

Breaking the cycle of exclusion: Embracing cultural competence in physical activity research for people with MS



Lack of representation in MS physical activity research

Physical activity and exercise can help people living with MS feel better, think better, move better and live better, but most of the evidence comes from white, middle-class adults. As of 2018, fewer than 2% of participants in physical activity-related research studies involving MS identified as Black or African American.

“Black persons with MS have a more aggressive progression of the disease, and this might be partially caused by lower levels of physical activity and exercise” explains Robert Motl, PhD, a professor at University of Illinois at Chicago (UIC).

As researchers gather a better understanding of the distinct characteristics of the Black experience with MS, we must embrace cultural competence in our research and the exercise and physical activity programs we develop.

What is cultural competence?

Cultural competence in research involves considering the culture and diversity of a population throughout the research process. Regarding MS and physical activity research, this means making sure the research question, study design, recruitment methods, data collection, analysis and sharing of the results are culturally appropriate for Black individuals and other minority groups. Cultural competence in these areas yields study findings applicable to underrepresented groups.

But what does a culturally competent research study look like?

Building culturally competent research teams

When seeking funding from the Bristol-Myers Squibb Foundation to develop the Targeted Exercise for African Americans with MS (TEAAMS) project, the first step in developing a culturally informed study involved building a research team that included individuals from various racial and ethnic backgrounds.

“We knew a more diverse team would build a better grant and research study, and the intervention and the results would better address the needs of the Black community with MS residing in the South,” says Motl.

To ensure recruitment efforts to seek participants are culturally sensitive, Motl partnered with Dorothy Pekmezi, PhD, and Whitney Neal at the University of Alabama at Birmingham (UAB). Pekmezi and Neal, both Alabama natives, collaborated with Motl on previous studies during the 5 years he worked at UAB as professor and director of research in the Department of Physical Therapy.

UAB is responsible for all project outreach activities that support participant recruitment for the TEAAMS project.

“We collaborate with community networks and organizations such as the National MS Society to help raise awareness of TEAAMS among Black individuals with MS living in the South,” explains Neal, the TEAAMS outreach coordinator.



Tailoring exercise programs to participants' cultural needs and preferences

“When developing our project, our diverse team had so many unique, thoughtful ideas on best approaches, and through mindful discussion we developed consensus on best approaches and steps for designing an appropriate program of exercise training for the Black community with MS,” Motl says.

The TEAAMS project was informed by community engaged research conducted by Dominique Kinnett-Hopkins, PhD, of the University of Michigan. She and Motl collaborated in gathering feedback from Black individuals with MS regarding exercise program component preferences. The home-based exercise program includes culturally tailored components such as images of Black individuals in the educational and motivational content and a certified coach from an underrepresented racial/ethnic group.

“Most participants appreciate having a coach who is specifically not white or a male,” says TEAAMS coach Victoria Flores, PhD. “For participants who are from other countries – we have representation from Nigeria and Jamaica – having a coach that also comes from a cultural background with first-hand experience as a family acclimating to America and navigating challenges like the education system or owning a business, seems to enhance our conversations and rapport/trust.”

Flores, a postdoctoral research associate at UIC, is Filipino-American.

Feedback on TEAAMS thus far

Individuals who choose to join TEAAMS are randomly assigned to complete either an exercise training or stretching and flexibility program. Participants are provided with all study materials such as a pedometer to count steps, yoga mat and program manual and complete the program at their own convenience in their home or community 3 times a week for 4 months. Flores provides remote support and encouragement throughout the program.

Although the study is ongoing and results have not been analyzed, participants seem to benefit from meeting with a coach and from the exercise program.