ALL ROADS LEAD TO CHANGE

Addressing Unmet Needs in the African American **MS** Community

Best Practices in Improving Care Quality and Mitigating Health Disparities from the Multiple Sclerosis Association of America Working Group

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Introduction

If asked to describe a typical patient living with multiple sclerosis (MS), a health care provider (HCP) might often describe a White woman in her 30s. While this prevailing stereotype may be somewhat accurate in the global MS community, the reality is that MS disproportionately affects certain racial and ethnic communities. African Americans—both male and female—have a higher incidence of MS compared with their Caucasian American counterparts. Furthermore, recent data show that the presentation of the disease in the African American community, including accelerated progression and greater mortality, underscores a challenging journey for those diagnosed with MS. African Americans living with MS also face systemic social issues that pervade general society but are uniquely challenging in a health care setting. This best practice monograph outlines the details of these issues and reports the recommendations of a specialized and solutions-focused working group, facilitated by the Multiple Sclerosis Association of America (MSAA).

As a chronic inflammatory disease with a typical onset during early- to mid-adult life, multiple sclerosis (MS) imposes a significant toll on the US health care system, affecting an estimated 1 million Americans and over 2 million people worldwide.[1,2,3] Extensive morbidity, progressive disability, and requisite ongoing treatment comprise an intricate set of needs among people who are often diagnosed within the age range characterized by active employment and family-related responsibilities, necessitating a specialized approach to care.[4] Unique characteristics with respect to disease incidence exacerbate the complexity of MS management, with women affected approximately 3 times more often than men and emerging data demonstrating a disproportionate impact in racial/ethnic communities.[4] Although the disease has historically been recognized as one that primarily affects individuals of Northern European descent, recent literature demonstrates higher incidence rates of MS in both African American males and females compared with their Caucasian American counterparts, and Black females in the United States have a 47% higher risk for MS than White females.[5] Furthermore, African American patients can be at risk for a more aggressive disease course, with an increased likelihood of transverse myelitis, more frequent relapses, worsening post-relapse recoveries, faster transitioning from relapsing-remitting MS to secondary-progressive MS, and more severe ambulatory impairment compared with Caucasian American patients.[6,7,8] Research also shows faster atrophy of the thalamus, a phenomenon linked to cognitive impairment.[6] Furthermore, African Americans with MS are at greater risk of dying at an earlier age and demonstrate substantially increased mortality trends versus those of Caucasian Americans.[9]

Introduction

Comorbidities can contribute to these worsening outcomes in African Americans with MS but also point to an underlying origin with respect to care access and health equity. In one analysis of a large MS registry, the risk of comorbidity in African American patients with MS was reported to be higher than that in non-Black patients.[10] This underscores presumably poorer overall health in the Black community and a proliferation of barriers to adequate care, including a longer delay between MS symptom onset and diagnosis, more severe disability at diagnosis even after accounting for diagnostic delays, greater disability progression, increased health care utilization, and higher mortality.[11,12,13,14] Aside from comorbidity-related considerations, African Americans with MS are far less likely than Caucasians to receive care in a neurologist's office or specialized MS clinic. As such, many of these patients may ultimately seek care in the primary care or hospital emergency department (ED) settings to resolve MS-related symptoms despite the fact that these sites of care are most often ill-equipped to appropriately treat the disease.[15]

The disproportionate disease burden of MS in the African American community is owed to a multitude of inherited and environmental factors but remains inadequately researched and characterized by the medical community. Resulting in part from an increased focus on social determinants of health (SDOH), research has shown that health outcomes overall are driven by a wide range of components, including genetics, behavior, social and environmental factors, and access to health care.[16] And although there is currently no consensus in the literature on the magnitude of the relative impact of each of these factors on overall wellness, studies suggest that the interrelated components of behavior and socioeconomic status (SES) are among the primary drivers of health outcomes.[16] The novel coronavirus disease (COVID-19) pandemic has further brought the bearing of SDOH into intense focus, with disproportionate disease burden and worsening outcomes in racial/ethnic demographics, most notably African Americans.[17,18] However, even prior to COVID-19, many Black patients with complex chronic diseases such as MS have historically demonstrated difficulty accessing appropriate health care—particularly specialist care—due to barriers associated with SES, education, and health literacy.[19] Beyond these widely accepted contributing factors, unique challenges within the African American population resulting from self-identified ethnicity, heterogeneity in genetic ancestry, and scant research devoted exclusively to the efficacy of disease modifying therapies (DMTs) within this subset of patients demand immediate attention. To meet these challenges and truly drive improved outcomes, it is necessary to develop a comprehensive and prescriptive effort that extends beyond purely clinical considerations and integrates initiatives to address the implications of SDOH, cultural factors, and disparities in the coverage and provision of care for MS in African Americans.

Introduction

Overview of the *All Roads Lead to Change* Working Group

In the initial phase of MSAA's African American MS initiative, an advisory board of patients, care partners, and HCPs met in November 2019 in Atlanta, GA. This group felt it was imperative to sustain the momentum of the initial discussion. As a result, the joint partners developed a proposal for a second phase of the program, which is now known as *All Roads Lead to Change*. This working group convened on October 10, 2020, enlisting the input of 12 clinicians specializing in MS care among African Americans. The one-day meeting was originally scheduled to be conducted in person, but due to the impact of the COVID-19 pandemic it was carried out using a virtual format. Sessions within the working group included brief presentations to inform participants and promote candid input, each followed by moderated discussions. The ultimate goal was to facilitate dialogue—allowing the faculty to share their views on the challenges that face African Americans living with MS and how their HCPs can be instrumental to addressing unmet needs in the community.

Unique Clinical and Situational Characteristics of MS in African Americans

Although its precise etiology has yet to be identified, MS is a heterogeneous disease presumed to result from complex interactions among genetic predisposition, gender, and environment.[20] Race represents another important factor, but due to its complexity and overlap with some of the aforementioned components, there is uncertainty around its role in MS.[21] Despite the fact that Caucasian females account for the majority of MS cases, many other racial/ethnic groups are substantively affected by MS, including African American men and women. Minority populations in the United States—notably African Americans and Hispanic Americans—have a higher incidence of MS compared with their ancestral countries of origin.[22] Over the course of the past decade, there has been a growing body of literature examining patterns of disease, magnetic resonance imaging (MRI) findings, and prognosis in African American versus Caucasian American demographics with MS. Multiple genes have been identified that are associated with an increased risk of MS, but its disparate presentation across racial/ethnic groups has yet to be fully characterized.[23] This is due, in part, to significant underrepresentation of non-Caucasian patients, including those of African descent, in clinical trials investigating potential etiologies of

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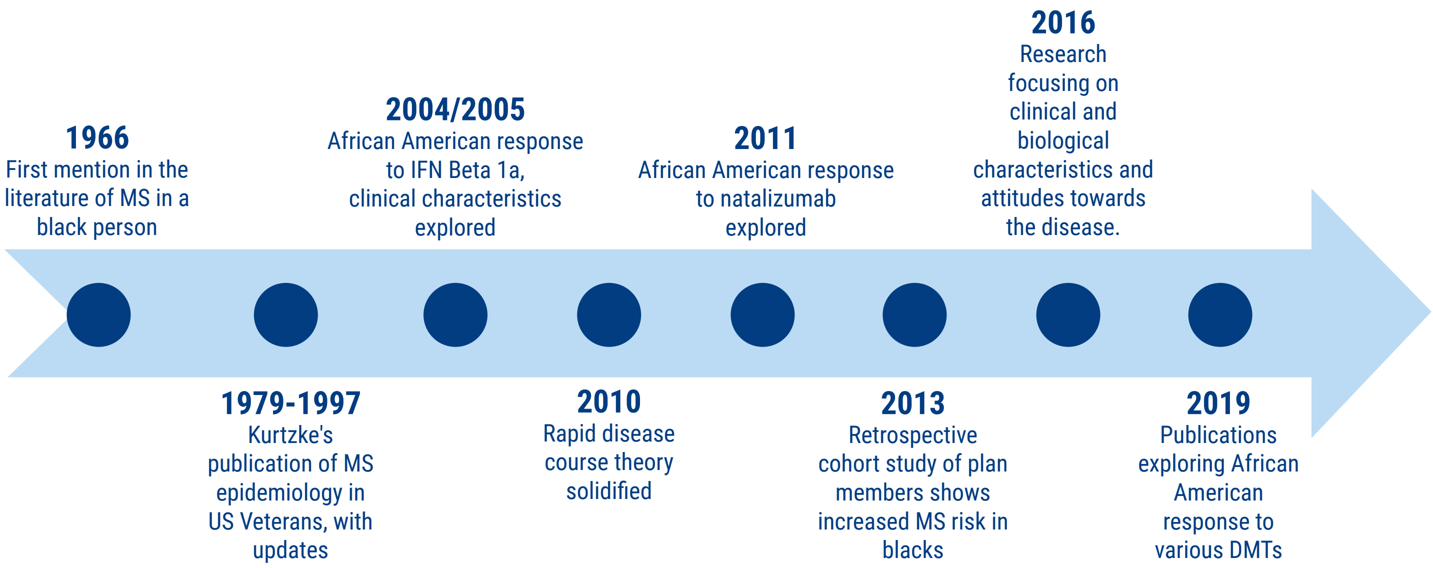
MS and treatment interventions for the disease. In fact, a review of studies published up until 2014 showed that <1% of the disease-specific literature focused on African American (or Black) patient populations with MS.[21]

While clinical trial enrollment remains largely limited, some knowledge has been gleaned from the available data regarding MS in African Americans as well as Black Africans. Still, despite MS being characterized in medical literature dating back to the 1800s, the first mention of MS in a Black individual did not occur until 1966, and the first well-described case of demyelinating disease in a Black African was not published until 1987 **(Figure 1)**.[24] The incidence trends reported in Black Africans with MS are somewhat consistent in the African American population, but the latter demographic's mixed genetic composition—derived from 20% to 30% European ancestry and 70% to 80% African ancestry—further confounds analysis.[25]

The most common form of demyelinating disease observed in Black Africans is neuromyelitis optica, which primarily involves the optic nerves and spinal cord and represents a distinct clinical phenomenon from MS.[24] Studies have shown that MS in African Americans features increased involvement of the optic nerves and spinal cord compared with Caucasian patients.

Figure 1. Brief history of MS studies pertaining to African Americans in the medical literature.



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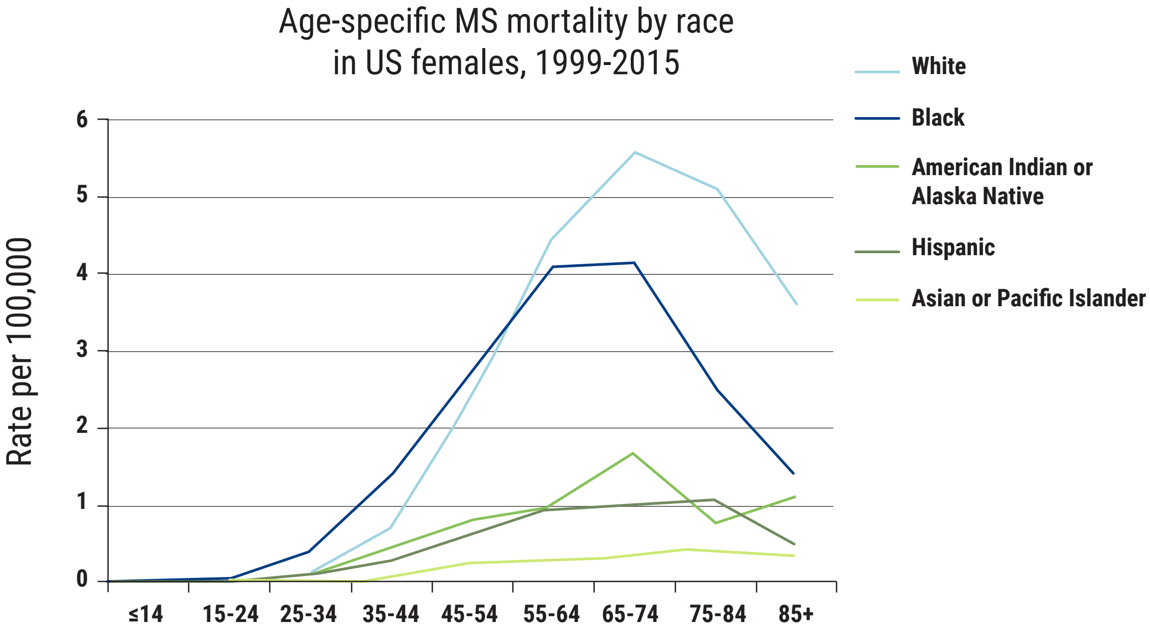
The course of MS is more severe in Black Africans, with case reports suggesting poorer recovery following exacerbations.[24] Disease progression is significantly faster in African American MS patients in both brain and retinal measures, and MRI scans show whole brain, gray, and white matter atrophy to progress twice as quickly in African Americans compared to Caucasian Americans. African American patients also demonstrate faster atrophy of the thalamus, which may be causally linked to cognitive impairment.[26,27] Collectively, these findings underscore a more aggressive course of MS, with younger age of symptom onset, increased relapses, and shorter time to ambulatory disability.[6,7,8] Beyond prevalence and severity, this population is further affected by worsening trends in disease-related mortality. 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 **(Figure 2)**.[9]

Although progress has been made in the way of characterizing the disproportionate disease burden of MS in African Americans, little can be done to mitigate disparities without identifying their underlying cause. It remains to be fully elucidated whether these evident disparities are largely attributable to a biological difference or due to socioeconomic and cultural factors such as poor health literacy, limited access to health care, and limited awareness and racial biases within the medical community. Environmental factors play a distinct role in MS etiology, and specific socioeconomic components of the African American life experience may contribute to disease predisposition and outcomes.

Figure 2. Age-specific MS mortality by race in US females, 1999-2015.[9]



Introduction

Timely Diagnosis and Access to Appropriate Treatment

In MS—as well as in a diverse array of other chronic conditions—cumulative clinical outcomes, total costs, and patient experience are exceedingly dependent on the delivery of timely, appropriate care. Overall, delayed or deferred care and limited access to specialists can be detrimental to patients with MS, a disease which, if left undiagnosed and untreated, can result in severe and permanent disability among all patients but particularly African Americans.[28] Because much of the autoimmune response inherent to MS occurs in the early stages of the disease, early and aggressive treatment is considered indispensable for slowing lesion formation and reducing relapse rate.[29]

Disease modifying therapies (DMTs) mitigate MS-related neurological damage and disease progression, thus potentially limiting disability.[30,31,32] Initiation of DMTs soon after confirmation of diagnosis may improve the long-term course of MS and reduce permanent neurological damage.[33,34,35,36] Furthermore, recent research suggests the faster DMT is initiated following confirmation of the MS diagnosis, the more effective the treatment is likely to be.[37,38] Conversely, delays in the diagnosis of MS and initiation of DMT therapy allow for the accumulation of axonal damage, progression of brain atrophy, and the development of severe and potentially irreversible neurological disability.[33] However, despite this abundance of evidence supporting an early, proactive treatment approach and the availability of more than a dozen DMTs for MS, there is some evidence that specific DMTs may be relatively less effective in African American patients compared with Caucasian Americans; however, the low numbers in these subanalyses make generalization of findings difficult.[39] Exacerbating this challenge is a deficit in the characterization of DMT treatment effect heterogeneity across patients of varying ethnicity due to underrepresentation of minority groups in clinical trials. Mistrust in the health system and fear of unequal treatment are among a myriad of factors precipitating a lack of minority representation in clinical trials as well as delays in care and efficient transitioning to optimal therapy.

One critical factor driving timely diagnosis and the initiation of DMT-centered intervention is the integration and oversight of subspecialist care. Specifically, neurologist involvement in the care of patients with MS minimizes delays in diagnosis, fosters more rapid initiation of appropriate treatment, and reduces adverse events and acute care hospitalizations.[15] However, patients with MS who are Black, physically disabled, or uninsured, or those who have lower income or live in rural areas, are nearly 30% less likely to be evaluated at an MS center, clinic, or neurologist's office compared to their White counterparts, even after adjustment for demographic, insurance, and health status differences.[15] Even insured African American patients may not be able to access neurologists trained in the management of MS or with the specialized experience to treat aggressive forms of the disease and familiarity with the latest therapies. This represents a substantial clinical disadvantage for these patients, since seeing a neurologist is associated with a higher likelihood of undergoing diagnostic or treatment-related tests, receiving DMTs and symptom-related medication, and being informed about a treatment plan.[40] In the absence of neurologist-led care, African American patients with MS are more likely to be cared for in the ED, where DMTs are not often available.[15] Instead, access to these therapies is often limited to the offices of neurologists specializing in MS or dedicated MS clinics.[28] Even among Medicaid home and community-based services (HCBS) recipients, African Americans with MS 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.[41]

The notion of the right care, delivered at the right time, by the right providers centers on a crucial component of health care quality: access. Within health care, access is consistently defined by the opportunity or ease with which consumers or communities are able to use appropriate services or leverage the clinical acumen of providers in proportion to their needs.[42,43] Access to care is influenced by key stakeholders along the health care delivery continuum, from the provider to the consumer, as well as the payers and purchasers of health care and the system itself.[43] At the consumer level, socioeconomic and racial disparities exact a sizeable impact on access to care, as do similar patient-specific characteristics such as age, living conditions, and geographic location.[44] Collectively, these components comprise SDOH, the significance of which have been defined more clearly in recent years. Interrelated with these factors are the concepts of insurance coverage and the patients' ability to pay their respective cost-share of prescription medications according to their specific coverage arrangements. Furthermore, as evidenced by recent developments in the midst of the COVID-19 pandemic, access is also significantly influenced by external factors beyond the funding, coverage, and provision of care.

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Contemporary Drivers of Health Disparities and SDOH-Related Considerations

Although advances in medicine over the past several decades have reduced mortality due to chronic disease and contributed to a longer life expectancy for most Americans, minority populations, including African Americans, have not generally benefited equally from these improvements.[45] These divergent outcomes resulting from social, economic, and/or environmental disadvantages are known as health disparities. The existence of health disparities is entrenched in the US care delivery system and affects 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.[46] The real-world impact of this concept in modern medicine is that certain racial/ethnic demographics bear a disproportionate burden of disease, injury, premature death, and disability.[47] The phenomenon is readily apparent among African Americans with MS and is realized in increased morbidity, reduced life expectancy, and decreased quality of life (QOL).

In ongoing efforts by the US government's Healthy People 2020 initiative and international panels such as the World Health Organization (WHO), addressing health disparities and improving health equity has long remained a principal goal. As a means to this end, experts continuously cite SDOH as a key target for intervention. Stated simply, SDOH are "the conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and QOL outcomes and risks."[16] These conditions are essentially organized into five key areas:[16]

- Economic Stability
- Education
- Social and Community Context
- Health and Health Care
- Neighborhood and Built Environment

Although well established, the effect of this conceptual framework can be overlooked in the care experience, and the factors affecting access to care, outcomes, QOL, and resource utilization are not directly or even indirectly addressed. Specifically, certain less conspicuous factors that are subcategorized among these primary SDOH—including culturally related beliefs, health-seeking behaviors and trust in the health care system, and poor health literacy—can play a significant role in affecting outcomes but are among those most frequently neglected.[48]

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The COVID-19 pandemic has provided a population-level case study into the breadth and depth of health disparities as well as the role of SDOH. Among 369 patients who tested positive for COVID-19 at one major metropolitan US hospital, 59.1% were Black and Black patients were 5.4 times more likely than those of other races to test positive.[49] ZIP code and poverty accounted for much of this variance, but after adjusting for these factors, Black race was still associated with nearly twice the likelihood of COVID-19-related hospitalization.[49] These data sets provide a glimpse into the sizeable effect of SDOH on outcomes specific to infectious disease, with minority populations living in more densely populated areas—often in multigenerational households—as well as frequently holding positions as "essential workers" and shopping for food and supplies in more crowded retail environments. Demonstrating underlying poorer overall health in racial/ethnic minorities during the COVID-19 pandemic, a separate study reported coronavirus positivity rates of 65.3% in Hispanics, 68.5% in Blacks, and 53.0% in Whites.[50] However, perhaps the most telling element of this dataset was that 34.3% of Hispanic patients and 39.5% of Black patients had two or more underlying conditions versus 28.9% of White patients.[50] And while the effect of comorbidities on mortality in COVID-19 has been thoroughly described, patients with MS may be in further peril. Available data point to worsening outcomes in patients with MS who are Black, of advanced age, have progressive disease and/or higher levels of disability, and/or are untreated or receiving anti-CD20 therapies.[51] From a more positive perspective, the pandemic has catalyzed the uptake of novel means of caring for patients with MS. Telemedicine has proven beneficial in encouraging patients to interact with providers in a care encounter when they may not have had transportation or been adherent to follow-up prior to COVID-19. Furthermore, African American patients tend to be more open and forthcoming with personal information from the comfort of their own homes. Still, the safety and efficacy of the COVID-19 vaccine will remain a key issue in this population with a long history of mistrust in a system that has left them wary due to unethical practices.

Throughout the COVID-19 pandemic, the impact of health disparities and SDOH on racial/ethnic communities have been palpable, brought to light by a once-in-a-generation public health crisis. However, the interplay of these factors and poorer overall health as well as disproportionate disease burden has been apparent in African Americans and other minority populations in the United States for decades and require immediate attention. In addition to the patient-related factors affecting health outcomes, HCPs are challenged by a lack of race-specific disease-related information and poor cultural competency, which leads to ineffective provider-patient communication. At a systematic level, limited clinical trial enrollment among African Americans and access and coverage issues further intensify barriers to quality care. There exists a clear and present need for increased multidimensional awareness of health disparities among HCPs, health systems, payers, and medical researchers to improve overall care quality and clinical outcomes in African Americans with MS. With these goals in mind, the *All Roads Lead to Change* working group offered recommendations in a number of key areas aligned with a roadmap for HCPs to assist patients in navigating all phases of care.

Best Practices: Working Group Recommendations

Considering the often complex and arduous journey faced by African Americans with MS, the *All Roads Lead to Change* working group identified several key areas requiring substantial improvement in care practices. These areas varied in terms of focus (ie, from broad considerations to specialized scenarios) and scope (ie, from immediate needs at the patient-provider level to systemwide changes necessitating multifactorial approaches). For purposes of the *All Roads Lead to Change* program, which is intended primarily for health care providers, key recommendations will focus on this group. There were several important, complimentary recommendations intended for patients that were discussed with the working group. Where appropriate, those are noted in the subsequent table and highlight the importance of patient-facing educational programs.

Key issues and corresponding recommendations put forth by the working group include the following:

Issue	**Recommendation**
The importance of early diagnosis and consideration of aggressive treatment	Educate providers on the importance of early diagnosis and why it is important to consider aggressive therapeutic intervention early on in the treatment process. Educate providers on available data, even if limited, regarding the key differences among African Americans with respect to treatment responses to various DMTs.
Barriers to care, both apparent and implicit	Facilitate cultural sensitivity and communication training for providers.
The importance of patient self-advocacy to providers	Equip providers with the awareness and skills to support their patients as advocates of their own care. Educate patients on how to be effective self-advocates.
Facilitating meaningful representation in clinical trials	Enhance provider understanding with respect to the value of enrollment in research for their patients beyond altruistic considerations. Educate providers on how to communicate to their patients the fundamental concepts of clinical trials while highlighting potential risks and rewards of enrollment (ie, the potential personal value).
The importance of effective transitional adolescent MS care	Facilitate communication and care coordination among adolescent and adult providers involved in the transitional care process while supporting patients in navigating insurance coverage and other psychosocial issues (self-advocacy, independent living, college/career readiness, etc.)
The impact of MS on family and care partner needs	Equip providers to thoughtfully include family and care partner input and needs throughout the entire care process.
The role of brain health in cognition and overall wellness	Enhance provider awareness regarding the importance of lifestyle and behavioral health on clinical outcomes in MS. Educate patients on the role of brain health in cognition and overall wellness and support them in making meaningful lifestyle changes.

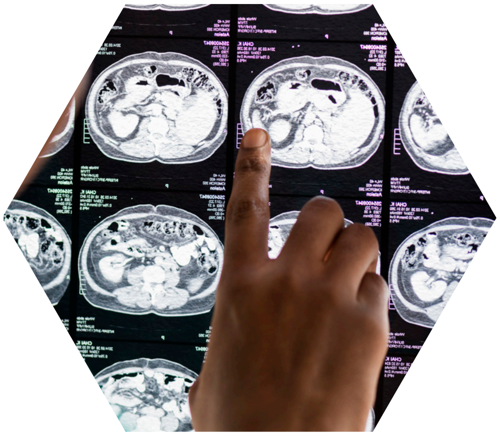
These individual areas represent vital touchpoints and opportunities for health care providers to meaningfully support and treat African Americans with MS. Each topic must be addressed, when applicable, to enhance patient experience, improve outcomes, and advance the quality of care for both the individual and the community as a whole.

Best Practices: Working Group Recommendations

Early Diagnosis and Consideration of Aggressive Treatment

Timely intervention remains a key driver in chronic disease outcomes; conversely, delayed or deferred care demonstrates deleterious effects that are highlighted by the natural course of specific chronic conditions. In MS, early treatment with DMTs is imperative for mitigating lesion formation, disease progression, and disability. Conversely, delays in diagnosis and treatment can be acutely detrimental. In African Americans with a particularly aggressive disease course, these delays can be devastating. Exacerbating these clinical challenges, the road to diagnosis can be a long and circuitous one for minority patients, who often seek care in hospital EDs rather than through a dedicated primary care physician, much less a neurologist or one specializing in MS. Taking these circumstances into consideration, the working group recommended widespread disease education among HCPs in alternative care settings to augment MS symptom recognition and enhance the guiding of patients to the appropriate specialists. Cultural factors may also come into play in the African American community, and the working group recommended broad, all-encompassing education to reach out to patients through church groups and other community organizations with which the patients may identify.

Further fundamental educational needs were also identified in the provider community pertaining to the clinical characteristics of MS in African Americans, where immediate diagnosis and treatment with DMTs is all the more vital to mitigate progression of lesion formation and disability. Limited data specific to the African American MS community contributes to this lack of knowledge among HCPs; all available information should be made readily available to support evidence-based medicine in this unique subset of patients. As more data become available specific to the key differences among African Americans with respect to treatment responses to various DMTs, this information should be immediately accessible for providers.



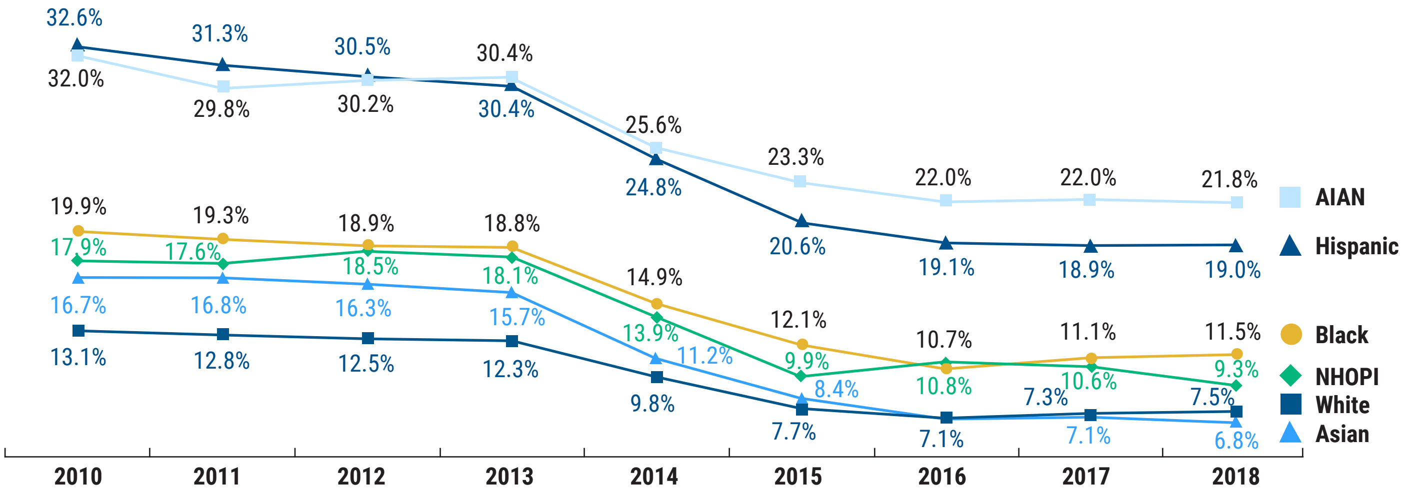
...delays in diagnosis and treatment can be acutely detrimental. In African Americans with a particularly aggressive disease course, these ***delays can be devastating.***

Apparent and Implicit Barriers to Care

The working group cited access to care and the associated annual costs of imaging and DMTs as being causative factors behind delays in seeking treatment among African Americans. Minority populations in the United States are often 2x to 3x less likely to have health insurance than Caucasian Americans **(Figure 3)**.[52] Even when coverage is in place, the requisite cost-share may be unbearable for certain socioeconomic demographics. Managing insurance issues, seeking available copay assistance and other forms of financial support, and resources available from national and local organizations all represent areas for increased intervention on behalf of African Americans with MS. When possible, patients should be directed toward these resources and furnished with the necessary support to capably navigate insurance coverage and facilitate access to care.

In addition to these apparent barriers with regard to care access, African American patients with MS face a number of implicit barriers that are less well characterized and poorly understood among HCPs. The working group noted that cultural nuances and religious beliefs can play a crucial role in care-seeking behaviors in the African American community, necessitating increased awareness and a specialized approach to the care interaction. Clinical and treatment-related challenges extend all the way to the basest of patient-provider interactions, with the existence of potential racial bias among some HCPs. The working group recommended addressing provider bias through educational interventions such as cultural sensitivity training and similar initiatives to guide HCPs in their dialogue with African American MS patients. By being cognizant of the cultural and religious factors at play with respect to medical care, in addition to the more obvious SDOH and insurance-related factors, HCPs can take a comprehensive approach to the provision of equitable care.

Figure 3. Uninsured rates for the non-elderly US population by race and ethnicity, 2010-2018).[52]



Patient Self-Advocacy

Effective communication between the patient and provider is critical to facilitate the delivery of timely, appropriate care. Patients must be equipped with information to guide their interactions with providers and be encouraged to advocate for their own care with knowledge and a catalog of resources. Research indicates that patients who self-advocate during medical encounters gain maximum benefit from professional care.[53] To instill this mindset, patients must be better educated and engaged on a personal and culturally sensitive level. As noted by the working group, this is a key concern with respect to African American patients with MS. In a sample of 7,419 women aged 45 to 64 years who had at least 1 physician visit in the previous year, those who obtained health information were almost 5 times more likely to mention that information to their physician than women who did not obtain information.[53] Black women were approximately half as likely to mention health information to their physician as White women. Even among women who obtained health information, Black women were also less likely to mention health information to their physician. These findings point to the existence of underlying barriers to self-advocacy in the African American community that are pervasive even among patients educated about their disease. These barriers may be the result of apprehension regarding racial bias, cultural influences, or religious beliefs. Regardless of their origins, the factors impeding patient self-advocacy among African Americans with MS must be addressed at the provider level via the dissemination of disease education and culturally sensitive communication. The working group noted that awareness must be raised among HCPs with respect to barriers to self-advocacy in the African American community, and HCPs must be equipped with skills to support their patients as advocates of their own care. En route to achieving these goals, patients must likewise be educated on the means by which they can be effective self-advocates.

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Best Practices: Working Group Recommendations

Meaningful Representation in Clinical Trials

Without knowledge of disease characteristics and treatment efficacy, making informed treatment decisions is exceedingly difficult. A wealth of evidence is indispensable to the provision of evidence-based medicine. For these reasons, the exceedingly limited enrollment of African Americans in MS clinical trials and a paucity of race-specific research in MS is particularly detrimental to the achievability of care quality. 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 in MS trials is disproportionately low compared with Caucasian Americans.[54] Socioeconomic and geographic influences contribute to this underrepresentation in clinical trials and exacerbate suboptimal disease characterization and health disparities among African Americans with MS, but cultural influences specifically were called out by the working group as representing an imperative need to be addressed. Religious beliefs and a distinct mistrust in the system comprise two of the most pressing cultural influences among African Americans with respect to clinical trial enrollment. Stemming from the controversy and wanton disregard for moral considerations borne by many unethical experiments, including the Tuskegee Syphilis Study, the working group noted that African American mistrust in clinical trials must be addressed directly, with shared testimony from members of the community that have participated in research and invitations to participate in research from a credible and ethnically diverse staff.

Beyond addressing specific barriers to participation, African American patients with MS require education on the overarching concepts of research (e.g., how clinical trials work, an explanation of placebo-controlled studies, etc.) and how the results of previous research have positively affected care quality in the community. There is an apparent gap in understanding with respect to the fact that it takes enrollment and participation to make clinical trials successful and informative for a particular community. In addition to this latter altruistic component of enrollment in clinical trials, patients should be informed on the individual benefits of enrollment, with an understanding that they may not receive the study drug after randomization. Providers are uniquely positioned to disseminate this information to their patients; therefore they should be well educated on available clinical trials and selection criteria for enrollment. In an effort to drive the future design of larger prospective clinical trials specific to African Americans with MS, HCPs should remain cognizant of pertinent paraclinical measures (eg, IgG index, median IgG synthesis rate, and magnetization transfer ratio [MTR] results, etc.) among African American patients and take an active role in advocacy.[55,56] Although progress is being made in the area of clinical trial enrollment—with initiatives such as the MS Minority Research Engagement Partnership Network, National African Americans with Multiple Sclerosis Registry, MS-UP, Advancing Inclusive Research External Council, and recent African American-centered clinical trials such as CHIMES—HCPs must be aware of the availability and results of current efforts in order to make informed treatment decisions and impart crucial knowledge to their patients.

Effective Transitional Adolescent MS Care

Although MS is typically diagnosed in adulthood, African American patients who are affected by the disease in adolescence face a number of distinct challenges with respect to care transition. Particularly, in young adulthood, patients are at risk for lapses in insurance coverage and access to specific elements of medical care, as well as a loss of independence or functioning. In these scenarios, African American patients with MS are more likely to seek care in the ED setting and may lack access to specialized care. To optimize care at all points of a patient's life, the working group noted that times of transition are of utmost importance, as it is during these times that patients are likely to get "lost in the system."

Care transition from adolescence to adulthood in MS requires careful coordination between the pediatric MS specialist, when available, and the receiving neurologist. Open communication between HCPs should be emphasized, with medical record sharing in an ideally seamless process. At this unique point in a patient's life, age-appropriate education and peer and community support should be administered to address the physical, emotional, and vocational challenges facing patients with MS in young adulthood.

Family and Care Partner Needs

As a chronic disease frequently diagnosed in early adulthood and featuring progressive disability, the importance of family and care partners cannot be overlooked. The working group cited the integral role these individuals play for African Americans with MS in attending medical care appointments and their involvement in making treatment-related decisions. Educational efforts and campaigns to increase awareness must be directed at family and care partners of patients with MS in addition to the patients themselves.

Family and care partners of patients with MS typically share the same struggles with respect to medical costs, childcare, employment, and decision-making, placing them at risk for undue stress and emotional burden. In response to these challenges, the working group recommended additional support services and informational materials to assist these vital individuals in their daily responsibilities of caring for MS-affected persons in their lives. In addition to clinical disease and treatment-related information, emotional support and coping mechanisms should be at the center of these efforts.

Best Practices: Working Group Recommendations

Brain Health in Cognition and Overall Wellness

MS features a unique interplay of physical, cognitive, and emotional components stemming from the role of the brain and nervous system in disease etiology. As a result, optimal management relies on a myriad of behavioral and lifestyle-related factors in addition to treatment with DMTs. Diet, exercise, and cognitive activity can all effect brain health and disease outcomes, but operationalizing these lifestyle changes is often difficult, even for individuals without MS. Considering the requisite ongoing medical care, emotional stress, and potential disability associated with the disease, implementing these changes becomes all the more challenging. To improve care quality and disease outcomes, HCPs must provide African American patients with MS with appropriate disease-related education and support tools with respect to lifestyle choices whenever possible. Suggested educational tactics for patients included puzzles, games, and experiential education programs such as music therapy tutorials. Topics to cover through these tactics included the following:

- the importance of healthy living overall
- the importance of cognitive therapy
- tips on diet, exercise, and brain exercises

Behavioral health comorbidities such as anxiety and depression, which are prevalent in patients with MS, must likewise be addressed. HCPs should be cognizant of coping mechanisms to share with their patients and provide guidance to support services and referrals to behavioral health specialists when necessary. In African American patients with MS, the working group noted a cultural inclination toward spiritual and faith-based beliefs, which can be leveraged in a supportive role to address some of the aforementioned emotional and cognitive needs.

Working Group Conclusions

In light of current disparities in disease severity/outcomes and care provision among African Americans with MS, a number of key areas have been identified by the *All Roads Lead to Change* working group to optimize education and outreach in this distinctive and underserved community. The aforementioned key areas for intervention on the part of HCPs represent landmarks in a patient's care journey, and addressing specific clinical, socioeconomic, and cultural needs at each point will help to ensure that African Americans with MS receive the care and support necessary to resolve disparities and optimize outcomes.

Beginning with a more comprehensive understanding of the unique challenges facing African American patients with MS, HCPs can assist in addressing delayed diagnosis and treatment with interventions to guide patients to the appropriate sites of care. Access issues and implicit barriers to care can be resolved with support and education for patients in need of both assistance navigating the health insurance landscape as well as the intricate knowledge of SDOH and community influences and their role in improving outcomes. Similarly, cultural sensitivity and HCP-disseminated patient education will be instrumental in fostering self-advocacy among patients as a means to improved outcomes. At the same time, an increased level of patient education pertaining to the value of clinical trial enrollment in this underrepresented population can help to grow the evidence base for accurate disease characterization and effective treatment. Coordination in adolescent transitional settings will ensure that patients receive a lifetime of quality care, with a specialized focus on physical, cognitive, and emotional needs. Finally, increased education and support for care partners and families, who face the same journey as their MS-affected loved ones, augments the entire process by ensuring that patients receive optimal care even when they are physically outside of the health care system. As part of the overall effort, community outreach and educational initiatives with HCPs may be instrumental in increasing awareness regarding access to clinical care and trial enrollment.

Although institutional and systemwide changes are needed to address health disparities and disproportionate disease burden in racial/ethnic communities at a national level, HCPs represent a direct conduit between the patient and the medical community. Armed with increased knowledge and a willingness to take an active role in advocating for their patients, these professionals are capable of evoking an immediate impact in improving the quality of care among African Americans with MS.

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