Health and Wellness for People of Color

An Encyclopedia of Issues, Problems, and Solutions

Multiple Sclerosis

Yanick Rice Lamb
Howard University
525 Bryant St. NW, #230
Washington, DC 20059
ylamb@howard.edu
(202) 806-4499, Direct
(202) 806-7927, Main
(202) 489-4850, Mobile

Multiple Sclerosis

By Yanick Rice Lamb

Identified at least 150 years ago, multiple sclerosis (MS) is one of the most common and debilitating neurological conditions (Reich et al. 2018). It is an unpredictable autoimmune disease that can attack the body in various ways, which can make it difficult to diagnose and easy to confuse with other illnesses, especially for children (Chitnis and Pohl 2016). Mental and physical symptoms can include numbness, weak muscles, vision loss, vertigo, fatigue, depression, cognitive problems, paralysis, and difficulty with balance, walking, speaking or swallowing (Halabchi 2017).

New research indicates that the prevalence of multiple sclerosis has increased steadily over the last five decades and that twice as many people might have multiple sclerosis than previously thought. MS affects nearly 1 million people in the United States — most of them young adults — and 2.3 million people internationally (Wallin 2019). In fact, it is the "most common cause of non-traumatic chronic neurological disability in young adults" (Johnson et al 2009).

Researchers were able to come up with a more precise figure, 913,925, than previous estimates, 300,000 to 400,0000, using a MS algorithm to analyze health claims data. They also took into account demographic changes, improved diagnoses of multiple sclerosis and evolutions in treatment (Wallin 2019). Diagnoses typically occurs between the ages of 20 and 50, but MS also affects the elderly and approximately 10,000 children. Up to 5% of people with MS had symptoms before they turned 18. In terms of gender, women are diagnosed with multiple sclerosis two to three times more often than men (NMMS 2019).

This chapter will discuss disparities affecting African Americans, symptoms, treatment and the future outlook for multiple sclerosis.

Disparities

Physicians and researchers have consistently stated that multiple sclerosis develops primarily among people of European descent (Cree et al. 2004), but that African Americans suffer with greater disability. However, Langer-Gould et al. challenge beliefs that blacks have a lower risk of MS than whites in a three-year study of participants from the Kaiser Permanente Southern California health plan. Their findings indicated that African Americans had a higher incidence of multiple sclerosis (10.2 per 100,000 people), compared to whites (6.9), Hispanic Americans (2.9) and Asian Americans (1.3). The risk of MS is 47% higher for blacks than whites, but 50% lower for Hispanic Americans and 80% lower for Asian Americans (2013). Multiple sclerosis is higher among African Americans than for Africans on the continent, and the same is true for other people of color compared to those in their countries of origin (Khan et al. 2015).

Researchers also found higher rates of a precursor to MS known as clinically isolated syndrome (CIS), which signals a problem with the central nervous system. The incidence of CIS among African Americans was similar to that of Caucasians (6.8 compared to 5.9). “These findings strengthen the probability that the old belief that blacks have a decreased risk of MS is no longer true,” Langer-Gould et al. stated (2014:1349).

African Americans continue to have worse neurological impacts and disabilities than whites. For example, African Americans with multiple sclerosis experience more spinal cord and optic nerve problems (Cree et al. 2004). They also have 29% higher levels of antibodies in their cerebrospinal fluid than Caucasians, which has been associated with

more severe disability (Rinker et al. 2007). On average, they need wheelchairs, walkers and canes twice as soon — nine years after MS diagnosis versus 17 years for white Americans (Rinker et al. 2007). And they end up in nursing homes six years earlier than other racial and ethnic groups (Buchanan et al. 2010).

In terms of specialized care, a larger proportion of African Americans participating in a voluntary national registry had been treated at a MS clinic or by a neurologist who specializes in multiple sclerosis than their white counterparts. They were also more likely to report that they had depression than other groups (Buchanan et al. 2010).

One under-researched area of study deals with the impact of environmental toxins on multiple sclerosis. Exposure to pollutants and other toxins has been associated with those who are genetically susceptible to multiple sclerosis (Goodin 2009). This could affect African Americans, who often live in communities with disproportionately higher levels of pollution and work in areas with higher levels of toxins. According to “Toxic Wastes and Race at Twenty 1987-2007,” African Americans are 79% more likely than whites to live in neighborhoods with unhealthy levels of industrial pollution. In addition, 46% of housing for impoverished residents are located within a mile of factories that have reported toxic emissions to the Environmental Protection Agency (Bullard et al. 2007).

How MS Works

Multiple sclerosis is incurable. Its specific cause is unknown, but it is thought to stem from a complex combination of genetic, gender, race and environmental factors such as vitamin D deficiency and the Epstein-Barr infection. This common virus can develop in childhood and remain latent, but can cause mononucleosis in later years (Goodin 2009).

“Tobacco exposure, obesity and mononucleosis are also associated with an enhanced risk of multiple sclerosis,” but only a small minority of people with mononucleosis or Epstein–Barr go on to develop multiple sclerosis (Reich 2018). In terms of vitamin D, African Americans tend to have lower levels, because of climate, geography and possibly melanin, which limits exposure to ultra-violet (UV) light from the sun. Researchers call for more studies on larger groups of African Americans for more details on the impact of vitamin D on this population (Gelfand et al. 2011). Multiple sclerosis has been found to be more prevalent in northern and colder regions of the world. In the United States, for example, the prevalence of MS is 353.1 per 100,000 in the Midwest and 377.4 per 100,000 in the Northeast, compared to 272.6 per 100,000 in the South (Wardin 2019).

In a healthy immune system, white blood cells assist in defense mechanisms such as fighting infections and repairing tissues. With autoimmune diseases, the body attacks itself. In terms of multiple sclerosis, MS attacks the central nervous system, which consists of the brain, spinal cord and optic nerve. These attacks interrupt information flowing within the brain and from the brain to the rest of the body. White blood cells from the thymus gland known as T cells cause inflammation and damage the insulation, or myelin sheath, protecting nerve fibers. This process is called demyelination, and the damaged areas develop hardened scar tissue or sclerosis in multiple areas — hence the name multiple sclerosis. T cells can also damage the nerve fibers, or axons, leaving them vulnerable to slow degeneration. If they create lesions on the spinal cord, disabilities can be more severe. Overall, lesions “may repair more effectively in younger people” (Reich et al. 2018).

There are four sub-types of multiple sclerosis and a newly identified form of MS:

1. Clinically Isolated Syndrome (CIS): This syndrome may or may not lead to MS. It depends on whether this initial episode of inflammation and demyelination exceeds the 24-hour mark and shows evidence of brain lesions. If high-risk individuals with CIS receive early treatment, multiple sclerosis can be delayed (Lubin et al. 2014).
2. Relapsing-Remitting Multiple Sclerosis (RRMS): This is the most common type of MS, accounting for about 85% of initial diagnoses. It features a series of relapses and remissions that vary from person to person, including adults as well as children (Lubin et al. 2014).
3. Secondary Progressive Multiple Sclerosis (SPMS): As disabilities progress, people can move from RRMS to this stage. The relapses of SPMS can be active or inactive, with or without progression (Lubin et al. 2014).
4. Primary Progressive Multiple Sclerosis (PPMS): This form has gradual damage, less inflammation and fewer lesions than relapsing multiple sclerosis. As with SPMS, relapses can be active or inactive, with or without progression. About 15% of MS patients are diagnosed with PPMS (Lubin et al. 2014).
5. Myelocortical Multiple Sclerosis (MCMS): Through research of brains pledged for donation by multiple sclerosis patients before their deaths, researchers at the Cleveland Clinic (Trapp et al. 2018) identified a new MS subtype. This form has demyelination of the spinal cord and cerebral cortex, but not the white matter in the brain. The research provides support that neuron damage and demyelination can happen independently as well as the need for customized treatment (Trapp et al. 2018).

Treatment

More than a dozen drugs are available to treat multiple sclerosis (Reich et al. 2018). However, not all treatment regimens work for African Americans, and it is difficult to determine this in advance because of insufficient data or data that has been primarily tested on white patients. “The only way this malady would be addressed correctly would be for the U.S. Food and Drug Administration (FDA) to set clear-cut guidelines for enrollment numbers,” said Avasarala (2015). “Without a set percentage number (as determined by statisticians) of patients enrolled, no study should be allowed to be filed for drug approval before the FDA.”

Injectable medications include interferon beta and glatiramer acetate. Oral drugs include fingolimod, dimethyl fumarate and teriflunomide. Long-term intravenous infusions range from ocrelizumab, the first therapy to target B cells from bone marrow, to the monoclonal antibodies natalizumab and alemtuzumab, which go after specific immune cells to prevent them from causing damage. Other drugs include dalfampridine to improve walking speed; corticosteroids such as prednisone for reduce inflammation and relapses; mitoxantrone, a chemotherapeutic drug, to suppress the immune system of those with Primary Progressive MS; and medication for symptoms, ranging from dizziness to pain (Khan et al. 2016; Reich et al. 2018; NMSS 2019). More research is being conducted on drugs to repair tissue or for remyelination; to reduce cerebral or spinal cord atrophy; and possibly to conduct stem-cell transplantation (Reich et al. 2018; Burt et al. 2019).

Some of the same data issues that affect African Americans also apply to children. Some of the same oral medications — vitamin D dosing and injectable drugs used for adults, such as interferon, glatiramer acetate — are also being administered to children. However, more research needs to be conducted to address safety issues and effectiveness (Chitnis and Pohl 2016).

“Major polypharmacy” — taking five or more medications at one time — is also an issue for MS patients, because of the risk of drug interactions, side effects, rehospitalization and overall non-compliance because of the difficulty in keeping up with multiple drugs. Sometimes polypharmacy is unavoidable, because of secondary illnesses and the increase in the number of medications as some people age. This points to the importance of medication management and having a physician review all of a patient’s prescribed drugs and over-the-counter supplements. Therapeutic options could replace some drugs, said the researchers, who focused only on RRMS patients. In terms of comorbidities, 53.1% of patient in the study had one or more secondary illnesses, and the average age was 43 (Frahm et al. 2019).

Physical therapy, exercise and healthy nutrition have also been effective for MS patients. However, African Americans exercise less frequently than their white counterparts. Social determinants of health also play a role in the fitness deficit for African Americans, some of whom lack access to safe walking areas and parks. Regardless of race and ethnicity, some people with multiple sclerosis avoid exercise, because they believe it will make their physical symptoms worse. However, African Americans may have more to gain through exercise given that multiple sclerosis has a greater impact on their bodies. Studies indicate that regular exercise has been associated with improvements in conditioning, flexibility, muscle strength and balance. Fitness benefits can also include reduced falls, spasticity and pain from contractions (Halabchi 2017).

Physicians recommend a pre-exercise evaluation to establish a patient’s physical baseline while also taking into account factors such as heat sensitivity and the risk of falling. Once medical clearance is obtained, the fitness plan would then be individualized to focus on a patient’s capabilities and primary need, such as endurance or coordination.

Fitness plans might incorporate integrated exercise such as aquatics or more rigorous movement for high-functioning individuals who are cleared to maintain routines established before their MS diagnoses. Even for patients with less or no mobility, therapists can perform assisted or passive stretching to target spastic muscles and "passive range of motion above the joint of a paralyzed area" (Halabchi 2017).

Healthy lifestyles are especially important for African Americans who suffer disproportionately from a host of conditions, including high blood pressure, diabetes, high cholesterol and obesity. The benefits of a good nutrition and exercise work in both directions: They help to manage other health conditions, and in the process they can slow down the progression of multiple sclerosis.

Future Outlook

One of the challenges in treating multiple sclerosis among African Americans is the lack of data. Some say this may partly be a function of systematic lack of attention to African-American populations in health research (Langer-Gould et al. 2013; Khan et al. 2015). For example, only 113, or 0.2%, of 60,000 articles on multiple sclerosis focused on African Americans (Khan et al. 2015). Having more studies would help to shed light on the causes and prognosis of multiple sclerosis as well as the precursor CIS, which indicates problems with the central nervous system (Langer-Gould et al. 2014).

Clinical trials would specifically help in this regard, because studying the progression of multiple sclerosis, the effects of medication and other factors directly with African Americans obviously provides the best information. While some MS patients want to take advantage of the possibility of receiving cutting-edge treatments through clinical trials, African-American participation has fallen. Black participation in phase three clinical

trials has dropped from about 10% in 1993 to 2% in 2013 (Avasarala 2015). Khan et al. suggests replicating and learning from the recruitment success of other clinical trials such as those for breastfeeding (2015). “Inadequate access to specialty care, mistrust of the health-care system, and cultural and religious beliefs are some of the common factors that affect participation in the health care system.” Trust is a persistent issue. The specter of the Tuskegee syphilis experiments makes many people reluctant to volunteer as what they consider to be human guinea pigs. From 1932 to 1972, African-American men participating in a government study didn’t not receive informed consent and were not treated adequately for syphilis (Khan et al. 2015). President Bill Clinton issued a formal apology in 1997, but for some African Americans that is not enough when it comes to their own personal health,

Pediatric clinical trials are also important for children as well as adults to improve overall diagnoses, monitor the course of multiple sclerosis over time and study age-related differences. For example, children are more likely to experience seizures than adults. And some studies have shown 50% higher nerve damage among children, particular those who haven’t reached puberty, compared to adults (Chitnis and Pohl 2016). Besides the diagnosis difficulties in differentiating between multiple sclerosis and conditions that mimic MS, another challenge in treating children is that they are still growing. This makes it hard to gauge the effect of multiple sclerosis on the immune system, brain growth and cognitive development, prompting calls for “complex algorithms” (Tardieu et al. 2016). “In addition to the need for clinical trials, pediatric MS care providers must also consider and contribute to evidence-based algorithms for diagnostic approaches and treatment management, including definitions for breakthrough disease” (Chitnis and Pohl 2016).

Another issue has been the lack of a national database to collect information and provide better statistics on how many people are affected by multiple sclerosis. Physicians are not required to report cases of MS. One current option is the North American Research Committee on Multiple Sclerosis (NARCOMS) registry, which was founded in 1993 and includes 38,000 adults who have been diagnosed with MS or CIS. In addition to some self-identified regional and state registries, there is also the African American Multiple Sclerosis Genetics Project, which is estimated to represent up to 5.4% of the black population with multiple sclerosis (Gelfand 2011).

However, the knowledge gap on multiple sclerosis could close to some degree in the future. After years of advocacy by medical professionals, patients, support groups and the National Multiple Sclerosis Society, Congress appropriated $5 million in 2019 for the Centers for Disease Control and Prevention (CDC) to develop the National Neurological Conditions Surveillance System (NNCSS) as part of the 21st Century Cures Act. Under the wide-ranging 2016 act, the CDC will use the new system to collect data and focus on ways to address neurological conditions, beginning with multiple sclerosis and Parkinson's disease (CDC 2018).

Despite the disparities, more African Americans are educating themselves to take better advantage of resources as well as turning to support groups and MS Navigators. Additionally, prominent people are drawing attention to multiple sclerosis from singer Tamia who has MS to former First Lady Michelle Obama, who frequently shares the story of how her father worked throughout his life while adjusting to MS.

Further Reading

Avasarala, Jagannadha. 2014. “Inadequacy of Clinical Trial Designs and Data to Control for the Confounding Impact of Race/Ethnicity in Response to Treatment in Multiple Sclerosis.” *JAMA Neurology.* 71(8):943–944. doi:10.1001/jamaneurol.2014.79

Avasarala, Jagannadha. 2015. “Multiple Sclerosis in U.S. Minority Populations: Clinical Practice Insights.” *Neurology Clinical Practice*. 5(3):186 187; DOI:10.1212/01.CPJ.0000466889.88876.d0 http://cp.neurology.org/content/5/3/186

Buchanan, Robert J., Zuniga, Miguel A., Carrillo-Zuniga, Genny, Chakravorty, Bonnie J., Tyry, Tuula, Moreau, Rachel L., Huang, Chunfeng, and Vollmer, Timothy. “Comparisons of Latinos, African Americans, and Caucasians With Multiple Sclerosis.” 2010. *Ethnicity & Disease 20:451-457.* https://www.researchgate.net/publication/49821725_Comparisons_of_Latinos_African_Americans_and_Caucasians_with_multiple_sclerosis

Bullard, Robert D., Mohai Paul, Saha Robin, and Wright, Beverly. 2007. *Toxic Wastes and Race at Twenty 1987-2007: A Report Prepared for the United Church of Christ Justice and Witness Ministries.* Cleveland: United Church of Christ. https://www.nrdc.org/sites/default/files/toxic-wastes-and-race-at-twenty-1987-2007.pdf

Burt, Richard K., Balabanov, Roumen, Burman Joachim, et al. “Effect of Nonmyeloablative Hematopoietic Stem Cell Transplantation vs Continued Disease-Modifying Therapy on Disease Progression in Patients With Relapsing-Remitting Multiple Sclerosis: A Randomized Clinical Trial.” *JAMA.* 2019;321(2):165–174. doi:10.1001/jama.2018.18743

Centers for Disease Control. 2018. “Project — National Neurological Conditions Surveillance System.” https://www.cdc.gov/surveillance/projects/nncss/index.html

Chitnis, Tanuja and Pohl, Daniela. 2016. “Pediatric Demyelinating Disorders: Global Updates, Controversies and Future Directions.” *Neurology* 87 (9 Supplement 2) S1-S3. DOI:10.1212/WNL.0000000000002882 http://n.neurology.org/content/87/9_Supplement_2/S1.full

Consortium of Multiple Sclerosis Centers. 2019. NARCOMS Registry for Multiple Sclerosis. North American Research Committee on Multiple Sclerosis, https://www.narcoms.org/

Cree, B.A.C., Khan, O., Bourdette, D., Goodin, D.S., Cohen, J.A., Marrie, R.A., Glidden, D., Weinstock-Guttman, B., Reich, D., Patterson, N., Haines, J. L., Pericak-Vance, M., DeLoa, C., Oksenberg, J.R., Hauser, S.L. 2004. "Clinical Characteristics of African Americans vs. Caucasian Americans with Multiple Sclerosis." *Neurology* 63(11):2039-2045. https://reich.hms.harvard.edu/sites/reich.hms.harvard.edu/files/inline-files/Cree.2004.pdf

Frahm Niklas, Hecker, Michael, and Zettl, Uwe Klaus. 2019. "Polypharmacy in Outpatients With Relapsing-Remitting Multiple Sclerosis: A Single-Center Study." *PLoS ONE* 14(1): e0211120. https://doi.org/10.1371/journal.pone.0211120]

Gelfand, J. M., Cree, B. A., McElroy, J., Oksenberg, J., Green, R., Mowry, E. M., Miller, J. W., Hauser, S. L., and Green, A. J. 2011. "Vitamin D in African Americans With Multiple Sclerosis." *Neurology*, *76*(21), 1824-30. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3100123/

Goodin, Douglas S. 2009. "The Causal Cascade to Multiple Sclerosis: A Model for MS Pathogenesis." *PLoS One* 4(2):e4565. https://doi.org/10.1371/journal.pone.0004565

Halabchi, Farzin, Alizadeh, Zahra, Sahraian, Mohammad Ali, and Abolhasani, Maryam. 2017. "Exercise Prescription for Patients With Multiple Sclerosis; Potential Benefits and Practical Recommendations." *BMC neurology*, *17*(1):185. doi:10.1186/s12883-017-0960-9 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5602953/

Johnson, Britt A., Wang, Joanne, Taylor, Elise M., Caillier, Stacy J., Herbert, Joseph, Khan, Omar A., Cross, Anne H., De Jager, Philip L., Gourraud, Pierre-Antoine F., Cree, Bruce C.A., Hauser, Stephen L., and Oksenberg, Jorge R. 2009. "Multiple Sclerosis Susceptibility Alleles in African Americans." *Genes and Immunity* 11:343–350. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2880217/

Khan, O., Williams, M. J., Amezcua, L., Javed, A., Larsen, K. E., & Smrtka, J. M. 2015. "Multiple Sclerosis in US Minority Populations: Clinical Practice Insights." *Neurology. Clinical practice*, *5*(2), 132-142. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4404283/

Langer-Gould, Annette, Brara, Sonu M., Beaber, Brandon E., and Zhang, Jian L. 2013. "Incidence of Multiple Sclerosis in Multiple Racial and Ethnic Groups. *Neurology* 80(19):1349-1355.

Langer-Gould, Annette, Brara, Sonu M., Beaber, Brandon E., and Zhang, Jian L. 2014. "The Incidence of Clinically Isolated Syndrome in a Multi-Ethnic Cohort." *Journal of Neurology* 261(7):1349-1355. (https://link-springer-com.proxyhu.wrlc.org/content/pdf/10.1007/s00415-014-7349-0.pdf)

National Multiple Sclerosis Society (NMMS). 2019. https://www.nationalmssociety.org/What-is-MS/Who-Gets-MS

National Multiple Sclerosis Society (NMMS). 2018. "African Americans." https://www.nationalmssociety.org/What-is-MS/Who-Gets-MS/African-American-Resources

National Multiple Sclerosis Society (NMMS). 2018. "What Is MS?" https://www.nationalmssociety.org/What-is-MS

Reich, Daniel S., Lucchinetti, Claudia F., and Calbresi, Peter A. 2018. "Multiple Sclerosis." *New England Journal of Medicine* 378:169-180. https://www.nejm.org/doi/10.1056/NEJMra1401483

Rinker, John R., Trinkaus, Kathryn, Naismith, Robert T. and Cross, Anne H. 2007. "Higher Igg Index Found in African Americans Versus Caucasians With Multiple Sclerosis." *Neurology* 69(1):68-72. DOI:10.1212/01.wnl.0000265057.79843.d9

Tardieu, Marc, Banwell, Brenda, Wolinsky, Jerry S., Pohl, Daniela, and Krupp, Lauren B. 2016. "Consensus Definitions for Pediatric MS and Other Demyelinating Disorders in Childhood." *Neurology*. 87 (9 Supplement 2) S8-S11; DOI:10.1212/WNL.0000000000002877 http://n.neurology.org/content/87/9_Supplement_2/S8.long

Trapp, Bruce D., Vignos, Megan, Dudman, Jessica, Chang, Ansi, Fisher, Elizabeth, and Staugaitis, Susan M. 2018. "Cortical Neuronal Densities and Cerebral White Matter Demyelination in Multiple Sclerosis: A Retrospective Study." *Lancet Neurology*. DOI: 10.1016/S1474-4422(18)30245-X

Wallin, Mitchell T., Culpepper, William J., Campbell, Jonathan D., Nelson, Lorene M., Langer-Gould, Annette, Marrie, Ruth Ann, Cutter, Gary R., Kaye, Wendy E., Wagner, Laurie, Tremlett, Helen, Buka, Stephen L., Dilokthornsakul, Piyameth,

Topol, Barbara, Chen, Lie H. and LaRocca, Nicholas G. 2019. “The Prevalence of MS in the United States: A Population-Based Estimate Using Health Claims Data.” *Neurology*. 92(10):e1029-e1040; DOI:10.1212/WNL.0000000000007035 https://n.neurology.org/content/92/10/e1029