

MULTIPLE SCLEROSIS and the African American Experience



Advisory Board Findings and Recommendations to Reduce the Burden of Health Disparities and Improve Care Quality

Marie LeGrand, MPH; Mitzi Joi Williams, MD; Oluwasheyi Akin Ayeni, MD; Angala B. Borders-Robinson, DO, FACN; Angela Lang Chandler, MD; Heidi Crayton, MD; Tirisham Gyang, MD; Yolanda S. Wheeler, PhD, CRNP, CPNP-AC, MSCN; Annette E. Howard, MD; Jacqueline Faulkner Rosenthal, MD; Aljoeson Walker, MD; Sophia D. Woodson, CNP; and the African American Advisory Group of the Multiple Sclerosis Association of America

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Multiple sclerosis (MS) is an immune-mediated inflammatory disease that specifically attacks myelinated axons in the central nervous system (CNS), compromising the myelin and the axon to variable degrees. In most cases, the disease follows a relapsing-remitting pattern, with short-term episodes of neurologic deficits that resolve almost completely. Conversely, a minority of patients experience steadily progressive neurologic deterioration throughout the disease's course.

While a definitive, single cause of MS has not been identified, its etiology likely involves a combination of genetic susceptibility, biological sex, and a presumed non-genetic trigger (e.g., viral infection, low vitamin D levels, etc.). These factors culminate in a self-sustaining autoimmune disorder, resulting in recurrent immune attacks on the CNS. Geographic variation in the incidence of MS supports the probability that environmental factors are involved in the etiology.

According to recent estimates, approximately 1 million people in the United States are living with MS, with females being affected nearly 3x more than males.¹ Although MS affects all races and ethnicities, specific minority populations may bear a disproportionate share of the disease burden. Specifically, recent research has suggested African Americans carry a higher risk of developing MS and appear to experience a particularly aggressive disease course, with increased severity and more rapid progression. The medical community has yet to fully characterize this phenomenon, with a multitude of inherited and environmental components contributing to MS risk in general and specific challenges within the African American demographic as a result of self-identified ethnicity, heterogeneity in genetic ancestry, and a paucity of research exclusively devoted to this subset of patients. Furthermore, the African American experience with MS extends beyond purely clinical considerations and features specific implications pertaining to socioeconomic factors, cultural considerations, and disparities in the coverage and provision of care.

Advisory Board Meeting Overview

The African American Experience & MS advisory board meeting convened on November 16, 2019, in Atlanta, GA. Coordinated by the Multiple Sclerosis Association of America (MSAA), the meeting was attended by 20 African American patients with MS, 11 MS health care providers (HCPs), and the care partners of African American patients with MS. Meeting sessions included brief presentations to inform participants and promote candid input, followed by moderated discussions. The ultimate goal was to facilitate dialogue, allowing the diverse group of participants to share their views on the challenges that face African Americans living with MS en route to developing programmatic initiatives that address unmet needs in the community. Information gathered from the meeting is being processed to aid in the development of an actionable plan, tailored educational offerings, and a selection of services to continue building on the work of the African American committees of MSAA.

Racial/Ethnic Disparities in US Health Care



Health disparities are defined as specific differences in health that are closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group or other characteristics historically linked to discrimination or exclusion.² As a testament to this concept, African Americans, Hispanics, American Indians/Alaska Natives, Asians, and Native Hawaiian or Other Pacific Islanders (NHOPIs) bear a disproportionate burden of disease, injury, premature death, and disability.³ For these racial/ethnic minority populations, health disparities can result in reduced life expectancy, decreased quality of life (QOL), loss of economic opportunities, and perceptions of injustice. For society as a whole, these disparities culminate in decreased productivity, increased health care costs, and social inequity. By 2050, today's racial/ethnic minorities are expected to account for nearly 50% of the total US population. Therefore, the adverse impact of such disparities on public health will be magnified if the precipitating issues are not swiftly addressed.

For many health conditions, African Americans bear a disproportionate burden of disease, injury, death, and disability. Disparities in mortality resulting from conditions such as heart disease, cancer, and diabetes between African Americans and Caucasian Americans not only exist but have grown increasingly wider in the new millennium.⁴ Researchers use the term “excess deaths” to characterize these disparities in mortality rates among African Americans and other racial/ethnic minorities. Socioeconomic factors notwithstanding, even educated African Americans tend to experience increased morbidity and earlier mortality than their educated Caucasian American peers. An African American will live, on average, approximately 3.5 fewer years than a Caucasian American with the same income.⁵

Since 1985, the US Department of Health and Human Services (HHS) has coordinated several initiatives to reduce or eliminate racial/ethnic health disparities. Despite recent progress and the sanguine goal of eliminating racial/ethnic disparities and achieving health equity as part of the Healthy People 2020 initiative, the epidemic persists.⁶ Nearly two decades have passed since the Institute of Medicine (IOM) released its landmark report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, which characterized the scientific evidence on health disparities at the time.⁷ Similar to the result of government-led interventions, the recommendations of the report have not been achieved. Myriad factors have been identified as potential causes of health care disparities, including access to care, quality of care delivered, patient–clinician communication, culture, and behavioral practices/personal beliefs. However, a substantial need exists to better understand the interplay of these factors and how they culminate in the incongruent access and differential care that lead to population-level health disparities.⁸ In addition to addressing these factors and their complex interaction, the elimination of racial/ethnic disparities will also ultimately require a renewed perspective regarding the means by which health care is delivered, covered, and funded.

Epidemiologic and Clinical Characterization of MS in African Americans



Just as the prevalence of MS in the general population has been elucidated in recent years—more than doubling from previous estimates of approximately 400,000 to nearly 1 million Americans—the medical community has gained an increasingly comprehensive understanding of the characteristics of the disease in African Americans. Although it was once a widely accepted assertion that blacks had a lower risk of MS than whites, findings published over the past decade tell a different story.

The commonly held misconception of lower MS risk in African Americans is likely the result of a lack of research specific to minority populations and broad assumptions based on the worldwide prevalence of MS in different regional and racial/ethnic demographics. Overall MS prevalence has been documented to be as high as 150/100,000 in the United States and 250/100,000 in Canada.¹⁹ Across the Atlantic, prevalence is noted to be as high as 190/100,000 in the UK, 132/100,000 in Scandinavia, and 150/100,000 throughout the rest of Europe.¹⁰ Populations with Arabic origins in northern Africa feature a similar MS prevalence to the Middle East at ~50/100,000, while prevalence among both white, black, and mixed genetic descent South Africans is markedly low at 13/100,000, 6/100,000, and 3/100,000, respectively.^{9,10} Throughout the rest of the continent, MS cases are only noted occasionally among black Africans, although official documentation may be limited. These statistics paint a picture of MS that is skewed toward white populations of European descent, including those that emigrated and settled in North America. With limited MS prevalence among black individuals in Africa, the presumption was that African Americans would share a similar risk. However, confounding this assumption is the fact that African Americans often feature a mixed genetic composition derived from 20% to 30% European ancestry and 70% to 80% African ancestry.¹¹ Furthermore, environmental factors play a distinct role in MS etiology and specific socioeconomic components of the African American experience may contribute to disease predisposition and outcomes.

A closer look at MS prevalence in the United States shows significant variation in MS incidence according to race/ethnicity. In 2013, a study among 496 patients with newly diagnosed MS reported that disease incidence was higher in blacks (10.2; $P < 0.0001$) and lower in Hispanics (2.9; $p < 0.0001$) and Asians (1.4; $p < 0.0001$) than whites (6.9).¹² In keeping with incidence trends according to gender, black females demonstrated an MS risk >1.5 times that of whites, with black males demonstrating a similar risk to whites (**Figure 1**).

An analysis of veterans from the Gulf War Era (GWE)—a cohort with abnormally high rates of MS and a range of other neurologic illnesses—reported a similar increased incidence among blacks (12.13/100,000) versus whites (9.32/100,000), and a further increased incidence among black females (26.34/100,000) that was marginally greater than that among white females (25.79/100,000).¹³ The findings also point to another unique phenomenon in the African American experience with MS: increased disease severity. In the GWE veteran cohort, males and blacks had significantly higher proportions of primary progressive MS.¹⁴ Disease-related disability at diagnosis was also significantly more severe in blacks versus whites and in women versus men. Meanwhile, the MS Severity Score, a disability measure that accounts for time with MS, was marginally greater in black males and other males compared to the other sex-race groups.

These findings, combined with those of other studies, point to distinct MS phenotypes in the African American population. Specifically, disease progression is significantly faster in black MS patients in both brain and retinal measures.¹⁵ In addition, MRI scans show whole brain, gray and white matter atrophy twice as fast in African Americans compared to Caucasian Americans. African American patients also demonstrate faster atrophy of the thalamus, which could be linked to cognitive impairment.¹⁶

Epidemiologic and Clinical Characterization of MS in African Americans (continued)



The disproportionate burden of MS in African Americans extends far beyond mere prevalence and severity components. Further investigation of mortality in MS provides a clearer understanding of these racial/ethnic disparities: While Caucasian Americans and females are more likely to experience MS-related mortality overall, disease-related mortality is demonstrated at an earlier age in African Americans.¹⁷ Differences in the clinical presentation of MS across race/ethnicity may be partially responsible for this unequivocal disease impact. It is also likely the result of reduced access to care among African Americans. Among 2,156 individuals with MS in one study, 72.2% of participants saw a neurologist. However, the probability of seeing a neurologist was significantly lower for people who lacked health insurance, were poor, lived in rural areas, or were African American.¹⁸ Since patients with MS who see a neurologist are more likely to undergo diagnostic and treatment-related tests, receive disease-modifying therapies and medication for symptoms, and be informed about a treatment plan, African Americans who do not have access to this level of care may be severely disadvantaged. In another study examining neurologic health care access in the United States, African Americans were more likely to receive care in the costly emergency department (ED) and inpatient settings and 30% less likely to see a neurologist in clinic than their Caucasian American counterparts.¹⁹ In a study of Medicaid home and community-based services (HCBS) recipients with MS, African Americans were less likely to receive case management, equipment, technology and modification services, and nursing services compared with Caucasian Americans despite being more likely to be impaired.²⁰

The factors contributing to reduced access to care and a disparate care experience in the African American MS population are varied and result from both internal and external influences. However, gaining a deeper understanding of these care disparities, the factors that precipitate them, and even the underlying epidemiologic and clinical characteristics of MS in African Americans has proven challenging due to a lack of research. A PubMed review conducted in 2014 revealed that there were nearly 60,000 published articles in total on MS, with nearly 52,000 written in English; however, only 113 focused on African American (or black) patient populations with MS, representing <1% of the disease-specific literature.²¹ Furthermore, despite the inclusion of minorities in clinical trials mandated by the National Institutes of Health (NIH) Revitalization Act of 1993, the participation of African Americans and members of other minority populations is disproportionately low in MS trials compared with Caucasian Americans.²² Socioeconomic, regional, and cultural (e.g., religious beliefs, distrust of the system) influences contribute to this underrepresentation in clinical trials and exacerbate suboptimal disease characterization and health disparities among African Americans with MS.

Organized efforts have been devoted to addressing these health disparities in African Americans with MS, with initiatives such as the MS Minority Research Engagement Partnership Network, National African Americans with Multiple Sclerosis Registry, MS-UP, and Advancing Inclusive Research External Council. These initiatives enlist the contributions of HCPs, patient advocacy organizations, and drug manufacturers to enhance the medical community's understanding of chronic disease in minority populations, facilitate minority participation in clinical trials, and advance the application of knowledge to minority populations in clinical practice. These endeavors—along a growing body of literature published during the past 10 years—demonstrate a heightened interest in more thoroughly characterizing the impact of MS in African Americans and resolving associated racial/ethnic disparities. However, continued efforts are needed to fully characterize the African American experience in MS and develop programmatic solutions, which served as an impetus for the aforementioned advisory board meeting.



The diverse viewpoints of patients, HCPs, and caregivers converged at *The African American Experience & MS* advisory board meeting, lending insights from different, unique perspectives along the health care continuum.

Individual Goals and Expectations for the Meeting

Following introductions, attendees were queried regarding what they sought to gain as an outcome of the meeting. Responses varied significantly but a resounding theme emerged: Advancing care quality and treatment outcomes for African American patients with MS, thereby improving QoL for the patients themselves and their caregivers.

Patients

African American MS patients in attendance sought a forum in which they could share their own experiences and learn from others with regard to accepting one's diagnosis, managing personal struggles with a loss of autonomy, and coping with the challenges of the disease in general. Distinct differences were noted between the male and female African American experience with MS, and patients were hopeful that outcomes of the meeting would acknowledge these differences. Patients also sought guidance on access to specific health care resources, such as verified specialist care, advanced specialty drug therapies, medical equipment (e.g., scooters, wheelchairs, adaptive devices for driving a motor vehicle, etc.), and support networks. Navigating Medicare to access services easily and affordably was cited as a common challenge among patients and one they sought to resolve. An emphasis was placed on a contemporary approach to managing MS that would resonate with millennials and other younger individuals. Education and materials supporting a holistic approach to disease management, including diet, exercise, and lifestyle modification, was another goal coming out of the meeting. Patient attendees also sought to facilitate more cultural understanding between HCPs and patients regardless of race. Knowledge of MSAA's distinct role in the process and outcomes of the meeting was also cited as a key goal for this group, with a definite action plan in place for the future.

HCPs

The providers in attendance sought to raise awareness of the African American experience with MS to generate resources devoted to this demographic of patients. HCPs also wanted to be empowered with the tools necessary to help African American patients with MS be their own advocates, particularly newly diagnosed patients. In addition to counseling given in the office visit setting, providers sought knowledge to direct patients to the appropriate resources in the greater community, including guidance on insurance coverage. Means by which to encourage other HCPs to offer equal, well-rounded MS care was another key goal voiced at the meeting. The prevailing theme in this group of attendees was to be able to better serve their current patients and build a rapport with new patients centered on the uniqueness of the African American experience in MS.

Care Partners

The care partners in attendance were cognizant of the critical role they play and sought information and resources regarding how to better support persons with MS. Considering the physical and emotional toll of the care partner experience, they also sought support and resources for themselves, including personal reflection tools and mental health/wellness support. The care partners remained focused on the importance of jointly managing MS and forming a united front against the disease at all times.



Identifying Gaps and Needs in the African American MS Experience

Prior to the development of value-driven solutions, attendees collaborated to identify needs and gaps distinct to patients and providers in the African American experience with MS.

Patients

Among patients in attendance, there was a prevailing opinion that individuals outside the African American MS community believe that the disease does not affect African Americans and, instead, occurs primarily in female Caucasian Americans of advancing age. As a result, African American patients with MS feel that they are often discredited or ignored. Even in their interactions with providers, African Americans with MS feel that they are often approached with skepticism and disrespect when reporting symptoms or concerns. As a result, members of the African American MS community often feel powerless and anxious with regard to communicating with health care providers and rarely develop strong relationships with their neurologists or other HCPs. This feeling of powerlessness is also antecedent to a lack of knowledge regarding their disease, with an unwillingness to ask questions exacerbating the underlying issue. Specifically, patients noted that minimal disease-related information is provided at diagnosis, which would be an opportune time to reach the African American MS community.

"Black people are nervous about talking to their doctor about all this; they feel powerless. More information would help address those fears." - MS Patient Attendee

Coupled with a perceived lack of knowledge among African Americans with MS, patients also voiced their opinion that information regarding available resources and how to access those resources is scarce. Gaps exist in available information pertaining to health insurance; copay assistance; and access to disability-related services, psychological counseling, and assisted living, among many other components of care provision. Patients asserted that they do not have the time or means to attend educational presentations that serve to impart knowledge in these particular areas. The resulting conclusion was that a more efficient and convenient mode of delivery for patient education is sorely needed. Another means of imparting knowledge and information that was cited as lacking are support groups specific to African Americans with MS and a directory of these support groups. Considering the central role of the ED in care provision for the African American community, patients in attendance also noted this setting as being ideal for the dissemination of disease- and resource-related information that is not currently being leveraged. Conversely, patients stated that the Veteran's Affairs (VA) setting provides MS-related information for African American patients but may be avoided due to inefficiencies and delays in service.

"We don't have the time and resources to go to the presentations where you can learn about how health insurance works, and that's an important piece of the puzzle." - MS Patient Attendee

Reiterating findings from the published literature on health disparities in African Americans with MS, patients also noted the apparent underrepresentation of minorities in clinical research. Patient attendees expounded on this point by stating that, until this issue is resolved, African Americans cannot receive optimal treatment. Similarly, the patient group spoke to the underlying cultural and religious barriers among African Americans documented in the literature. Reliance on faith and widespread trust in church communities is indicative of another key avenue for the dissemination of MS-related information that is not currently being leveraged among African Americans with disease.



HCPs

Providers in attendance reiterated many of the same gaps noted by the patients, particularly with regard to a lack of knowledge and information. HCPs also echoed the notion that the ED or primary care settings represent initial points of patient contact and ideal venues for the dissemination of education but are rarely, if ever, capitalized on for this purpose. For this reason, and because HCPs believe that patients do not see specialists early enough in the disease course, provider attendees cited a need to educate primary care and ED staff on MS considerations specific to the African American community. One desired end result of such education would be African American patients with MS seeing neurologists sooner than they typically do at present and, perhaps more importantly, seeing one of the very few neurologists nationwide who actually specialize in MS. Such an approach would allow for clinically appropriate management to be deployed before significant disease progression, presumably improving outcomes in the African American MS community.

"A number of neurologists in the community claim to be MS specialists, but few can actually meet the unique needs of patients with MS, especially African American patients with MS."

- HCP Attendee

HCPs further noted that the provision of disease-related information at the provider-patient level is often encumbered by specific personal and systemwide factors. Physicians may be viewed as arrogant or unsympathetic, thereby propagating patient distrust and anxiety. This distrust and anxiety likely also impacts patient participation in clinical trials, according to HCP attendees. To combat this resistance, HCPs noted that patients should be assured that participation in clinical trials often results in desired outcomes, that it advances the treatment of MS for all patients, and that research is typically conducted at no cost to the patient. However, financial barriers may still remain for some African American patients who do not have the means of funding travel to trial sites or taking the necessary time off of work. The providers asserted that open, honest dialogue is critical to these interactions with patients, and health coaching and other communications skills are applicable but lacking among HCPs. However, provider attendees noted that conversations with other African American patients with MS are likely even more compelling than interactions with HCPs, particularly with respect to participation in clinical trials. Furthermore, HCPs asserted that the patients themselves must be encouraged to modify their own mindset and approach to dialogue with providers and be instructed to ask more questions and seek information regarding a treatment plan. In this capacity, African American patients must be comfortable with the specific MS management strategy being employed, provide ongoing, regular feedback to providers, and voice their opposition to inadequate care. The provider's role in this interaction, as noted by HCP attendees, is to invariably provide their patients with options rather than applying a unilateral approach to clinical practice.

In addition to these personal factors impacting provider-patient interactions, a lack of educational materials in a format ideal for delivery during an office visit (i.e., packets, pamphlets, etc.) represents another barrier to patient education cited by providers. HCPs noted significant workloads and limited time available during office visits for didactic dialogue. Such "easily digestible" informational materials should be written and/or presented in a manner suitable for patients of various reading levels, according to provider attendees. Beyond disease-specific and clinically oriented content, HCPs asserted that information on insurance coverage and cost burden should also be offered to encourage patients to be responsible health care consumers.



Care Partners

The resounding sentiment among care partners in attendance with respect to gaps and needs was that they are largely ignored by the MS community as a whole. Despite playing a key role in the experience of African American patients with MS, care partners noted that they were rarely directly addressed or provided with valuable information regarding their loved one's treatment plan or the responsibilities designated to them. Specific informational needs cited by care partners included requisite adaptations for managing disability in the home, guidance on making arrangements for home health care or assisted living, and the nuances of navigating insurance coverage. Furthermore, care partner attendees cited a need for information and guidance on means by which to deal with the physical and emotional stresses of their role in the care process, particularly as the children or spouses of African Americans with MS. It was also noted that African American females who developed severe disability in particular experienced a high rate of male care partners/spouses ending the relationship. Care partners noted that targeted information should be provided early on in the disease process, even for younger children of patients with MS due to the likelihood that they would eventually grow into the role of a care partner.

"Care partners want to be addressed directly by the doctor and given information about their role in addition to information about the MS affecting the person they love."

- MS Care Partner Attendee

Similar to the needs cited by patients, care partners voiced a need for access to resources such as support groups, psychological counseling, and community forums. Care partners also noted that their patients should be coached on contextual clues suggesting the care partners are overburdened and provided with coping mechanisms that both parties can work through together.



General Recommendations

Throughout the course of the entire advisory board meeting, attendees offered generalized and specific, solutions-based recommendations with regard to improving care quality and reducing health disparities in the African American experience with MS. The following interrelated themes prevailed—with specific suggested initiatives to address the basis of each theme—and encompass the general recommendations of the participants:

◆ *Patient and caregiver education is vital.*

• **Basis**

- African American patients do not seek specialist care early enough in the care process, make informed treatment decisions, or access specific resources because they lack a comprehensive knowledge of their disease and the surrounding health care environment.

• **Suggested Initiatives**

- Informational packets or fact sheets for newly diagnosed African American patients, their care partners, and their HCPs
- List of frequently asked questions (FAQs) about MS in African Americans
- Registry of neurologists specializing in MS with an African American focus
- List of community resources for African American patients with MS and their care partners
- Easily accessible, web-based programming outlining the specifics of navigating the health insurance environment

◆ *Identification with a peer group is a key component of support.*

• **Basis**

- Patient-to-patient dialogue is more influential than patient-to-provider dialogue and identifying with others who share similar struggles and triumphs empowers patients and enhances the care experience.

• **Suggested Initiatives**

- Regional roundtable meetings between African American patients with MS and HCPs to foster interaction and advocacy on across the country and gain further insights
- Directory of support groups for African American patients with MS
- Web-based patient forums allowing interaction and open discourse among patients with a relatively small peer group and who may have limited mobility/transportation challenges
- Partnerships with key community and faith-based organizations to disseminate information

◆ *Real-world experience influences attitudes and action.*

• **Basis**

- The stories of patients and their interaction with HCPs in case studies with accompanying background and imagery resonate with patients and providers alike.

• **Suggested Initiatives**

- Patient stories with detailed information outlining key “teachable moments” in navigating the African American experience with MS and resolving the “unknowns” of participating in clinical trials
- Case studies outlining the unique challenges faced by African American patients with MS
- Sample question and answer dialogue between patients and HCPs that demonstrate best practices on both sides of the interaction

Workgroup Recommendations

Prior to concluding the advisory board meeting, participants divided into workgroups on the basis of their identification with one of the three groups in attendance: patients, HCPs, and care partners. Each workgroup was tasked with prioritizing programmatic recommendations for enhancing the African American experience with MS in the short and long term.

Patients

Patient attendees recommended the development of peer-to-peer forums as a priority initiative, with interpersonal support and guidance being key outcomes. In this manner, African American patients with a relatively small peer group can access the advice and guidance of others in similar situations who are effectively navigating life in a minority demographic with a chronic disease. Recommended accompanying initiatives included public service announcements (PSAs) to raise awareness of the African American experience with MS and ultimately the development of an African American MS patient registry to expand peer-to-peer networking and support beyond the initial forums.

"Patients need someone they can talk to and get guidance on how to navigate their lives with this disease." - MS Care Patient Attendee

HCPs

The education of patients, providers, and care partners was the primary initiative recommended by HCP attendees, ideally in multiple formats but prioritizing informational packets/fact sheets for patients upon diagnosis and throughout the course of disease as applicable. Among the recommended subject matter of these informational pieces for patients was a comprehensive review of treatment options and lifestyle modification factors, the importance of participation in clinical trials, and advice on navigating the health insurance landscape. Provider education was recommended to be delivered via a best practices monograph and publications outlining the manner in which MS directly affects African American patients, including appropriate means by which providers can address minority-specific challenges, and the importance of further clinical research focused on the demographic. HCP-recommended follow-on initiatives included closer attention and education specific to touchpoints in the MS care team, such as nurse practitioners and physical therapists, as well as an MS mentorship program and telemedicine-related education and promotion.

Care Partners

Care partners prioritized guidelines and standards pertinent to their specific role in the form of mandated protocols for home needs and transportation needs. Complimentary initiatives recommended by this group included educational support on topics such as techniques for lifting/moving a patient, patient exercise needs, and means of coping with the physical and emotional stress of the role. Retreats for care partners were recommended as a follow-on initiative for future consideration.



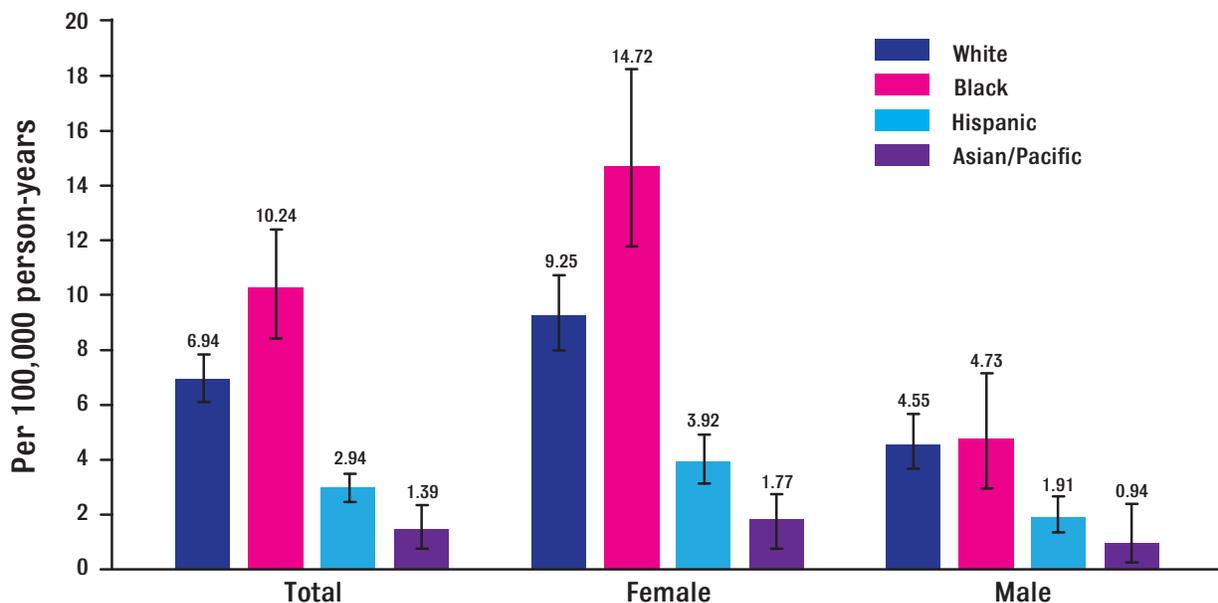
Findings from The African American Experience & MS advisory board meeting demonstrated that patients, HCPs, and care partners acknowledge the racial/ethnic disparities specific to the African American MS community that have been well documented in published literature. However, the insights of attendees also identified another dimension of these disparities in moving from journal articles to human experience. This element of experience from individuals immersed in the African American MS community also allowed for a renewed look at developing programmatic solutions for addressing racial/ethnic disparities specific to MS.

Efforts to resolve minority health disparities are not a novel concept in the United States. HHS began their crusade against racial/ethnic disparities in 1985, and the Healthy People initiative has had this public health scourge on its radar for the past 3 decades. Still, the disparities remain, even for high-profile conditions such as heart disease and cancer. Presumably, the African American MS community is particularly vulnerable to the impact of health disparities, with certain minority-specific disease characteristics being identified less than a decade ago.

On the basis of the findings of this advisory board meeting, future efforts centered on education, advocacy, and community support must be deployed to begin to resolve racial/ethnic disparities in MS. This endeavor must be comprehensive and built upon the initial recommendations made herein, with stakeholder-specific interventions in multiple formats to address the learning gaps and meet the educational needs of the patient and provider groups.

Moving forward, steps should be taken to further investigate the specific means by which to implement the priority and complimentary initiatives recommended by the advisory board. Educational interventions (webcasts, case-based learning, etc.); formal best practice recommendations; and resources for patients, providers, and care partners alike serve as the foundation of this panoramic approach. Building upon the progress of this advisory board, regional roundtable meetings will be deployed to stimulate further interaction and advocacy on local levels nationwide. At the same time, ongoing input from the attendees of this advisory board will be enlisted to guide these initiatives and ensure that they remain optimally focused on the needs of real-world patients and practitioners.

Figure 1. Variable incidence of MS according to ethnicity and gender.¹²



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