A new study has attempted to establish the global epidemiology of MS at every corner of the globe. Do your assumptions match emerging realities?

By Zac Haughn, Senior Associate Editor

Even a casual observer of modern politics recognizes that citizens are preoccupied with the concept of blame. From blatant finger-pointing to subtle insinuation, people are nearly obsessed with assigning responsibility. And the tendency goes far beyond elected officials. When something goes wrong, there seems to be an inherent human desire to know why.

So it is with disease. When a person develops a neurodegenerative disease like MS, both the patient and those around her want to know why. Are genes to blame? Diet? Some chemical or infectious exposure? Maybe just the person’s environment?

Health professionals and researchers also want to determine why diseases develop, who’s at risk, and why. Finding the answers to these questions can improve diagnostic strategies, enhance the availability of existing treatments, and even point the way to treatments and preventive measures. That’s why a cadre of experts surveyed 112 countries, representing 87.8 percent of the world population, between 2005 and 2007, about the incidence of MS. Their findings contradict some long-
The Changing World of MS

standing notions about who’s at risk for the disease and sheds light on the ever-expanding population of affected people.

Dubbed “The Atlas of MS,” the publication provides for the first time information and data on the global epidemiology of MS and the availability and accessibility of resources for people with MS at the country, regional, and global levels. “Knowing what resources are available in different countries helps to provide useful insights and highlight differences, gaps, and inadequacies,” the authors write. “Such internationally comparable statistics on resources enable assessment and comparison of the performance of national health systems and the health of the particular populations they serve.” Here, we take a look at total numbers, prevalence and incidence; age of onset and male/female ratio; number of MS groups, diagnosing trends and methods of data collection.

Data Collection

All the information and data contained in the Atlas of MS was collected in a large international study from 2005 to 2007, which included more than 100 countries spanning all WHO regions and continents. The first step in developing the Atlas was identifying specific areas where information related to MS resources and services were lacking. To obtain this information, researchers drafted a questionnaire in English in consultation with a group of people from the World Health Organization (WHO) and Multiple Sclerosis International Federation (MSIF). They added a glossary of terms used in the questionnaire to ensure that different respondents understood the queries the same way. Subsequently, experts reviewed the draft questionnaire and glossary. This questionnaire was then tweaked, in consultation with the Atlas of MS Oversight Group, before being pilot tested. The definitions used in the glossary are working definitions for the purpose of the Atlas of MS project, and do not constitute official WHO definitions.

The final version of the questionnaire covered a wide range of issues broken down into the following eight separate sections:

• epidemiology of MS
• MS groups and organizations
• support available to people affected by MS
• diagnosis of MS
• management of MS
• treatment of MS
• quality of life of people with MS
• issues in MS care.

A “country coordinator” was then named to head up gathering information and data within that country and organizing it. The Atlas says the most important limitation of the dataset “is that in 67 of the 112 countries a single key person was the source of all information.” They add that while most respon-

dents had access to a variety of official and unofficial sources of information (and were able to confer with neurologists within their country), “the data received should still be considered as reasonably, and not completely, reliable and accurate. In some instances the data are the best estimates by the respondents.”

Total Numbers, Prevalence and Incidence

Globally, researchers found the median estimated prevalence of MS is 30 per 100,000 (with a range of five–80). More specifically, the regional median estimated prevalence of MS is greatest in Europe (80 per 100,000), followed by the Eastern Mediterranean (14.9), the Americas (8.3), the Western Pacific (5), South-East Asia (2.8) and Africa (0.3).

The study puts to bed any claims that MS is not a global disease and only a disease of the more developed “northern” and “western” countries. No responding country was free of MS, although the survey did show relatively wide variations in both incidence and prevalence. The groups say “an improved understanding of both the genetic and environmental factors influencing the disease is likely to lead to an understanding of why this is the case.”

• The median estimated prevalence of MS is greatest in high-income countries (89 per 100,000) trailed by upper middle (32), lower middle (10) and low-income countries (0.5).

• Hungary led with the highest estimated prevalence (176 per 100,000). The list of the highest estimated prevalence of MS following Hungary includes Slovenia (150), Germany (149), United States of America (135), Canada (132.5), Czech Republic (130), Norway (125), Denmark (122), Poland (120) and Cyprus (110). Globally, the median estimated incidence of MS is 2.5 per 100,000 (with a range of 1.1–4).

• When broken down regionally, the median estimated incidence of MS is greatest in Europe (3.8 per 100,000), trailed by the Eastern Mediterranean (2), the Americas (1.5), the Western Pacific (0.9) and Africa (0.1). No countries in South-East Asia provided data.

• The median estimated incidence of MS is greatest in high-income countries (5.6 per 100,000), followed by upper middle (2.2), lower middle (1.1) and low income countries (0.1).

• The countries reporting the highest estimated incidence of MS include Croatia (29 per 100,000), Iceland (10), Hungary (9.8), Slovakia (7.5), Costa Rica (7.5), United Kingdom (6), Lithuania (6), Denmark (5.9), Norway (5.5) and Switzerland (5).

• The total estimated number of people diagnosed with MS reported by responding countries is approximately 1.3 million. Approximately 630,000 reside in Europe, 520,000 in the Americas, 66,000 in the Eastern Mediterranean, 56,000 in the Western Pacific, 31,500 in South-East Asia and 11,000 in Africa.
The Atlas wants readers to “keep in mind that there are no data for some of the mega countries such as Russian Federation, where the total number of people has been suggested to be quite high in anecdotal reports.”

As it has been thought, the disease is less common among non-white individuals than whites, but comments from the respondents in a number of countries in Africa suggested that they were finding more MS as the availability and accessibility of diagnostic facilities, particularly MRI, improved. Typically, the report finds, “the results confirmed the well-established suggestion that there are strong geographical patterns to the disease and that the frequency of MS varies by geographical region throughout the world, increasing with distance from the equator in both hemispheres.”

The unbalanced allotment of valuable diagnostic tools (such as MRI scanners) is likely to cause under-recording of MS in many low-income countries. The study authors believe this effect is also likely to be reinforced “by either ignorance among professionals or the belief, in some of those countries that MS does not occur in these countries.”

The dearth of data in almost two thirds of responding countries exposes a deficiency of published reports in medical literature concerning the epidemiology of MS.

**Age of Onset, Male/Female Ratio, Number of MS Groups**

While not stop-the-presses news, data show that MS is more common among women than men and that symptoms appear at around 30 years of age, “when people are most economically active and when they would be most likely to be starting or supporting a family.” This makes it important that policy-makers fully comprehend the repercussion of lost production, as well as of the treatment regimes, on the full costs of MS, so that the value of policies targeting MS can be properly and fully accounted for, the Atlas study argues.

Globally, the interquartile range for age of onset of MS symptoms is between 25.3 and 31.8 years with an average age of onset of 29.2 years, the researchers found.

- Regionally, the average age of onset is lowest in the Eastern Mediterranean (26.9) followed closely by Europe (29.2), Africa (29.3), the Americas (29.4), and South-East Asia (29.5) with Western Pacific coming in at the highest (33.3).
• Dividing into income category, the estimated average age of onset is 28.9 years for the low and upper middle-income countries and 29.5 and 29.3 years for high and lower middle-income countries.

• Overall, the median estimated male/female ratio is 0.5, or two women for every one man (with a range of 0.40 to 0.67).

• On the regional level, the median estimated male/female ratio is lowest in Europe (0.6), the Eastern Mediterranean (0.55) and the Americas (0.5), while the highest ratios are in South-East Asia (0.4), Africa (0.33) and the Western Pacific (0.31).

• The median estimated male/female ratio was no different in all income groups of countries (0.50).

And although the sample size is relatively small, findings also suggest that the age of onset is lower in many developing countries and the Atlas suggests this might be an avenue for future research.

MS Groups
Researchers also tried to calculate how many MS groups exists. Globally, they found an MS group or organization in 73.2 percent of responding countries that responded. An MS group or organization exists in 92.1 percent of all high income countries with nearly as many in upper middle income countries (91.3 percent), and fewer in lower middle (76.7 percent) and low income countries (14.3 percent). At least one MS group or organization exists in 95 percent of the countries that responded in the Americas, followed by Europe (93.2 percent), South-East Asia (75 percent), the Western Pacific (66.7 percent), the Eastern Mediterranean (50 percent) and finally, Africa (22.2 percent).

That many countries in the world have no patient-driven support for people with MS, will negatively impact people with MS in those countries, the authors argue, because, “MS groups or organizations usually play an important role in distributing information and providing support and services.”

The authors note there is no solid connection between support and incidence, with, for example, the Eastern Mediterranean having the second-highest incidence but lying fifth in provision of patient-driven MS support. “The lack of an MS group or organization in a country will affect its reporting on cases of MS, as such groups are well placed to provide qualitative as well as quantitative data,” they write.

Diagnosis
Atlas researchers found that the McDonald Criteria are used in 66 percent of reporting countries, making the most commonly utilized tool. The Poser Criteria follows in second (31 percent of countries) and the Schumacher Criteria (three percent of countries).

• The McDonald criteria are the criteria most commonly used in the Eastern Mediterranean (83.3 percent) followed by the Americas (70.6 percent), Europe (70 percent), South-East Asia (66.7 percent), Africa (50 percent) and the Western Pacific (42.9 percent).

• However, the Poser criteria are the criteria most commonly used in the Western Pacific (57.1 percent) followed by Africa (35.7 percent), South-East Asia (33.3 percent), Europe (30 percent), the Americas (29.4 percent) and the Eastern Mediterranean (8.3 percent).

• High-income countries prefer the McDonald criteria. It is most commonly used in 79.4 percent of high-income countries, 65 percent of upper-middle-income countries, 56.5 percent of lower-middle income countries and 52.9 percent of low-income countries.

• The Poser criteria are the criteria most commonly used in 43.5 percent of lower-middle-income countries, 35 percent of upper-middle-income countries, 29.4 percent of lower income countries and finally, 20.6 percent of high-income countries.

• MRI was found to be available in all of the countries that responded; spinal tap can be found in 96.9 percent of countries and evoked potentials in 95.3 percent.

• On the global level, the median estimated number of MRI machines is 0.12 per 100,000 (with an interquartile range of 0.04–0.43).

• While regionally the median estimated number of MRI machines per 100,000 is greatest in the Western Pacific (0.35), followed by Europe (0.31), the Eastern Mediterranean (0.17), the Americas (0.08), South-East Asia (0.03) and Africa (0.004).

• By income category, the median estimated number of MRI machines per 100,000 is not surprising: it is greatest in high-income countries (0.76 per 100,000), followed by upper middle (0.15), lower middle (0.07) and low income countries (0.01).

• Globally, the median time from initial presentation to MRI is between one week and six weeks with a range of 0 to 144 weeks (12 years). The median time from initial presentation to diagnosis is between 4 weeks and 48 weeks with a range of 1 week to 480 weeks (40 years).

• Of the countries that responded, 31 percent noted that MS is diagnosed in their country without MRI.

The results presented by the Atlas highlight how inequalities in global wealth impact on the provision of diagnostic services for people with MS, and how difficult and long the path to diagnosis is for many. PN

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