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Editors Welcome

“Is this new medicine going to help me walk again?”



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With the approval of the first medication to prevent relapses in neuromyelitis optica spectrum disorder (NMOSD) in June 2019, patients are eager to understand how this new approach could potentially help them walk again. NMOSD attacks affecting the spinal cord are usually severe and lead to permanent neurological damage; 34% have difficulty walking and 23% are confined to wheelchairs (Kitley et al., 2012). When they roll into the clinic to hear about this medication, and the other two medications that have reported positive results in phase 3 trials, they are expecting to hear how these medications helped patients recover neurological function. They are often let down when they learn these new medications are only designed to prevent the *next* attack, not heal any of the previous attacks that caused so much disability.

The same expectation gap occurs in multiple sclerosis (MS) except that MS patients tend to recover from previous attacks better than those with NMOSD. But in the patients' minds, that natural recovery process is often falsely attributed to the MS immunotherapy. The consequence is that when these patients experience a worsening in their symptoms, they often believe their medication is failing even if there is no evidence of disease activity by MRI.

In this issue of *Multiple Sclerosis and Related Disorders* (MSARD), Dr. van Oosten and his colleagues in the Netherlands assessed patients' expectations of hematopoietic stem cell transplantation (HSCT) as a therapy for MS compared to available disease-modifying therapy (De Kleermaeker et al.). More than half of patients believed HSCT was more effective than conventional therapy and almost half believed the treatment would not only stop disease progression but would also improve neurological function. HSCT is often portrayed in the press as a panacea to cure all diseases, and that may have influenced the survey results in this study except that more than 80% reported their neurologist as the preferred source of reliable information about MS. These data indicate that patients have an expectation, not just a hope, that HSCT will restore and regenerate damaged neural tissue and lead to improved function.

According to another article in this issue of *MSARD* by Dr. Galea and

his colleagues in Argentina (Carnero Contentti et al.), the vast majority of persons with MS want to learn about their disease prognosis and almost a third of patients spend every single day thinking about it. Yet almost half have no idea what their long-term prognosis is despite talking about it in clinic with their neurologists. Part of this disconnect is the lack of available therapy to address long-term issues related to neurological degeneration.

The goal of preventing attacks in critical in NMO, and very helpful in MS, but from the patients' points of view, they expect new medications to help them recover function. Despite our successes in developing disease-modifying therapies in MS and NMO, there is a large unmet need in the area of regenerative therapy. In the opinion of this editorial board, resources need to be allocated to the development of therapies that will actually improve patients function and quality of life including symptomatic treatments for pain, sleep problems, urinary retention and spasticity. Potential approaches include neural stem cell transplantation – not to be confused with hematopoietic stem cell transplantation – and therapies that stimulate and support the “natural” healing process in the central nervous system.

References

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