

Addressing the Research Gap: Exploring Barriers and Facilitators of Minority Participation in Multiple Sclerosis Research

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Background

- In the U.S., racial minority groups continue to be underrepresented in medical research, and multiple sclerosis (MS) research is no exception to this.
- iConquerMS, based in Waltham, MA, is the research initiative of the Accelerated Cure Project for MS. It is a research network composed of people with MS, providers, and researchers, who contribute health data and other input to advance research into MS.

Activities

- Developed interview questions and conducted interviews of persons with MS, researchers and providers from underrepresented populations on their perspectives of MS
- Assisted with organization and implementation of a pilot project to gather information on possible barriers and facilitators of minority research participation in iConquerMS.

Methods

- I interviewed 11 individuals from racially diverse groups regarding their perspectives on MS research and research recruitment.
- The interviewees included:
 - 3 persons with MS from Black, Hispanic, and mixed-race backgrounds
 - 3 MS researchers from Black and Hispanic backgrounds
 - 5 MS healthcare providers (1 RN, 1 NP, 2 MDs, and 1 rehabilitation neuropsychologist) from Black and South Asian backgrounds

Learning Objectives

- Complete interviews with racial minority researchers, providers, and persons with MS and review findings.
- Evaluate possible methods for increased minority involvement in MS research.
- Aid in the development of recruitment materials for iConquerMS' minority research recruitment pilot project.

Findings

What studies do people with MS want?

- MS research does not always align with what people with MS - especially those from racial minority groups – want.
- At the root of this issue is a key question: “**who is this study helping?**”
- Many people with MS feel empowered by research, but research needs to turn its focus to the actual wants and needs of those living with MS.
- People with MS want more studies looking into:
 - Behavioral changes (such as exercise)
 - Complementary medicine
 - Demographic factors (such as SES and social conditions)
 - The needs of specific racial subgroups (genetic factors, trust, and medication side effects).

Starting the conversation

- Knowing how to engage can be a major barrier to research involvement for people of color.
 - There need to be more and better conversations about research in the doctor's office and beyond.
- When such conversations do not occur, individuals from understudied groups have much to lose – as one interviewee stated, “**would you want to take an FDA-approved drug that hasn't been tested on someone like you?**”
- Physicians can be the most effective communicators about research, especially to answer the questions and concerns of their patients.
 - Doctors from minority backgrounds can be particularly powerful advocates, with one person with MS stating, “**I'd trust a doctor who looks like me.**”
- Many providers have also reported success with research coordinators, who can answer questions after the provider has spoken to a prospective study participant.

Conducting respectful research

- The differences in experiences of white and non-white persons with MS tends to create “**a parallel universe,**” making it hard for people of color to feel included in MS research.
- Individuals from racial minorities expressed frustration with past research experiences, noting that some studies made them feel “**like a guinea pig,**” or that the studies seemed “**predatory.**”
- Research teams should be diverse and work to generate relationships with participants by being understanding, culturally competent, and open to feedback.
- Some of the healthcare professionals interviewed expressed a desire for more open discussions in research about race, cultural competence, and the impact on communities of color.

Research recruitment styles – what works and what doesn't

- Physical objects (postcards, pamphlets) tended to be viewed more positively than advertisements, which are more forgettable.
- Materials should be eye-catching, clear about the study design, and should include people of color in the visuals.
- Methods that include opportunities to ask providers or research coordinators about studies are more powerful than advertisements alone.
 - Some pointed to social media as another useful tool as it enables researchers and providers to achieve wide reach and interact directly with their patients.

Deliverables

1. Written summaries of persons with MS, provider, and researcher interviews regarding perspectives on the experiences of individuals from racial minorities in MS research and research recruitment.
2. Final report on interview findings to be shared with iConquerMS interviewees, affiliates, and stakeholders.

Public Health Implications

- Historical inequities have led to a strained relationship between people of color and the medical and academic establishment and MS researchers must work to establish that trust.
- Research should focus on the wants and needs of persons with MS – especially those from groups that have been historically underrepresented in research.
- As trusted sources, providers are the best voices to start the research conversation with their patients and should take the time to listen to and address questions or concerns.
- MS researchers should work to generate respectful study environments, based on diversity, cultural competence, and openness to questions and feedback.
- Researchers should enable for prospective participants to easily ask questions and address any concerns about their studies prior to enrolment.

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