Cognition and its relation to brain health in patients with MS: Response to letter

Jeremy Hobart and Gavin Giovannoni

Dear Editor of MSJ,

We agree that measuring and monitoring cognition are important aspects of multiple sclerosis (MS) care and ought to be standard, as proposed by Hulst and Penner.1 The timing of publication was unfortunate in that our manuscripts were submitted, revised and accepted within a few days of each other. During our modified Delphi process and manuscript preparation, we were not aware of Rosalind Kalb’s work2 – hence our omission. When our guidelines are updated, cognition measurement will certainly be revisited.

We hope the MS community will continue to debate standards, their content, parameters and how they might be refined until we have the internationally adopted, clinically meaningful, globally endorsed set of standards that people with MS desperately need. In this regard, we believe the MS Brain Health consensus on quality standards3 provides a firm start. We define metrics the wider MS community needs in order to measure their care provision within a global frame of reference. We provide scope to develop and broaden this consensus in the future. We welcome collaborations with those seeking to raise MS care standards and provide evidence-based direction for MS management. As part of this wider process, the MS community should review Kalb’s work and consider how best to incorporate it within a unified set of guidance. Likewise, Soelberg Sorensen’s proposal of MS Care Units4 provides another opportunity for collaboration and the implementation of globally recognised standards.

Developing standards is the necessary first step, but we recognise it is not, in itself, sufficient to ensure successful adoption. This requires processes that enable painless data collection in routine, hectic, daily clinical care. For this reason, we are developing, testing and refining a clinical tool.5

Gratifyingly, the standards recommended by MS Brain Health appear to be gaining traction. The publication’s Altmetric score in MSJ is 63, meaning it ranks in the top 5% of all research outputs scored by Altmetric. Interestingly, but not surprisingly to us, 81% of the readers of our paper3 are ‘members of the public’, implying that people with MS want to understand the standards. Part of MS Brain Health’s continuing work will be to encourage MS healthcare professionals and people with MS globally to embrace an acceptable and realistic care standard – whether at a ‘core’, ‘achievable’ or ‘aspirational’ level, depending on local circumstances.

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References


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