



# Podcast on Identifying and Understanding Barriers to Care in Underserved Populations With MS in the United States

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## ABSTRACT

Multiple sclerosis (MS) can affect people from all racial and ethnic backgrounds, but, historically, the incidence of MS in the United States was thought to be highest in White individuals. More recent data suggest that the incidence of MS in Black or African American individuals is comparable to that in White individuals. In Hispanic or Latino individuals, incidence of MS is lower, but age of onset may be earlier compared with White individuals. Additionally, there are important differences in MS disease severity, disease progression, and mortality in Black or African American and Hispanic or Latino populations. Compared with their White counterparts, individuals from these underrepresented groups are more likely to be affected by MS in specific areas of the nervous system, such as accelerated loss of retinal and brain tissue in

Black or African American individuals and optic neuritis in Hispanic individuals. Additionally, Black or African American individuals with MS tend to have an aggressive disease course, earlier disability, and higher risk of requiring ambulatory assistance. Although these differences may be attributed to genetic factors, systemic racism and biases and barriers to accessing care may perpetuate health disparities. Moreover, non-White communities remain broadly underrepresented in clinical trials; however, it is vital that these populations are appropriately represented so that any potential differences in drug efficacy or safety implications are detected. Thus, it is important to increase awareness of MS in these populations. In this podcast, the authors discuss characteristics of MS in Black or African American and Hispanic or Latino populations, identify barriers to care, and propose solutions to improve access to MS care in these populations.

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### Key Summary Points

Multiple sclerosis (MS) affects people from all racial and ethnic backgrounds, but there are important differences in the incidence, prevalence, and clinical characteristics of MS in Black or African American and Hispanic or Latino populations in the United States compared with their White counterparts.

Black or African American and Hispanic or Latino individuals with MS may have a more aggressive disease course, earlier disability, and higher risk of requiring ambulatory assistance.

Non-White communities have been traditionally underrepresented in clinical trials, with potential deterrents including cultural and social factors, such as a distrust of clinical research and misuse of personal information.

Researchers and healthcare professionals can begin to address these barriers through effective communication of patient safeguards and participation benefits, as well as building relationships with individuals and community organizations.

There are several registries, initiatives, and patient advocacy groups available; however, more work needs to be done to improve access to care and address systemic barriers to ensure that all patients, regardless of race or ethnicity, receive optimal treatment and care for MS.

## DIGITAL FEATURES

This article is published with digital features, including a podcast, to facilitate understanding of the article. To view digital features for this article, go to <https://doi.org/10.6084/m9.figshare.24316282>.

## INTRODUCTION

**Sandra Parawira:** Hello, and welcome to our podcast on identifying and understanding barriers to care in underserved populations with multiple sclerosis in the United States (US). My name is Dr. Sandra Parawira, and I'm an Advanced Practice Provider at the Waddell Center for Multiple Sclerosis at the University of Cincinnati. On this podcast, I'll be joined by my wonderful colleague, Victoria Reese.

**Victoria Reese:** Hi Sandra! It's my pleasure to be here with you today. My name is Victoria Reese, and I am a Patient Advocate and the President and Co-Founder of the patient advocacy organization We Are ILL.

**Sandra Parawira:** Thanks Victoria! The aim of this podcast is to increase healthcare practitioner (HCP) awareness of multiple sclerosis, or MS, among Black and Hispanic populations in the US. We'll first provide some background about MS in these patient populations. Then we'll discuss the barriers to care faced by these populations and, lastly, propose solutions and improvements that are currently in progress to address them.

## MS AMONG BLACK OR AFRICAN AMERICAN AND HISPANIC OR LATINO POPULATIONS

**Victoria Reese:** To begin, Sandra, can you provide some information about the global prevalence of MS, and whether any specific populations are affected more than others?

**Sandra Parawira:** That's a great place to start! According to a survey conducted by the Atlas of MS, the prevalence of MS increased in every world region between 2013 and 2020, up to an estimated 2.8 million people worldwide [1]. The highest prevalence rate was observed for Europe, where, for every 100,000 people, approximately 143 were affected by MS. This was closely followed by the Americas, where the prevalence rate per 100,000 was 118. On the other end of the spectrum, the lowest rates were observed in the Western Pacific, Southeast Asia, and Africa regions, which were 4.8, 8.6, and 8.8,

respectively. Additionally, it was reported that the mean age at diagnosis in 2020 was approximately 32 years, and, globally, females were twice as likely to have MS compared with males.

**Victoria Reese:** Thank you, Sandra. So, we know that the prevalence of MS varies geographically, and is more likely to affect females. Additionally, historically, the incidence of MS in the US was thought to be higher in White individuals than in Black individuals [2]. However, what is our current understanding of the incidence and prevalence of MS in Black and Hispanic individuals as compared to White individuals?

**Sandra Parawira:** Actually, a recent regional study published in 2020 found that the reported incidence and prevalence of MS may be higher in the Black or African American population compared with White Americans [3]. The long-held belief that MS is a disease that predominantly affects young White females may have resulted from under-recognition of MS in Black or African American communities, as well as underrepresentation in clinical trials [4, 5]. In fact, individual study findings suggest that the higher incidence rate in Black individuals [3] appears to be driven by higher rates in Black women [3, 4]. However, in Hispanic or Latino individuals, the incidence rate is thought to be lower compared with White Americans [3, 4].

**Victoria Reese:** Interesting! Do MS disease severity and mortality also differ for Black and Hispanic individuals compared with White individuals?

**Sandra Parawira:** Yes, it is thought that Black [2] and Hispanic individuals may have worse baseline disability than White individuals [6], and may also experience faster disability progression and greater disease severity [2, 7]. In fact, this is the case even after adjusting for disease-modifying therapies, disease duration, and other factors [8]. Moreover, mortality risk is higher at a younger age in Black individuals compared with White individuals [9]. And Black and Hispanic individuals also have worse overall survival without ambulatory disability 5 years after diagnosis [6].

**Victoria Reese:** Wow, I can see why it's important to raise awareness of MS symptoms in these patient populations, so as to enable

recognition and early diagnosis. Are there common MS symptoms that healthcare providers should be aware of in Black and Hispanic populations?

**Sandra Parawira:** The symptoms of MS are generally similar between populations, but some symptoms may be more pronounced in Black and Hispanic individuals. For example, compared with their White counterparts, Black individuals more frequently present at disease onset with multisite signs and symptoms of MS [2, 5]. This is defined as presenting with simultaneous sites of demyelination events, for example, both cerebellar and optic nerve symptoms, such as cerebellar ataxia and optic neuritis [2]. There is also evidence to suggest that Black individuals are more likely to be affected by MS in specific areas of the nervous system [2, 10–13]. For example, compared with White individuals, Black individuals with MS may have a higher incidence of cerebellar dysfunction [10]. Additionally, Black individuals with MS are more likely to develop transverse myelitis and opticospinal MS [2] and experience accelerated loss of retinal and brain tissue compared with White Americans [11].

**Victoria Reese:** I believe that individuals of Hispanic descent are also more likely to be affected by MS in specific areas of the nervous system [13, 14]. Could you please tell me a bit more about the clinical presentation and symptoms of MS in Hispanic patients?

**Sandra Parawira:** Hispanic individuals with MS are more likely to present with optic neuritis compared with White individuals in the western US [13], and sensory symptoms have been reported as the most common presentation of MS in Hispanic individuals of Caribbean origin [14]. Lastly, many comorbidities, such as diabetes, depression, and anxiety, may also be more common in Black and Hispanic individuals with MS [15].

**Victoria Reese:** Genetic factors are thought to have a vital role in determining MS susceptibility and may have an effect on clinical outcomes [16]. Could you discuss how genetic factors impact the risk of developing MS and disease severity in the Black and Hispanic populations?

**Sandra Parawira:** The human leukocyte antigen, or HLA, region on chromosome 6 is recognized as the most important MS susceptibility locus [16]. Allelic differences within the HLA locus between individuals of African origin and White individuals correlate with more severe MS disability in individuals with African ancestry [16]. The more severe MS observed compared with White individuals may be a result of genetic variation of a major MS susceptibility gene within the HLA region, called *DRB1*, in individuals with African ancestry [16]. In Hispanic individuals, a genetic link to Native American ancestry has been associated with optic neuritis and earlier age of MS onset [13]. Genome-wide association studies have identified more than 200 MS candidate genes of interest outside of *HLA* in White individuals, but there is minimal information available regarding candidate genes in other populations [13].

**Victoria Reese:** It sounds like it would be more important to encourage future research in this area to address the data gap and further our understanding of the role genetics plays in minority groups with MS. Now, let's discuss treatment response and treatment burden in patients with MS. Are there any known differences between Black and Hispanic individuals compared with White individuals?

**Sandra Parawira:** Actually, yes. Rates of first-line treatment discontinuation due to poor treatment tolerance or adverse events are higher in Black and Hispanic individuals compared with White individuals, with rates of 53%, 43%, and 37%, respectively [6]. Black individuals may experience worse responses to disease-modifying therapies compared with White individuals [17]. For example, following treatment with interferon, glatiramer acetate, or natalizumab, Black individuals have worse disability progression than White individuals, despite shorter disease duration [17]. And, in one clinical trial of interferon beta-1a, Black patients did not respond to treatment as robustly as White patients [18]. Furthermore, it has been recently reported that, compared with their White counterparts, Black individuals with neuroinflammatory disorders have different responses to anti-CD20 infusion therapies [19]. Some

disease-modifying therapies appear to have similar efficacy and/or safety in Black individuals, but, unfortunately, data are severely limited. One potential cause for this is the underrepresentation of Black patients in clinical trials, which we'll discuss shortly.

## DESCRIBE THE BARRIERS TO CARE FACED BY THESE PATIENT POPULATIONS

**Sandra Parawira:** Victoria, could you please provide some information about the barriers to care faced by these patient populations?

**Victoria Reese:** I certainly can! Access to care, including specialized care, insurance restrictions, and systemic racisms and biases, could actually perpetuate health disparities. For example, high-risk individuals with MS from underserved, socioeconomically challenged populations are often not on high-efficacy therapy [20]. And, in low-income minorities with MS, a lack of understanding due to inadequate provision of education around immunomodulatory drugs was found to be associated with deficiencies in MS care [21]. Furthermore, due to inadequate service reimbursement for underinsured or uninsured individuals, Black individuals with MS admitted to nursing facilities often have limited rehabilitation, despite their poorer cognitive and physical performances [5]. Finally, it has been reported that undocumented status may also be a barrier to care in some immigrant populations [22].

**Sandra Parawira:** Those are really critical points. Now, we had briefly mentioned that Black and Hispanic individuals are not appropriately represented in MS research and clinical trials—what are some of the barriers to representation?

**Victoria Reese:** One issue is the lack of information and understanding about these patient populations. Most population health data on MS are based on commercial health insurance [20]. However, socioeconomically disadvantaged individuals are not necessarily covered by commercial health insurance and may therefore be underrepresented. For example, African American individuals represent

12% of the US population but only 5% of clinical trial participants [23]. Additionally, the reporting of race and ethnicity in MS clinical trials is lacking. Patient- and healthcare professional-facing disease-modifying therapy websites often do not report these data in pivotal trials. However, when available, the data highlight the significant underrepresentation of non-White communities [24].

**Sandra Parawira:** That is a real problem! Why is representation so important, and what are potential reasons for this underrepresentation?

**Victoria Reese:** Underrepresentation in clinical trials is problematic because differences in MS characteristics and genetics in Black or African American and Hispanic or Latino individuals could affect how drugs work. Therefore, any reduced drug efficacy or safety implications in these populations could go undetected. Moreover, opportunities to develop drugs to target the genetic factors more prevalent in Black individuals may be missed. This is of increased importance, considering that minority groups often have a disproportionate burden of disease, including neurological disorders, as previously discussed [25].

**Sandra Parawira:** Are there any cultural and social factors of Black and Hispanic individuals that may hinder participation in clinical trials?

**Victoria Reese:** Yes, there are a few. Minority groups may have distrust of clinical research, with concerns around being experimented on, being taken advantage of, or having personal information misused [26, 27]. Religious beliefs could conflict with participation in clinical trials, especially among Hispanic communities [28]. It has been reported that Hispanic individuals may also be concerned that participation could risk their job, health insurance coverage, or legal status [26]. Furthermore, African American individuals may be wary of clinical trials due to historical racism, discrimination, and a lack of research integrity [26].

**Sandra Parawira:** Thank you for sharing those very compelling insights!

## SOLUTIONS TO BARRIERS AND IMPROVEMENTS IN PROGRESS

**Victoria Reese:** Now that we have discussed the barriers faced by these populations, what are some potential solutions to improving both minority participation in clinical trials and treatment, and clinical outcomes of minority populations?

**Sandra Parawira:** To begin, researchers and healthcare professionals need to address the barriers that deter individuals from minority groups in participating in clinical trials. These can include clearly explaining safeguards to protect the rights and well-being of patients [26], highlighting how the research will benefit their communities [26], and, finally, building relationships with individuals and community organizations that can provide important perspectives on the needs and concerns of their community [26]. Furthermore, there may be opportunities for collaborations with religious organizations and clinical trial educators to increase the accrual of individuals from the Hispanic and other communities into clinical trials [28].

**Victoria Reese:** Those are some great points. Involving individuals from diverse groups in activities can engender greater engagement, trust, respect, and development of evidence, benefiting all groups [26].

**Sandra Parawira:** Precisely! Other opportunities include ensuring that studies focus on understanding the effects of disease-modifying therapies, including high-efficacy therapy, in underserved populations and equipping healthcare professionals with cultural and social awareness to assist in their communication with patients. Are you aware of any registries or initiatives that are currently available or being developed?

**Victoria Reese:** There are actually several available! To start, there is the MS Minority Health Hub, which collates articles, reports, patient information, research, and news in and

for minority communities [29]. There is also the National African Americans with MS Registry that was created to help address the unmet needs in the Black or African American population by identifying barriers and improving access to MS care, as well as improving patient and healthcare professional education [30]. And, in a bid to improve care for Hispanic individuals, the first Hispanic MS network in the US, the Alliance for Research in Hispanic Multiple Sclerosis, was formed in 2016 and aims to combine biospecimen repositories and clinical databases [14]. Their objective is to help facilitate better understanding among providers of how MS affects Hispanic or Latino individuals and the unique challenges or needs they may face. Its goal is to provide better and more targeted treatment and care to this patient population [14]. Finally, communication initiatives, such as films, can change Hispanic or Latino individuals' perceptions regarding their understanding and treatment of MS [31].

**Sandra Parawira:** Are there any initiatives or registries specifically aimed at increasing diversity and inclusion in clinical research?

**Victoria Reese:** Yep, there are! First, the Multi-Regional Clinical Trials Center provides toolkits and practical measures for this purpose [32]. And, in 2020, the US Food and Drug Administration released guidance on "Enhancing the Diversity of Clinical Trial Populations," which provides recommendations on increasing clinical trial participation of underrepresented populations [33]. Furthermore, despite the lack of MS studies in Hispanics, both the University of Southern California and the University of Miami have Hispanic MS registries that are actively recruiting Hispanic patients [14].

**Sandra Parawira:** Those sound like great initiatives! Are there also advocacy groups and communities designed to overcome barriers to care?

**Victoria Reese:** Yes! There are several advocacy groups and communities for minority patients with MS. For example, Multiple Sclerosis: You Are Not Alone, is an organization established to empower, educate, and encourage African Americans (and others) living with MS [34]. And the National MS Society runs a

Black MS Experience Summit, which is an opportunity for Black people with MS to connect with other Black individuals, learn from leading experts, and amplify the voice of the Black MS community [35]. The National MS Society also runs a Hispanic or Latino MS Experience Summit to connect and empower Hispanic and Latino individuals with MS [36]. Additionally, the MSAA, or MS Association of America, has MS educational materials specifically aimed at Hispanic or Latino individuals [37]. Last but not least, We Are ILL is a patient advocacy group that focuses on supporting, educating, and improving health equity for Black women and women of color living with MS [38].

## CONCLUSION

**Sandra Parawira:** It's great that there are so many resources available and that we can raise awareness about these organizations. Thank you so much for participating in today's podcast with me. I hope we have increased HCP awareness of the barriers to care faced by Black and Hispanic individuals with MS and familiarized them with potential solutions to overcoming these barriers.

**Victoria Reese:** Thank you for this interesting and incredibly important conversation.

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#### Declarations

**Conflict of Interest.** Sandra Parawira: None. Victoria Reese: None.

**Ethical Approval.** This article does not contain any studies with human participants or animals performed by any of the authors.

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