STRENGTH IN DIVERSITY: HOW A MULTI-STAKEHOLDER PARTNERSHIP NETWORK IS ADDRESSING MINORITY UNDERREPRESENTATION IN MS RESEARCH

Hollie Schmidt, MS
Accelerated Cure Project for Multiple Sclerosis
ABOUT MULTIPLE SCLEROSIS

MS is a disease of the central nervous system that affects nearly 1 million Americans

It is the most common disabling neurological disease among young adults

Effects include visual impairment, motor weakness/paralysis, bowel and bladder dysfunction, cognitive impairment, depression and anxiety, and many others

There are 17 FDA-approved disease-modifying therapies with more in the pipeline

  • But no evidence to support personalized choice of therapy

MS is found worldwide, and is more common away from the equator
TWO MISCONCEPTIONS ABOUT MS

Misconception #1:
MS is a white matter disease
TWO MISCONCEPTIONS ABOUT MS

Misconception #1: MS is a white matter disease

Misconception #2: MS is a white person’s disease
MINORITIES ARE MISSING IN MS RESEARCH

Siponimod, approved for MS in 2019

Table 1. Demographics of Trials by Race

<table>
<thead>
<tr>
<th>Race</th>
<th>Number of Patients</th>
<th>Percentage of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>1563</td>
<td>95%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>10</td>
<td>Less than 1%</td>
</tr>
<tr>
<td>Asian</td>
<td>49</td>
<td>3%</td>
</tr>
<tr>
<td>Other*</td>
<td>29</td>
<td>2%</td>
</tr>
</tbody>
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From FDA’s Drug Trials Snapshots
WHY DOES IT MATTER?

We can’t apply results of studies to populations that weren’t represented

- No hope of personalized medicine for minorities with MS without greater inclusion and participation

We have an incomplete picture of MS if everyone isn’t included

- For instance, what causes MS may be different from group to group

Research priorities won’t reflect topics that matter to everyone

- Lack of inclusion and participation means lack of engagement; lack of engagement leads to lack of a voice in decision-making
With funding from a PCORI Engagement Award:

- Formed a multi-stakeholder network to combine knowledge and assets
- Researched the barriers and facilitators affecting minority engagement in MS research
- Conducted outreach activities aimed at promoting minority research recruitment and participation
THE MS MINORITY RESEARCH ENGAGEMENT PARTNERSHIP NETWORK – ORIGINAL MEMBERS

People with MS/Project Advisors
  • Shawn Feliciano
  • Anita Williams

MS Researchers/Clinicians
  • Lilyana Amezcua
  • Mitzi Williams
  • Daniela Pimentel Maldonado

MS Advocacy Organizations
  • Accelerated Cure Project – Hollie Schmidt
  • MS Association of America – Gina Murdoch
  • National MS Society – Deb Frankel and Coleen Friedman

Minority Health Associations
  • MANA – Amy Hinojosa
  • National Black Nurses Association – Erica Davis
  • National Hispanic Medical Association – Minerva Campos
  • National Minority Quality Forum – Laura Lee Hall

Pharma/Biotech
  • Biogen – Terrie Livingston
  • Genentech – Daniel Machemer and Damian Fiore

Strategy/Public Health and Science Communications
  • Feinstein Kean Healthcare – Monique LaRocque and Melissa Glim
UNDERSTANDING THE PROBLEM

Literature review – see bit.ly/MSMHH

**MS Minority Health Hub**

Research and Reports on Minority Participation in Clinical Trials and MS in Minority Communities:

The Partnership Network is collecting articles, reports, and news about MS in minority communities, minority participation in research and in the research sciences, ongoing projects, and patient information for minority audiences. We hope you find these resources useful. If you know of any additional resources that could be shared here, please email us at msminorityresearch@acceleratedcure.org.

In Journals

**Hispanic Americans and African Americans with multiple sclerosis have more severe disease course than Caucasian Americans**

**The Significant Impact of Education, Poverty, and Race on Internet-Based Research Participant Engagement**
Sarah M. Hartz, M.D., Ph.D., Tiffany Quan, Ablye Ibiebele, Sherri L. Fisher, M.S., Emily Olfson, M.D., Ph.D., Patricia Salyer, M.Ed., Laura J. Bierut, M.D. Genetics in Medicine (July 2016)

**Diversity in Clinical and Biomedical Research: A Promise Yet to Be Fulfilled**

**Multiple Sclerosis in US Minority Populations: Clinical Practice Insights**
Omar Khan, M.D., Mitzi J. Williams, M.D., Lilyana Amezcuca, M.D., Adil Javed, M.D., Ph.D., Kristin E. Larsen, Ph.D., Jennifer M. Smrtka, N.P. Neurology: Clinical Practice (April 2015)

**Role of the Patient-Centered Outcomes Research Institute in Addressing Disparities and Engaging Patients in Clinical Research**
Romana Hasnain-Wynia, Ph.D., Anne C. Beal, M.D., M.P.H. Clinical Therapeutics (May 2014)

**A Systematic Review of Barriers and Facilitators to Minority Research Participation Among African Americans, Latinos, Asian Americans, and Pacific Islanders**
Sheba George, Ph.D., Nelida Duran, R.D., M.S., and Keith Norris, M.D. American Journal of Public Health (February 2014)
Literature review

Original research

• Internet-based survey of 2600 people with MS
• See lay language report at bit.ly/msresall
UNDERSTANDING THE PROBLEM

Literature review

Original research

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Community events (Atlanta and LA)
UNDERSTANDING THE PROBLEM

Literature review
Original research
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Community events (Atlanta and LA)
Conversations with researchers and clinicians
BARRIERS TO MS MINORITY RESEARCH ENGAGEMENT

People with MS
- Mistrust, fear, concerns
- Lack of information
- Healthcare site
- Cultural norms

Clinicians
- Time pressures
- Lack of awareness about research studies
- Concern about losing patients to research site

Researchers
- Cost and time pressures
- Lack of translation resources
- Anticipation of rejection
- Exclusion criteria / comorbidities
FACILITATORS OF MS MINORITY RESEARCH ENGAGEMENT

- People with MS
  - Access to treatment and information
  - Benefits to community
- Clinicians
  - Offering an opportunity to their patients
  - Contributing to the evidence base for MS minority healthcare
- Researchers
  - Funder requirements/expectations
  - Ability to answer more questions
OUTREACH EFFORTS

Partner and professional toolkits
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Conference posters and presentations
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  • NMSS African-American conferences
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Community events – planting a seed
RESULTS, REFLECTIONS, LEARNINGS

Strength in diversity: Multi-stakeholder network approach led to greater learning, greater impact

Priorities changed during the project

- Expansion of survey, addition of manuscript
- Recognition of pivotal roles of researchers and clinicians; addition of professionals toolkits
- Reduced emphasis on social media; removed MS Sunday event

Engagement and communication challenges

- Only one face-to-face meeting; monthly conference calls
- Inconsistent awareness of goals and status
IDENTIFIED NEEDS AND NEXT STEPS

New needs identified:

- Absence of (and desire for) organized communities and channels around MS in minority groups
- Need for more research focused on people with MS in minority groups
- Need for education addressing misconceptions about research

Next steps:

- Hold “Mythbusters” webinars and live events
- Hold regional events to learn about research interests and priorities in minority communities
- Conduct research and education about needs of MS caregivers in underserved communities
- Continue to meet and add new members
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Create opportunities to share findings and strategies across conditions!
THANK YOU FOR YOUR ATTENTION!
DISCUSSION #2: WHAT CAN WE LEARN/ADAPT FROM WHAT HAS ALREADY BEEN DONE IN OTHER FIELDS?

Allison Willis, MD, MS
Moderator
Assistant Professor of Neurology
University of Pennsylvania
THANK YOU