Editorial

Atlas of MS 2020 – Informing Global Policy Change

Timothy Coetzee and Alan J Thompson

National Multiple Sclerosis Society 733 Third Avenue, New York, NY, USA 10017 ORCID - 0000-0002-3031-7549

UCL Faculty of Brain Sciences Queen Square Institute of Neurology University College London, London, UK ORCID – 0000-0002-4333-8496

Corresponding author: timothy.coetzee@nmss.org

As the second decade of the 21st century draws to a close, we can take stock and potentially congratulate ourselves on the remarkable progress in the treatment and care of multiple sclerosis MS). Improvements in the diagnosis of MS, proliferation of treatment options for relapsing forms of MS and some, albeit modestly useful, treatments for the progressive forms the disease, alongside a robust research and patient organization community are all cause for measured celebration. In this issue, Walton et al(1) remind us, however, that MS continues to be a growing global problem with variable access to treatment and that we need to calibrate our plaudits.

The third edition of the Atlas of MS reveals findings that many of us likely expected intuitively – the global prevalence of MS continues to increase and every populated continent is affected by the disease.

This edition of the Atlas has benefited from important methodological improvements over the 2013 edition.(2) Enhanced country recruitment yielded data contributions from 115 countries representing 87% of the global population and there were substantial increases in data submissions which cited published data rather than unsubstantiated personal estimates. This impressive effort was further enhanced by rigorous data cleaning and validation efforts. Collectively these improvements strengthen our confidence in these global figures.

On the other side, there are, as always, limitations that must be weighed. This effort relies on individual countries through their MS organizations or a designee to report data – an approach fraught with methodological and data variations. There are also substantial challenges in comparing data across countries given differences in data collection. Another limitation is that the reported estimates are confined to period prevalence rather than being linked to specific point in time.

Furthermore, there is limited information on incidence and an absence of mortality data. The notable gap in data from Africa must also be taken into account, as this could simply be an indicator of poor data collection and reporting, rather than being an indicator that MS is indeed rare on the African continent.

These limitations should not dampen our enthusiasm for this important effort. Indeed, we would be well served in remembering Voltaire's maxim that the best is the enemy of the good. While the best approach would have involved epidemiologically rigorous data collection to allow greater country comparability and comparison to the 2013 Atlas, the more pragmatic approach taken by the Atlas 2020 group has yielded a good result that provides us with a starting point for future collaborations to address these gaps and a strong foundation for engaging global policymakers.

While the increased global prevalence growth in MS is of concern, it is generally consistent with findings reported by more local efforts such as the recent updated prevalence in the United States.(3) We should also consider the effects earlier diagnosis, improved ascertainment and longer survival – almost certainly due to the availability of disease modifying treatments – are having on prevalence estimates – a conclusion that was also noted by the Global Burden of Disease Study 2016.(4, 5) Collectively these are positive developments reflective of an increased sophistication in the diagnosis and treatment of MS.

This edition of the Atlas also points to continued challenges that require focus from the global MS community. We are still unable to accurately estimate the numbers of individuals living with a progressive form of the disease. The varied approaches and datasets employed at national levels obscures efforts to assess critical differences due to race and ethnicity as well as the effect of health

disparities on MS. At the root of these challenges are the paucity of resources – whether governmental or non-governmental – to support data collection and the need for sustained leadership at national and global level from all the stakeholders.

The growing globalization of MS illustrated by the Atlas also reminds us that in our quest to find solutions for MS, we will also need to embrace the responsibility of ensuring that these solutions (whether a pharmacological treatment, rehabilitative intervention, clinical diagnostic tool etc.) reach affected individuals regardless of whether they live in in a lower-middle income country or in a high-income setting. This is a demanding challenge whose realization involves many stakeholders.

Nonetheless it is incumbent on the entire MS research community to lead and partner with patient organizations to ensure that the advances that are change the lives of so many people reach everyone who hears the words – 'you have MS'.

This edition of the Atlas of MS is a remarkable testament to the power of global collaboration to advance our understanding of MS. We have an obligation as the global MS community to leverage its power and advocate at national and international levels to ensure that everyone living with MS have access to effective treatments and ultimately a cure.

Disclosures

The authors have declared no potential conflicts of interest or specific funding in relation to this Editorial.

References

- 1. Walton C, King R, Rechtman L, Kaye W, E L, RA M, et al. Rising prevalence of multiple sclerosis worldwide: Insights from the Atlas of MS third edition. Multiple Sclerosis. 2020;TBD:TBD.
- 2. Browne P, Chandraratna D, Angood C, Tremlett H, Baker C, Taylor BV, et al. Atlas of Multiple Sclerosis 2013: A growing global problem with widespread inequity. Neurology. 2014;83(11):1022-4.
- 3. Wallin MT, Culpepper WJ, Campbell JD, Nelson LM, Langer-Gould A, Marrie RA, et al. The prevalence of MS in the United States: A population-based estimate using health claims data. Neurology. 2019;92(10):e1029-e40.
- 4. Collaborators GMS. Global, regional, and national burden of multiple sclerosis 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol. 2019;18(3):269-85.
- 5. Sorensen PS, Sellebjerg F, Hartung HP, Montalban X, Comi G, Tintoré M. The apparently milder course of multiple sclerosis: changes in the diagnostic criteria, therapy and natural history. Brain. 2020;143(9):2637-52.