

# MS Fitness Specialist

## Module 1

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### MS and Epidemiology

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#### **Learning Objectives**

1. Obtain a knowledge of gender differences in MS
2. Obtain a knowledge of the age at which MS is mostly diagnosed
3. Gain a knowledge of ethnicity in relation to MS
4. Understand the economic implications of MS

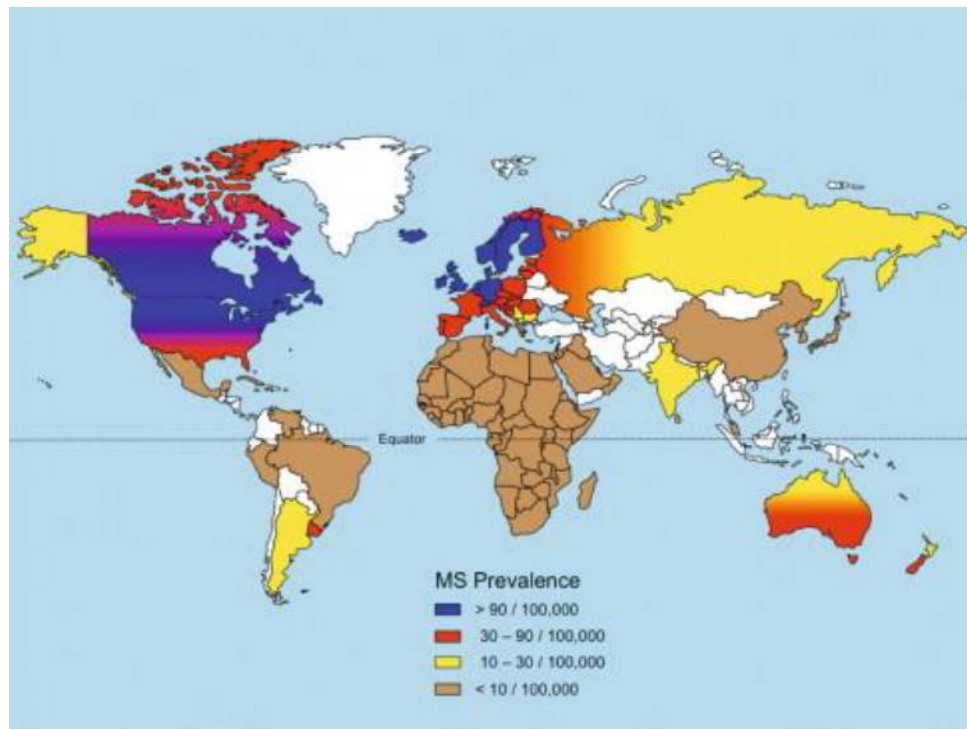
# Chapter One

## Multiple Sclerosis and Epidemiology

Epidemiology is the study of disease in people. It looks at the patterns, causes and effects of health and disease conditions in defined populations. Epidemiological studies have helped to identify factors that may be related to the risk of developing MS, such as latitude, migration patterns, genetics and infectious processes – read more within the section of *Causes of MS*.

### Incidence and Prevalence

- The incidence of a disease is the number of new cases occurring in a given period of time (usually a year) in a given population (usually 100,000).
- The prevalence of MS is the total number of people with MS at a particular point in time, in a particular place. Most epidemiological studies in MS focus on prevalence.



According to *Atlas*, an MS resource put together jointly by the World Health Organization (WHO) and the MS International Federation in 2008, on a global level, "the median estimated prevalence of MS is 30 per 100,000," and the United States has one of the highest prevalence of MS cases. Data on the prevalence of MS per 100,000 people were estimated for 122 countries by the World Health Organization (WHO) and the Multiple Sclerosis International Federation (MSIF) (WHO and MSIF, 2008). Countries with the highest estimated prevalence included Hungary (176), Slovenia (150), Germany (149), United States (135), Canada (133), Czech Republic (130), Norway (125), Denmark (122), Poland (120), and Cyprus (110).

Although, the number may be much higher as it is likely that many people with MS remain undiagnosed in certain parts of the world. MS is not a "reportable" disease, which means that there is no requirement for healthcare providers to inform any central database when they make the diagnosis. Without this kind of centralized reporting system, there is no easy way to count people with MS.

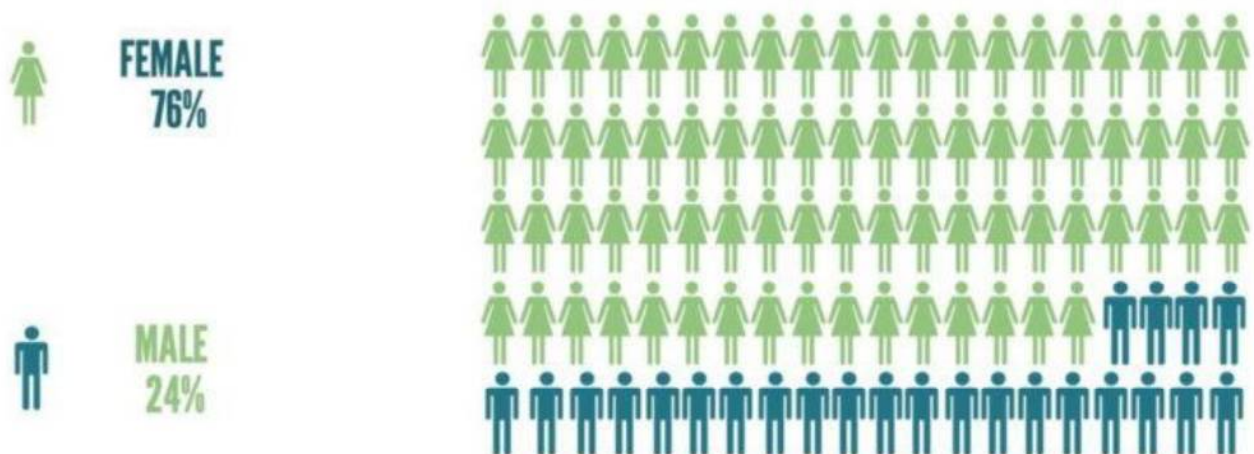
Although MS is found in all parts of the world, its prevalence varies greatly, being highest in North America and Europe, and lowest in sub-Saharan Africa and East Asia. It is almost unheard of in certain populations such as the Inuits, New Zealand Maoris and Australian Aborigines. MS affects two to three times as many women as men, suggesting a role of hormones in the disease process.

The National MS Society is working with the Centers for Disease Control (CDC) to help with the development of a neurological disease surveillance system. The scientific community will be able to learn more about MS with such as system in place.

## Gender Differences

The influence of gender on multiple sclerosis (MS) has been demonstrated in all aspects of the disease, from increased susceptibility in women to a worsened disease course and outcomes in men. Although the pathophysiology of MS is not yet clear, a number of studies have revealed gender-based patterns that point to hormonal mechanisms — and the potential for hormonal-based therapies.

Female gender is considered an independent risk factor for MS, at a commonly reported ratio of 3:1 over men, although several large cohort studies have reported a higher differential. More importantly, the gender gap is widening over time. Estrogen plays a continued role in promoting inflammation throughout the disease. Despite the increasing trends toward a gender bias for the development of MS, the role of hormones, particularly as a therapeutic option, remains controversial. More research needs to be conducted to completely understand the role of hormones in the development of MS furthering the supported theory that the cause of MS is more than just hormones.



## Age

Most people are diagnosed between the ages of 20 and 40, although around three to five per cent of people with MS are diagnosed as children, and it can occur in much older adults. The average age of onset for MS is about 34 years of age. The disease typically follows a pattern, moving through different variations or types over the years. This is because as one gets older, MS symptoms are likely to change.

## Ethnicity

Worldwide, approximately 2.3 million people are affected by MS. The disease is seen in all parts of the world and in all races, but rates vary widely. In general, the prevalence of MS tends to increase with latitude (e.g., lower rates in the tropics, higher rates in northern Europe), but there are many exceptions to this gradient (e.g., low rates among Chinese, Japanese, and African blacks; high rates among Sardinians, Parsis, and Palestinians).

The presence of these exceptions implies that racial and ethnic differences affect risk. In addition, a substantial increase in MS incidence has been reported from different regions, suggesting that environmental factors, as well as geographic and genetic ones, play an important role in MS.

Epidemiologic studies indicate an increase in MS prevalence in Latin America. Susceptibility to MS and clinical behavior of the disease varies genetically in Latin America; for example, MS apparently does not occur in Amerindians with Mongoloid genes.

One research project looked at information from 26,967 Caucasians, 715 Latinos, and 1,313 African Americans with multiple sclerosis. The researchers published the results in the *Journal Disease & Ethnicity* and reported that:

- Caucasians are one to two years older than Latinos or African Americans when they first experience symptoms and are diagnosed.
- Latinos appear to retain bladder function and mobility longer than Caucasians.
- Caucasians are less likely to report MS and depression than Latinos or African Americans, but Latinos are less likely to get mental health care.
- African Americans are less likely to get care from a neurologist specializing in MS or to go to an MS clinic.



This research found one commonality among the three groups. According to Staley Brod, MD, professor of neurology at the University of Texas at Houston, the time gap between the first symptom to getting a diagnosis is no different. It's about a six-year span between the first symptom and the diagnosis for all ethnicities.

The strongest data about differences between races or ethnicities comes from the way it progresses among African Americans and Caucasians. According to Jonathan Howard, MD, assistant professor of neurology and psychiatry at the NYU Langone Multiple Sclerosis Comprehensive Care Center in New York City, African Americans get multiple sclerosis much less, so it's less common, but it's much more severe. Research in this area is complicated by the fact that many African Americans in the United States have Caucasian ancestry as well.

African Americans often have poorer health outcomes for a number of chronic diseases because they might be diagnosed at a later or more advanced stage or have less access to health care. However, for an as-yet unknown reason, even when African Americans take the same medications given to Caucasians, their MS progresses more quickly to an advanced state and a loss of mobility.

Dr. Howard was part of a team that observed more severe MS lesions on MRIs of African Americans compared to Caucasians, which indicates disease progression, but not an explanation of why the disease moves more quickly.

## Economic Implications

MS can substantially and adversely affect an individual's quality of life (QOL) and is associated with high costs for MS patients, their families, and society as a whole. Moreover, these burdens span a broad range of impacts, including prevalence of MS, direct costs, indirect costs, QOL, and other intangible costs (Trisolini, et al, 2010). A key issue for policy makers and advocacy organizations is the cost to society of MS. Cost of illness studies quantify the economic burden of specific diseases and can be used by policy makers to allocate research and service funding. Several cost-of-illness estimates for MS in many different countries have been published over the past 10 years, with all finding a high cost on a per person basis.

- According to the National MS Society, the average annual cost for someone with MS in the U.S., including both direct and indirect costs (i.e. lost wages), is approximately \$69,000. Of this, approximately \$39,000 consists of health care costs. Total cost for all people with MS in the U.S. is approximately \$28 billion annually.
- Among people with MS, 5% of family incomes and 25% of individual incomes fall below the federal poverty level. (Minden et al, 2006)
- Compared to those with relapsing-remitting MS, people with primary progressive MS are more likely to be unemployed (82% vs 42%) and have lower family income. (Sonya Sifika Study, 2006)
- The costs associated with MS increase with greater disability. Costs for severely disabled individuals are more than twice those for persons with relatively mild disease. (Kobelt, et al, 2004)