

Clinical and scientific letters

Meeting the clinical needs of patients with progressive multiple sclerosis

For people who develop progressive multiple sclerosis (MS), no disease modifying treatments are currently available although there are an increasing number of potential therapies currently under investigation.¹ The management of progressive MS is concerned with symptom control and maintenance of general health, particularly as impairments become more advanced.² Depending on how services are organised locally, the needs of patients with progressive MS may be met by primary care physicians, specialist nurses, therapists, neurologists, rehabilitation physicians, care of the elderly physicians or palliative care services.³

In order to establish the specific clinical needs of patients with advanced progressive MS, we performed a retrospective analysis of clinical records for patients with primary or secondary progressive MS attending an outpatient clinic who had an Expanded Disability Scale Score (EDSS) of 6 or more. The EDSS is a ten-point scale used to quantify the degree of impairment in MS. All clinic appointments were held with the same clinician in the same setting using the same semi-structured interview around the secondary complications of MS as identified in the last National Institute for Health and Care Excellence guidelines.⁴ The issues identified were then assessed against the Royal College of Physicians' higher specialist training syllabus content for the different medical subspecialties that may be involved in the management of patients with MS.

Between 2010 and 2015, 200 individuals with a diagnosis of primary or secondary progressive multiple sclerosis were seen in the clinic setting. Within this sample, 18 different types of MSRI (MS related issues) were identified. A total of 531 MSRI occurred within this population.

The clinical competencies within the Royal College of Physicians postgraduate training curricula for neurology, rehabilitation medicine, elderly care medicine and palliative care were compared against the most frequently occurring MSRI seen in this cohort. Although pain is covered by all, the management of spasticity, continence and mobility are only explicitly included within rehabilitation medicine.

While neurologists are fundamental to the initial diagnostic process and oversight of disease modifying therapy, their clinical training may not place them in the best position to address the particular problems that develop in people with the progressive disease. Because the management of the most common MSRI involve pharmacological interventions and

because of the complexity in differentiating the particular issues and their precipitating and prolonging factors, there is a need for responsive medical oversight of these patients.

Conclusions

Spasticity, pain, immobility and incontinence are the most commonly occurring clinical issues in advanced progressive MS. Although there are some promising developments in disease modification, clinicians involved with the ongoing care of patients with progressive MS should have appropriate experience, skills and resources to address these issues. While there is a fundamental role for secondary (and tertiary) neurology services in the diagnosis and early treatment of MS – given the specific problems experienced by this patient group – rehabilitation physicians should be involved in the longer-term medical management of patients with MS. ■

Conflicts of interest

The authors have no conflicts of interest to declare.

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References

- 1 Salvetti M, Landsman D, Schwartz-Lam P *et al*. Progressive MS: from pathophysiology to drug discovery. *Mult Scler* 2015;21:1376–84.
- 2 Khan F, Amatya B, Turner-Stokes L. Symptomatic therapy and rehabilitation in primary progressive multiple sclerosis. *Neurol Res Int* 2011;2011:740505.
- 3 Patten SB, Williams JV, Lavorato DH *et al*. Perceived met and unmet health-care needs in a community population with multiple sclerosis. *Int J MS Care* 2012;14:2–8.
- 4 National Institute for Health and Care. *Multiple sclerosis: management of multiple sclerosis in primary and secondary care*. NICE clinical guideline No 186. London: NICE, 2014.