremor, etc.).
- Disability refers to impaired function in the performing tasks (e.g., walking, bathing, etc.).
- Handicap refers to the reduced ability to participate in various life situations (e.g., driving, employment, etc.) and the environmental restrictions that the patient endures.^[13]

Ideally, rehabilitation should begin as soon as the patient develops some disability. The MS rehabilitation can be divided into three main settings.

Hospital setting

Patients with acute MS with significant persisting neurologic deficit such as impaired mobility, communication, swallowing and sphincter control, and who have the endurance to participate in the active program to achieve therapeutic goals should be hospitalized in the rehabilitation centre. The acute rehabilitation setting is appropriate for patients who meet the admission criteria and are able to tolerate three hours or more of active therapy per day.^[14] Reading *et al.*^[15] observed that 56% of 168 consecutive admissions to the acute care unit could have been managed in the less expensive setting of a rehabilitation unit. Inpatient rehabilitation can produce short term benefits in the levels of activity and participation for patients with MS.^[16]

Outpatient setting

Patients whose neurological disability has stabilised and who are mobile are ideal for outpatient rehabilitation. Initially, the

patient needs to come at least twice a week for a month and later, visits can be reduced to once a month for few months, depending on his/her progress.

Home setting

The family plays an integral part in the care of the MS patient at the house. Home based rehabilitation should undoubtedly be the mainstay of therapy for patients with chronic disability in a resource-poor country like India.

Patients with restricted family support, (for instance, the spouse is working and cannot frequently visit the rehabilitation centre) or those staying far away, or who are bed ridden or have violent behaviour or cannot afford frequent travelling to the centre are considered in the family based rehabilitation (FBR).

In a joint family, responsibility is shared by other members who take care of the emotional, social and financial problems of the patient. Each family member learns the rehab plan and executes it as per availability of time. The FBR helps in early diagnosis and treatment, thus preventing or minimizing disability. Stress is also shared and depression and anxiety are reduced.

The Multiple Sclerosis Society of India (MSSI) is a charitable organization working for the welfare of MS patients. Established in 1985, it is involved in the care of nearly 4000 patients across India. The MSSI members not only provide professional care but also offer emotional, medical and social support to the patient as well as the family. It plays an important role in bridging the gap between the patients and the rehabilitation team member.

Assessments for MS

Owing to the wide range of symptoms and disabilities in MS, a comprehensive assessment of functional disturbances and of personal needs is essential for an individualized, goal-oriented treatment program.^[13] The timing and mode of rehabilitation treatment should be set individually, based on the degree and extent of disability, and personal and environmental factors.

Because of the unpredictable course of the disease, various standardised systems of assessment are used to establish the disease status of the patient.

Minimal Record of Disability (MRD) profiles the main dysfunctions associated with MS and consists of five parts:

1. Demographic information.
2. Kurtzke Functional Systems (FS).
3. Kurtzke Expanded Disability Status Scale (EDSS).
4. Incapacity Status Scale (ISS), and
5. Environmental Status Scale (ESS).^[17]

Quality of life (QoL) is also significantly affected in MS and depends on patient characteristics as well as the emotional and social support that the patient gets from his caregivers. The main predictors of QoL in MS are the EDSS score, disease course, fatigue and depression. Female gender and advanced age are the main predictors of lower QoL in caregivers.^[18]

Limitations in Rehabilitation Management of MS

Co-existence of following can be challenging for rehabilitation program:

- a. Severely disabled people derive equal or more benefit from rehabilitation than those who are less disabled but cognition and ataxia are refractory.^[19]
- b. Cognitive disabilities such as memory trouble affects learning abilities and lack of progress and hindrance to reach the desired goal of improvement.
- c. Cerebellar syndrome causing ataxia and imbalance are a continuous challenge for rehabilitation specialist to make patient ambulatory.

Goal Setting

The goals of MS rehabilitation should be identified and prioritised according to the patient's condition. The treatment and interventions are included in the strategy and followed up for a reasonable long-term period. Initially, the patient needs to follow up every month and later every three months depending on their need for rehabilitation. As MS is a progressive disease with remissions and relapses, the goals and planning for rehabilitation change from time to time.

Advantages of a Multidisciplinary Team

Rehabilitation should be undertaken by a multidisciplinary team (MDT). Each team member contributes to the successful management of specific problems. They coordinate with each other, as well as with family members and the patient in order to prioritize their goals and strategize treatment regimens.

The MDT should be headed by the neurophysician or physiatrist with specialized training in Neurorehabilitation. Other team members should include a physiotherapist for improving muscle strength, and balance, an occupational therapist who evaluates the patient's vocational abilities and helps in improving quality of life, a speech and language therapist who improves language and communication skills and addresses swallowing difficulties, a psychologist or psychiatrist who imparts counselling, retraining, and teaching strategies to cope with cognitive and affective impairment, and a urologist who deals with bladder, bowel and sexual dysfunction. The entire team together with the family and the patient are vital to the success of rehabilitation.

Management of Specific Symptoms

The main symptoms that need to be specifically attended to are spasticity, cognitive impairment motor, sensory and visual disturbance, and fatigue and bladder dysfunction.

Spasticity

Spasticity in MS occurs due to demyelinating lesions in the brain and/or spinal cord. It can cause severe pain and disability, resulting in a chain of secondary complications. Spasticity may result in muscle fibrosis and joint contracture, leading to skin breakdown, osteomyelitis and sepsis. The restricted mobility

affects the quality of life, leading to isolation and depression. Spasticity can be generalised or focal. It can be aggravated by noxious stimuli like pain, full bladder, infection, extreme temperature and stress.

In assessing a patient with spasticity, it is important to identify new onset or a change in pattern of spasticity, to ascertain any precipitating or aggravating factors and to determine if it is causing a functional limitation or impairment. These factors will determine the plan for spasticity management.

Generalised spasticity can be treated by the judicious use of drugs like baclofen and tizanidine, along with carefully supervised physiotherapy. Unfortunately, spasticity drug treatment can be associated with undesirable side effects like sedation, reduced cognition and limb weakness.^[20]

Focal spasticity in both upper and lower limbs can be effectively treated by the use of local botulinum A toxin.

In rare cases, when spasticity is refractory to standard pharmacologic and physical management strategies, irreversible surgical procedures like phenol nerve block or sectioning of nerves to specific muscles may be considered. Intrathecal Baclofen pump can be considered for the severe spastic paraplegia.

Balance and Gait

Gait ataxia and limb incoordination are difficult symptoms to treat. They require prolonged training and patience for improvement. The physiotherapist focuses mainly on improving posture and balance exercises. Drugs have little role to play in this disability.

Gait can be improved by providing artificial support appliances like ankle foot orthoses, canes, crutches, and walker, until the patient gains confidence in mobilizing by himself/herself. Wheel chair of various types are useful to prevent fall and injury with ataxia.

Specific balance and gait interventions depend on the type of impairments that contribute to the problem.^[15] Maintaining postural control is an important outcome.^[21] Programs such as Tai Chi,^[22] Yoga, aquatics^[23] and Feldenkrais^[22] may be helpful in maintaining gait and balance function. Recently use of body weight supported treadmill training and use of robot like Lokomat[®] has been used at advance rehabilitation centres.

The occupational therapist and/or the rehabilitation nurse can help patients improve their activities of daily living as well as their mobility. Practical techniques and assistive devices ease the burden of dressing, bathing, eating, household chores, and daily care.^[13]

Cognitive Dysfunction

Cognitive deficits occur in up to 60% of patients of MS.^[24] It is, at times, difficult to diagnose cognitive dysfunction. Mini mental scale test, IQ tests and small questionnaires are required to detect deficits in learning, memory, reasoning, spatial or geographical understanding. The neuropsychologist and speech therapist

work for correction of these deficits. Compensatory strategies such as appropriate time management, improved sleep hygiene, medication adjustments, memory cues and calendars are often helpful. Modafinil (Provigil) and CNS stimulants may improve attention span, working memory, and phonemic fluency.^[24] Immunomodulating therapies have been shown to improve cognition in some clinical trials.^[25-27]

Bladder, Bowel, and Sexual Dysfunction

For bladder disturbance, simple pelvic floor exercises can be taught. The patient may be trained for self catheterisation when needed. Anticholinergic drugs like oxybutynin (tolterodene tartrate is a useful alternative) are usually sufficient to address the incomplete emptying and hyperreflexia commonly seen in this condition.^[28,29]

Bowel disturbance and constipation and faecal incontinence can be managed by establishing a bowel programme. The patient needs to change his/her routine life style, increase dietary fibre and take laxatives such as lactulose for mild, and stimulant laxatives, such as senna and bisacodyl for severe constipation.^[30]

For sexual dysfunction, Sildenafil (Viagra) represents a major breakthrough in the management of erectile dysfunction in men. In a randomised, placebo controlled trial involving 217 men with MS, the ability to achieve and maintain erections was significantly better in the treated group, with 92% reporting an improvement in sexual activity.^[31]

Fatigue

Most MS patients complain of fatigue. The cause of fatigue could be due to multiple factors like weakness, spasticity, ataxia, depression, heat, poor sleep pattern and drugs used in MS. Fatigue management requires multidisciplinary therapy, including exercise program, behaviour modification, psychological counselling and medicines. Patients need to be trained in time management, pace of work, simplification of work and energy conservation techniques etc. Several medications have been tried like pemoline, amantadine, acetyl L-carnitine, modafinil, methylphenidate, and amino pyridines.^[32-35]

Pain

Pain is a common symptom in MS and can have a major impact on both activity and participation (disability and handicap).^[36] It is chronic in nature in about 85% of cases and acute or paroxysmal in the remainder. Commonly encountered pain syndromes include trigeminal neuralgia, painful tonic spasms, and sensory symptoms including Lhermitte's symptom. Carbamazepine is most commonly used for acute paroxysmal pain. Gabapentin and pregabalin are also used. Chronic pain is usually multifactorial and often refractory to treatment. Amitriptyline is useful for dysaesthetic pain. Non-steroidal anti-inflammatory drugs, transcutaneous electrical nerve stimulation (TENS), and local heat can also be tried.

Speech and Swallowing

The speech and language therapist specializes in evaluating and treating speech, communication, cognitive, and swallowing problems. Speech and swallowing difficulties are due to spasm or stiffness of the muscles and patients learn to overcome this problem with the help of the speech and language therapist. The patient is taught various exercises to relax and strengthen the muscles controlling the vocal cords and to coordinate movements of jaw, tongue and lips for articulation and pronunciation. The therapist should lay more emphasis on communication than on accurate sound. This is called functional communication therapy. This includes developing techniques to simplify sounds, words or sentences in a way that ensures that the message is conveyed. Dysphagia evaluation may include video fluoroscopic or barium swallow studies to track the movement of food during swallowing.^[37] Treatment is rehabilitative and educational. Changing the head or body position during eating may sometimes help. Eating smaller quantities at any one time may also reduce fatigue and choking.

Conclusion

MS affects individuals in the prime of their lives. The economic, emotional and social consequences of this disorder can be devastating, not only for the patient but for the entire family and society at large. Increased public awareness, timely and appropriate drug therapy and optimum neurorehabilitation form the cornerstones of successful MS management.

Organisation like MSSSI could play an important role in bridging the gap between the patients and the rehabilitation team member in our country.

Without a doubt, neurorehabilitation plays a vital role in improving and minimizing impairment, disabilities and handicaps. A multidisciplinary approach is the ideal model for neurorehabilitation in MS. In the Indian setting, the Family Based Rehabilitation programme could be the answer to fulfilling the long term needs of disabled MS patients.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

1. Beck CA, Metz LM, Svenson LW, Patten SB. Regional variation of multiple sclerosis prevalence in Canada. *Mult Scler* 2005;11:516-9.
2. Burden of illness of multiple sclerosis. Part II: Quality of life. The Canadian Burden of Illness Study Group. *Can J Neurol Sci* 1998;25:31-8.
3. Benito-León J, Morales JM, Rivera-Navarro J, Mitchell A. A review about the impact of multiple sclerosis on health-related quality of life. *Disabil Rehabil* 2003;25:1291-303.
4. Motl RW, McAuley E. Symptom cluster and quality of life: Preliminary evidence in multiple sclerosis. *J Neurosci Nurs* 2010;42:212-6.

5. Multiple Sclerosis International Federation. Global economic impact of multiple sclerosis. Available from: http://www.msif.org/includes/documents/cm_docs/2011/g/global_economic_impact_of_ms.pdf? f=1. [Last accessed on 2012 Jul 03].
6. Singhal BS. Multiple sclerosis--Indian experience. *Ann Acad Med Singapore* 1985;14:32-6.
7. Bharucha NE, Bharucha EP, Wadia NH, Singhal BS, Bharucha AE, Bhise AV, *et al*. Prevalence of multiple sclerosis in the Parsis of Bombay. *Neurology* 1988;38:727-9.
8. Wadia NH, Bhatia K. Multiple sclerosis is prevalent in the Zoroastrians (Parsis) of India. *Ann Neurol* 1990;28:177-9.
9. Kuroiwa Y, Iwashita H. The current status of multiple sclerosis in Japan. *Asian Med J* 1977;20:335-51.
10. Clarke S, Li L, Owolabi M, Selzer M, Surya N, Tong Z, Wasti SA. Neurorehabilitation in Developing Countries Time for Action. Available from: <http://wfnr.co.uk/education-and-research/position-statements/>. [Last accessed on 2015 Aug 11].
11. Surya N. Neurorehabilitation in the developing world. *Pak J Neurol Sci* 2012;7.
12. Surya N. Neurorehabilitation News. 2010. Available from: [http://www.asnr.com/files/116023__ASNR_SpringNwsLet_\(2\).pdf](http://www.asnr.com/files/116023__ASNR_SpringNwsLet_(2).pdf). [Last accessed on 2015 Aug 11].
13. Burks JS, Bigley GK, Hill HH. Rehabilitation challenges in multiple sclerosis. *Ann Indian Acad Neurol* 2009;12:296-306.
14. Freeman JA, Thompson AJ. Rehabilitation in multiple sclerosis. In: McDonald WI, Noseworthy JH, editors. *Multiple Sclerosis 2*. Philadelphia: Butterworth-Heinemann; 2003. p. 63-107.
15. Reding MJ, LaRocca N, Madonna M. Acute-hospital care versus rehabilitation hospitalization for management of non-emergent complications in multiple sclerosis. *J Neuro Rehab* 1987;1:13-7.
16. Khan F, Turner-Stokes L, NgL, Kilpatrick T. Multidisciplinary rehabilitation for adults with multiple sclerosis. *Cochrane Database Syst Rev* 2007;CD006036
17. Srivastava A, Taly AB. Multiple sclerosis: A rehabilitation approach. *Rev Neurol* 2007;250-82.
18. Patti F, Amato MP, Battaglia MA, Pitaro M, Russo P, Solaro C, *et al*. Caregiver quality of life in multiple sclerosis: A multicentre Italian study. *Mult Scler* 2007;13:412-9.
19. Stanescu I, Dogaru G. Neurorehabilitation strategies in multiple sclerosis. *Balneo Research Journal* 2014;5:180-7.
20. Haselkorn JK, Balsdon Richer C, Fry Welch D, Herndon RM, Johnson B, Little JW, *et al*; Multiple Sclerosis Council for Clinical Practice Guidelines. Overview of spasticity management in multiple sclerosis. Evidence-based management strategies for spasticity treatment in multiple sclerosis. *J Spinal Cord Med* 2005;28:167-99.
21. Lord SE, Wade DT, Halligan PW. A comparison of two physiotherapy treatment approaches to improve walking in multiple sclerosis: A pilot randomized controlled study. *Clin Rehabil* 1998;12:477-86.
22. Husted C, Pham L, Hekking A, Niederman R. Improving quality of life for people with chronic conditions: The example of t'ai chi and multiple sclerosis. *Altern Ther Health Med* 1999;5:70-4.
23. Gehlsen G, Beekman K, Assmann N, Winant D, Seidle M, Carter A. Gait characteristics in multiple sclerosis: Progressive changes and effects of exercise on parameters. *Arch Phys Med Rehabil* 1986;67:536-9.
24. Thompson AJ. Symptomatic management and rehabilitation in multiple-sclerosis. *J Neurol Neurosurg Psychiatry* 2001;71(Suppl 2):ii22-7.
25. Wilken JA, Sullivan C, Wallen M, Rogers C, Kane RL, Rossman H, *et al*. Treatment of multiple sclerosis-related cognitive problems with adjunctive modafinil. *Intel J MS Care* 2008;10:1-10.
26. Pliskin NH, Homer DP, Goldstein DS, Towle VL, Reder AT, Noronha A, *et al*. Improved delayed visual reproduction tests performance in multiple sclerosis patients receiving an interferon beta-1b. *Neurology* 1996;47:1463-8.
27. Freedman MS, Kappos L, Polman CH, Edan G, Hartlung HP, Miller D, *et al*. Impact of early interferon beta-1b treatment on disease evolution over 5 years in patients with a first event suggestive of multiple sclerosis. In: Freedman MS, Kappos L, Polman CH, Edan G, Hartlung HP, Miller D, *et al*, editors. *Multiple Sclerosis*. Montreal, Canada: Sage Publications Ltd; 2008. p. S-295-6.
28. Havardova E. The effects of natalizumad on a test of cognitive function in patients with relapsing multiple sclerosis (MS). *Eur J Neurol* 2006;13:307.
29. Hussain I, Fowler C. The cause and management of bladder, sexual and bowel symptoms. In: Hawkins CP, Wolinsky JS, editors. *Principles of Treatments in Multiple Sclerosis*. Oxford: Butterworth-Heinemann; 2000. p. 258-81.
30. Attar A, Lémann M, Ferguson A, Halphen M, Boutron MC, Flourié B, *et al*. Comparison of a low dose polyethylene glycol electrolyte solution with lactulose for treatment of chronic constipation. *Gut* 1999;44:226-30.
31. Fowler C, Miller J, Sharief M. Viagra (sildenafil citrate) for the treatment of erectile dysfunction in men with multiple sclerosis. *Ann Neurol* 1999;46:497.
32. Krupp LB, Coyle PK, Doscher C, Miller A, Cross AH, Jandorf L, *et al*. Fatigue therapy in multiple sclerosis: Results of a double-blind, randomized, parallel trial of amantadine, pemoline, and placebo. *Neurology* 1995;45:1956-61.
33. Tomassini V, Pozzilli C, Onesti E, Pasqualetti P, Marinelli F, Pisani A, *et al*. Comparison of the effects of acetyl L-carnitine and amantadine for the treatment of fatigue in multiple sclerosis: Results of a pilot, randomised, double-blind, crossover trial. *J Neurol Sci* 2004;218:103-8.
34. Rammohan KW, Rosenberg JH, Lynn DJ, Blumenfeld AM, Pollak CP, Nagaraja HN. Efficacy and safety of modafinil (Provigil) for the treatment of fatigue in multiple sclerosis: A two centre phase 2 study. *J Neurol Neurosurg Psychiatry* 2002;72:179-83.
35. Rossini PM, Pasqualetti P, Pozzilli C, Grasso MG, Millefiorini E, Graceffa A, *et al*. Fatigue in progressive multiple sclerosis: Results of a randomised, double-blind, placebo controlled, and crossover trial of oral 4-aminopyridine. *Mult Scler* 2001;7:354-8.
36. Archibald CJ, McGrath PJ, Ritvo PG, Fisk JD, Bhan V, Maxner CE, *et al*. Pain prevalence, severity and impact in a clinic sample of multiple sclerosis patients. *Pain* 1994;58:89-93.
37. Logemann JA. Evaluation and Treatment of Swallowing Disorders. 2nd ed. Austin, TX: PRO-ED, Incorporated; 1999.