A focus on patient outcomes in cervical myelopathy

Cervical myelopathy, also known as cervical spondylotic myelopathy, is a common spinal cord disorder. The disease can reduce quality of life similarly to diabetes or cancer, but data on its prevalence and incidence are scarce. Myelopathy is a progressive condition that can cause irreversible spinal cord damage, but treatment options are limited. Thus, a timely diagnosis and treatment are crucial to prevent further damage, reduce disability, and improve patients' quality of life. To confront the numerous unmet needs of patients with cervical myelopathy, the organisation Myelopathy.org was officially launched on May 7, 2019, at the first Academic Spine Symposium in London (UK).

Cervical myelopathy is estimated to affect up to 5% of people older than 40 years, and incidence is expected to rise in ageing populations. Although myelopathy is common, the condition is often underdiagnosed and diagnosis is usually delayed. Reasons are likely multifactorial, but the absence of a diagnostic algorithm, poor awareness of the disease, and the often subtle and non-specific symptoms (eg, pain and numbness in limbs, poor coordination, imbalance, and bladder problems) that are often mistakenly attributed to ageing or to other conditions (eg, carpal tunnel syndrome, multiple sclerosis) seem to be the key drivers contributing to delayed diagnosis. Furthermore, treatment options are limited. Clinical guidelines recommend decompressive surgery for patients with moderate or severe cervical myelopathy and for those with disease progression, but functional improvement is limited in most cases, and damage is often permanent. For patients with mild cervical myelopathy, non-operative treatment or decompressive surgery is recommended. Pharmacological treatments are not available yet. Additionally, our understanding of the pathopsysiology of degenerative cervical myelopathy remains very limited.

Myelopathy.org is the first global charity dedicated to degenerative cervical myelopathy, and brings together researchers, health-care professionals, patients and their carers to raise awareness and increase understanding of the disease, and improve patient outcomes through research, education, and collaboration.

Currently, Myelopathy.org is supporting two international research projects. RECEDE Myelopathy—a multicentre phase 3 trial—will assess the efficacy of a six month course of ibudilast, a phosphodiesterase inhibitor, versus placebo as adjuvant treatment for cervical myelopathy after decompressive surgery in improving functional outcomes. An estimated sample of 360 patients with moderate cervical myelopathy will be randomised before decompressive surgery to either ibudilast or placebo and evaluated 3, 6, and 12 months following decompressive surgery. The hypothesis is that ibudilast might promote nerve regrowth, stimulate the repair of myelin sheaths, and alleviate the consequences of reduced blood flow in the spinal cord, thus improving functional outcome after surgical decompression through inhibition of phosphodiesterase-3 and phosphodiesterase-4.

The second project is RECODE-DCM, an international initiative to improve research efficiency, that involves patients, health-care professionals and professional bodies such as the National Institute for Health Research, the James Lind Alliance (an initiative of patients, carers, and health-care professionals to set research priorities), and AOSpine (the world's leading community of spine surgeons, researchers, and allied spine professionals). The aims are three-fold: to harmonise terminology for cervical myelopathy (currently multiple terms are used, including cervical spondylitis myelopathy, degenerative cervical myelopathy, cervical stenosis, cervical spondylosis, and ossification of the posterior longitudinal ligament); to agree on a standardised set of baseline characteristics and outcomes for clinical studies, including Core Data Elements, as per NIH definition; and to set up the top ten research objectives for degenerative cervical myelopathy, ranked according to patients' priorities.

The mission of Myleopathy.org to give patients a voice and improve clinical practice is ambitious, but long overdue. The research initiatives will take time to have an impact; further work and funding will still be needed to educate and train health-care professionals, develop diagnostic guidelines, identify predictors of disease progression, and determine the optimal timing of surgery. However, this new global organisation is the necessary first step to ensure that, in a few years, patients with cervical myelopathy worldwide receive an earlier diagnosis and adequate treatment to improve their quality of life.

■ *The Lancet Neurology*

For more on the **impact of degenerative cervical myelopathy on quality of life** see *World Neurosurg* 2017; **106:** 699–706

For more on **Myelopathy.org** see https://myelopathy.org/

For more on the **incidence of cervical spondylotic myelopathy** see *Spine* 2015; **40:** e675–93

For the **clinical guidelines for management of cervical spondylotic myelopathy** see *Global Spine J* 2017; **7** (3 Suppl): 21S–27S

For more on the **RECEDE Myelopathy trial** see http://www.recede-myelopathy.org

For more on the **RECODE-DCM initiative** see https://recode-dcm.com/