MULTI-REGIONAL CLINICAL TRIALS
THE MRCT CENTER of BRIGHAM AND WOMEN'S HOSPITAL and HARVARD

Case Study: Multiple Sclerosis Research Mythbusting Series

Summary

While multiple sclerosis (MS) affects all races and ethnicities, minority populations may bear an unequal burden from the disease. Blacks may not only have a higher risk of developing MS, but it may be more aggressive, with more severe effects and faster progression.[1,2,3,4,5,6,7,8,9] Latinos may have an earlier onset of disease and may be more prone to lesions located in the spinal cord and optic nerve.[10,11]

Genetic, environmental, and social factors may contribute to the development of MS and the treatment received for the disease. In fact, minorities in the U.S. have higher rates of MS compared to people living in their ancestral communities.[12] Additional disparities relating to access to health services, differing cultural beliefs, and distrust of the medical profession may also contribute to worse outcomes.

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[11] Rivas-Rodríguez E, Amezcua L. Ethnic Considerations and Multiple Sclerosis Disease Variability in the United States. Neurologic clinics. 2018 Feb;36(1):151.
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Minority populations are severely underrepresented in scientific research in general, and this is true of MS as well. According to FDA Drug Trials Snapshots[13] reports showing the demographic characteristics of clinical trials for four recently approved MS drugs, fewer than 6% of the combined participants for these trials belonged to a race other than White. Without the participation of minority populations in MS research studies, it is impossible to understand how the disease manifests and which treatments work best in all people with MS.

People affected by MS from underserved populations may be reluctant to participate in research due to misconceptions about what participation entails, the benefits of research to individuals and their communities, and the risks and demands of participation. To address these needs and concerns, two advocacy organizations that serve the MS community decided to join forces and develop an educational event series, focused on providing current, factual information about research participation and study opportunities that may be of interest to individuals with MS.

Program approach

Building upon the work of the established MS Minority Research Engagement Partnership Network (MS MREPN),[14] Accelerated Cure Project (ACP) and the Multiple Sclerosis Association of America (MSAA) joined together to create and conduct a “Research Mythbusting Series” of events planned and held across the span of one year. The “Research Mythbusting Series” was designed to educate and inform people with multiple sclerosis and their care partners on topics related to participation in research. Four in-person educational events and one broadly accessible webinar were held to address the misconceptions (i.e., “myths”) associated with participation in, regulations around, and goals of research.

MS Research Mythbusting:
Addressing Common Misconceptions about Research and Clinical Trials in Minority Groups

The desired outcome of the “Research Mythbusting Series” was that people living with MS and their care partners, particularly those from racial and ethnic minority populations, would be interested in and open to participation in research as a result of an improved understanding of the role research plays in improving the health and quality-of-life of people affected by MS, and the benefits that a diverse research participant base could provide to underserved communities.

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[13] U.S. Food and Drug Administration. Drug Trials Snapshots. 07/15/2020. Available at https://www.fda.gov/drugs/drug-approvals-and-databases/drug-trials-snapshots. [Accessed 17 July 2020].

[14] For more information, see https://www.acceleratedcure.org/ms-minority-research-network

The specific educational objectives included:

1. An understanding of what participation in research entails including addressing misconceptions;
2. The regulations in place to provide protection to research participants;
3. The role research plays in providing evidence for treatment and quality-of-life decisions;
4. The importance of participating in research so that the evidence generated is applicable to the diverse population of people affected by MS;
5. How to assess the benefits and risks of participation; and
6. How to learn about research opportunities that are available to individuals with MS.

The in-person educational events were held in population centers where there is significant racial and ethnic diversity (i.e., Atlanta, GA; Houston, TX; Chicago, IL; and Pasadena, CA). The webinar was scheduled to accommodate both the eastern and western parts of the U.S. and was also recorded for access by those unable to attend the live event.[15,16] Each event was facilitated by a Black or Latino MS specialist using a common set of slides developed by ACP with input from MSAA and the presenters. MSAA led the recruitment efforts and managed the meeting and webinar logistics. Financial support for the series was provided by Biogen and Genentech.

Most attendees were Black and Latinos living with MS and their care partners. The live events were very interactive, with participants encouraged to ask questions throughout the events. Comments made during and after the presentations supported earlier findings by the MS MREPN that people with MS belonging to minority groups support and recognize the value of clinical research to enable future breakthroughs but are not necessarily aware of the issues arising from the lack of diversity in research studies.

Learnings from ACP and MSAA's "Research Mythbusting Series" illustrate that patient advocacy organizations working in a disease area can help to make their communities aware of the need for all groups to participate in clinical research in order for the benefits of research to be distributed more fairly. Following their joint Mythbusting series, MSAA and ACP are each continuing to communicate with underrepresented groups about research awareness and participation in order to expand the reach and impact of their message.

Points to consider

- Interactive engagement strategies, such as educational events, can help organizations identify gaps in community knowledge about clinical research more broadly
- Engagement of communities from diverse backgrounds requires intentional selection of sites and population demographics
- Community engagement works best when organizations commit to sustaining relationships and partnership through outreach activities
- Patient advocacy organizations can be an important and critical partner in building and sustaining community engagement

[15] Available online at: https://www.youtube.com/watch?v=oWMcx1BLz7c
[16] Available online at: https://mymsaa.org/videos/ms-research-mythbusting/