

Multiple sclerosis: Myths and realities

Evidence-based knowledge now available can improve our ability to care for patients with this potentially disabling neurological disease.

ABSTRACT: The physical and cognitive effects of multiple sclerosis can range from mild to severe and can have a significant impact on the patient's life. All members of the health care community need to be aware of the common myths about multiple sclerosis and the evidence-based realities regarding disease progression, symptoms, and treatment options. This awareness is essential for the general practitioner, who is often the first contact for patients during diagnosis and disease process changes, and who plays an important role along with the multidisciplinary MS clinic team when it comes to caring for patients with multiple sclerosis.

Multiple sclerosis (MS) is the most common neurological disease affecting young adults in Canada. There is still no cure and only theories as to the cause. The effects of MS can range from mild to severe and can have a significant impact on many areas of the patient's life, including physical and cognitive function, family relationships, and employment. Because of the diversity of symptoms and the involvement of the central nervous system (CNS), a multidisciplinary approach to the care of the MS patient is essential. Through international collaboration among all medical and allied support disciplines, increasingly significant contributions have been made to more evidenced-based approaches to patient care in the past few decades.

In BC, all five health authorities have MS clinics to address the unique challenges faced by this patient population. These clinics rely on multidisciplinary teams consisting of neurologists, MS-certified nurses, physiotherapists, occupational therapists, and social workers. Referral partnerships also exist with psychiatry, neuro-ophthalmology, rehabilitation medicine, urology, speech language pathology, and clinical counseling. MS clinic research coordinators are

also able to offer additional therapies for patients when treatments have failed or been declined.

The general practitioner plays an important role as the first contact for many MS patients during diagnosis and when changes occur during the disease process. GPs and other members of the health care community need to be aware of the common myths about MS that exist today and the realities of current knowledge regarding disease progression, symptoms, and treatment options.

Myth 1: MS always leads to disability

All patients with MS eventually progress to the point where they will need to use a wheelchair.

Reality

MS presents uniquely for each patient. Although predicting the course of the

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disease is not generally possible at the initial diagnosis, over time the course may be classified into one of several categories. At diagnosis, approximately 85% of patients present with relapsing-remitting MS, with approximately 50% of these patients eventually converting to secondary-progressive MS over a decade or more. The remainder generally fall within the categories of primary-progressive MS, progressive-relapsing MS, or benign MS. An additional very small percentage of patients present with MS, which behaves unlike the other forms by resulting in rapid disability and death in a shortened period of time.¹ Leaving aside patients with malignant MS, most MS patients have an overall life expectancy after diagnosis of only 6 or 7 years less than that of the general population.²

Although physicians and nurses in a clinical setting are more likely to see patients experiencing acute relapses of symptoms and patients with progressive forms of MS, the reality is that those with milder forms of MS are often carrying on their day-to-day lives with little need for medical care. Many patients with milder forms of MS also make the choice not to disclose their diagnosis to employers and other associates if they are symptom-free, suggesting that their daily lives are not adversely affected. We now also have clear evidence from magnetic resonance imaging (MRI) that there can be significant MS disease activity in the absence of clinical symptoms.³ Thus, the actual number of people living with MS may be much higher than reported. Paty and Ebers suggest that undiagnosed MS may be as prevalent as diagnosed disease.⁴

Myth 2: Infection leads to relapse

Infection is a causative factor for a relapse in a patient with MS.

Reality

A relapse in MS has been defined as the development of a new symptom or a recurrence of previous symptomology that lasts for at least 24 hours in the

absence of fever or infection and for which no other cause can be found.¹ Pseudo-relapses are common and may present as symptoms suggestive of a neurological change when they are actually physiological changes due to concurrent infection or another factor that causes a slight change in body temperature. This change in body temperature causes a transient blockade of nerve conduction in the previously demyelinated fibres² and a consequent recurrence of previous symptoms. For instance, a patient presenting with a significant increase in spasticity or leg weakness may have a urinary tract infection as the causative factor.³ Thus, once the infection or core body temperature is restored to baseline, the symptoms usually subside. A careful assessment should be done to rule out infection when considering a potential relapse, as the treatment will differ depending on the causative factor.

Sensitivity to external heat sources is also common in patients with MS, who need to be reassured that heat-related neurological worsening from hot weather, hot tubs, or fever caused by infection can usually be managed

by simply leaving the hot environment, bathing in cooler water, treating the infection, or using antipyretics as needed.¹

Myth 3: Use of steroids

Although physicians are more likely to see patients experiencing acute relapses of symptoms and patients with progressive forms of MS, the reality is that those with milder forms of MS are often carrying on their day-to-day lives with little need for medical care.

will minimize deficits

Intravenous or oral methylprednisolone will speed recovery from the MS relapse and minimize residual deficits caused by the relapse.

Reality

Postrelapse recovery symptomology is not affected by treatment with steroids. It is important for the patient to understand that this treatment is used simply for decreasing the duration of the relapse and will not have an impact on the degree of residual deficit once the relapse is over. The outcome at recovery will be the same but the time to this recovery period may be reduced.

Intravenous or oral methylprednisolone is still considered the gold standard for treating acute relapses/exacerbations in patients with MS. Studies and years of practice have shown that administration of steroids earlier rather than later during the relapse is effective in helping to expedite recovery time from the event. There is no evidence to support long-term use of steroids in MS.¹

Myth 4: Only patients

unable to cope become depressed

Depression in patients with MS is associated with the severity of the disease and is related only to the patient's inability to cope with physical, vocational, and familial changes brought about by the disease.

Reality

Depression is common in all forms of MS. Researchers believe that MS-related depression may result from a combination of several factors, including a psychological reaction to the diagnosis of a chronic illness and the anxiety related to a new future of uncertainty brought on by the diagnosis. In addition, there is an ongoing grieving process as multiple and often cumulative losses occur for the individual. Evidence clearly shows, however, that depression can also be related to the neuropathology of the disease itself.⁵ The new disease-modifying medications available to treat relapsing forms of MS can also contribute to and exacerbate an existing predisposition toward depression in patients with MS, although this latter association requires further study.¹ The literature clearly shows a much higher suicide rate for patients with MS, with one Canadian study reporting a rate 7.5 times higher than the rate for the general population.⁶ Whatever the reason for depression associated with MS, there is wide agreement on the effectiveness of psychiatric and pharmacological intervention in addition to family education and support surrounding psychological and cognitive issues.⁴

Myth 5: Only advanced MS causes cognitive symptoms

Cognitive symptoms are rare and only present in advanced and/or progressive forms of MS.

Reality

Until recently, the prevalence of cog-

nitive symptoms in patients with MS was drastically underestimated. New studies have shown that when proper cognitive evaluation is performed, more than 50% of patients with MS experience some degree of cognitive decline,⁴ with several MRI studies confirming the relationship between cognitive dysfunction and demyelination.¹ There is consensus among experts in the field that there is little or no correlation between the presence of cognitive symptoms in a patient with MS and the duration and severity of the disease.⁷ A patient presenting with few or mild symptoms can have significant cognitive symptoms, while a patient who is severely compromised physically may be cognitively intact. Memory loss is the most common cognitive symptom reported by patients with MS, followed by a decline in abstract reasoning ability and judgment, including speed of information processing, word-finding ("tip of the tongue" phenomenon), and attention and concentration. Language function and intellect are generally preserved. Halper and Holland note that close to 90% of patients with MS show either no obvious changes or relatively mild cognitive symptoms that generally do not affect daily functioning.⁷ However, this 90% figure is likely higher than new studies indicate¹ because it is based on the limited availability of proper cognitive evaluation and retraining services in many cities. It is important to note that approximately 5% to 10% of MS patients can develop a severe global dementia resembling Alzheimer disease, rendering them unable to manage their personal affairs.⁷ Patients with milder cognitive symptoms respond well to a multidisciplinary approach to cognitive retraining.

Myth 6: People with MS are difficult patients

Patients with MS are more likely to be demanding and belligerent toward members of the medical community.

Reality

Patients are most commonly diagnosed with MS between the ages of 20 and 40, right at the beginning or in the middle of their prime career and family planning years. Naturally, these young people may feel they have lost control of their lives and will struggle as they learn to accept a new future that includes daily unpredictability and multiple losses over time. It is only to be expected that these patients will wish to understand the facts and be involved in decision making in order to regain some control of their lives. Helping a patient with an unpredictable and potentially disabling disease often requires a nonjudgmental approach that includes educating and supporting both the patient and the family.⁴ This approach may involve the GP, the MS clinic team, and community support programs.

Myth 7: Therapy is not needed for milder cases

When a patient presents with milder and less frequent relapses, prognosis is good and disease-modifying therapies need not be considered.

Reality

Natural history studies have shown that if an MS patient presents with milder relapses with complete remissions after 5 to 10 years, the disease is more likely to continue in this pattern, whereas if more disabling symptoms and incomplete recovery from relapses are present at an early stage, prognosis is less favorable.⁸ Paty and Ebers cite several early prognostic factors related to better outcomes: being female and young at onset, presenting initially with sensory and relapsing symptoms, having a low relapse rate

in the first 2 years, and having a delayed time to a score of 3 on the expanded disability status scale (EDSS) indicating very minimal functional deficit.⁴ Further, we now know from several recent premorbidity and post-morbidity studies that although a patient may present with mild disease, there can be significant lesion activity evident on MRI and early axonal damage before the patient even recognizes symptoms.³ This evidence combined with the data from clinical trials has led the Consortium of MS Centres to advocate for early intervention with MS disease-modifying therapies and additional support for treating a first demyelinating event,⁹ making timely assessment and specialist referral from the GP for further diagnostic investigations especially important.

The four MS disease-modifying therapies available are interferon-beta-1a by intramuscular injection (Avonex), interferon-beta-1a by subcutaneous injection (Rebif), interferon-beta-1b (Betaseron), and glatiramer acetate (Capaxone). Because these MS disease-modifying therapies are currently classed as Special Authority medications in BC, they can be prescribed only by MS clinic neurologists with appropriate authorization and are available only to patients who meet specific eligibility criteria, which include a confirmative diagnosis of MS in a relapsing-remitting form with a history of at least two relapses within the past 2 years, and an ambulation ability of 6.5 on the EDSS scale. Clinical trials showed no benefit when these medications were used for primary-progressive MS and thus the eligibility criteria ensure that the patient has active MS and is likely to benefit from the treatment.¹

Myth 8: Treatment options are limited

If a patient is not eligible for one of the MS disease-modifying therapies, treatment options, apart from steroids for acute events, are few.

Reality

Since a large number of MS patients do not meet the criteria for disease-modifying therapies, it is important for physicians to know that there are other evidence-based symptom management strategies now available. For a multifaceted disease where numerous areas within the CNS can be affected, symptom-specific medications and rehabilitation therapies need to be considered.¹⁰ A multidisciplinary team can effectively address many specific MS symptoms. Muscle spasticity, for example, may be managed well through appropriate lifestyle education, dose titration of medications, and physiotherapy. In more severe cases, options may also include the use of botulinum toxin (Botox) or the implantation of a baclofen pump. Likewise, fatigue, bladder abnormalities, and other symptoms of MS may benefit from medication, nursing, physiotherapy, occupational therapy, or psychological therapy as indicated. It is important to remember that fatigue is one of the most challenging and misunderstood of MS symptoms. This symptom alone can cause significant disability and result in the need to alter familial and vocational roles dramatically.

Conclusion

T.J. Murray recently chronicled the evolution of MS research and care dating from the early 1800s to the present, a history Murray sees as a true testament to the importance of collaborative efforts. As we strive for a better understanding of MS and an improved ability to treat patients, we will be relying on all the evidenced-based

knowledge now available, the studies continuing within MS clinics around the world, and the work of GPs and other health professionals in the multidisciplinary teams caring for patients with MS.

Competing interests

None declared

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