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MS in US Minorities: Continuation of a Research Study Designed to Understand Educational Needs of Hispanic and African American Patients With MS

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INTRODUCTION

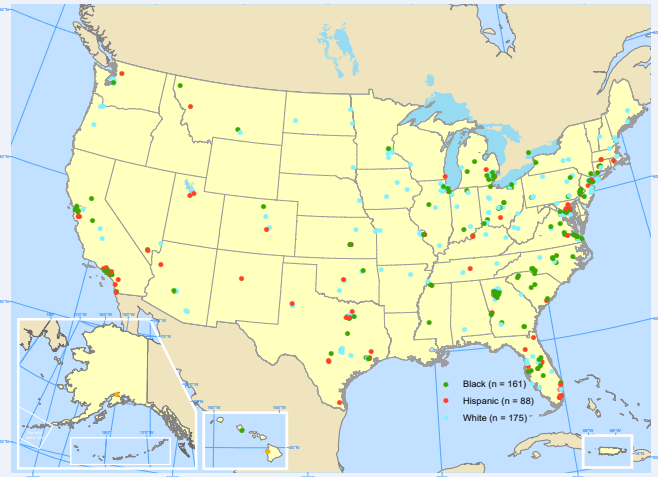
- Identifying multiple sclerosis (MS) patient needs is a critical component to developing the appropriate tools for identifying barriers to treatment and designing successful education interventions to address these symptoms and improve patient health.
- Access to therapy and socioeconomic support, increased information regarding MS, and psychological support have previously been identified as patient needs impacting quality of life.¹ However, most literature focuses primarily on the general population, with limited attention to African Americans and Hispanics.
- Patients with nonwhite ethnicity are younger at onset of symptoms and diagnosis,² have a greater likelihood of opticospinal MS, transverse myelitis, and a more aggressive disease course when compared with white patients.³ Studies suggest that the incidence of MS may be higher in African Americans than Caucasian Americans.^{4,5}
- Minority patients are underrepresented in clinical trials for emerging MS therapies, potentially due to distrust of the medical community.^{6,7}
- This study was previously reported, focusing on minority patients. Here, we collected an additional group of white/Caucasian patients in order to understand the impact of race/ethnicity and other patient characteristics to help predict the contributors to barriers to living with MS.

METHODS

- A survey was developed focusing on understanding patient attitudes towards care and educational need.
- Recruitment materials and questionnaires were made available in English and Spanish languages.
- All materials and consent protocols were reviewed by Western Institutional Review Board (WIRB; Puyallup, WA) and approved on Jan 20, 2015; updated materials approved on Dec 23, 2015.
- Online survey criteria: 21 years of age or older, US resident, diagnosed with MS by a healthcare professional.
- Survey data were compiled and analyzed with IBM Statistics 20. Inferential statistics, including Chi-squares, ANOVAs, and multiple linear regressions, were conducted post-hoc to detail differences between responses of the 3 main groups and other key patient characteristics.

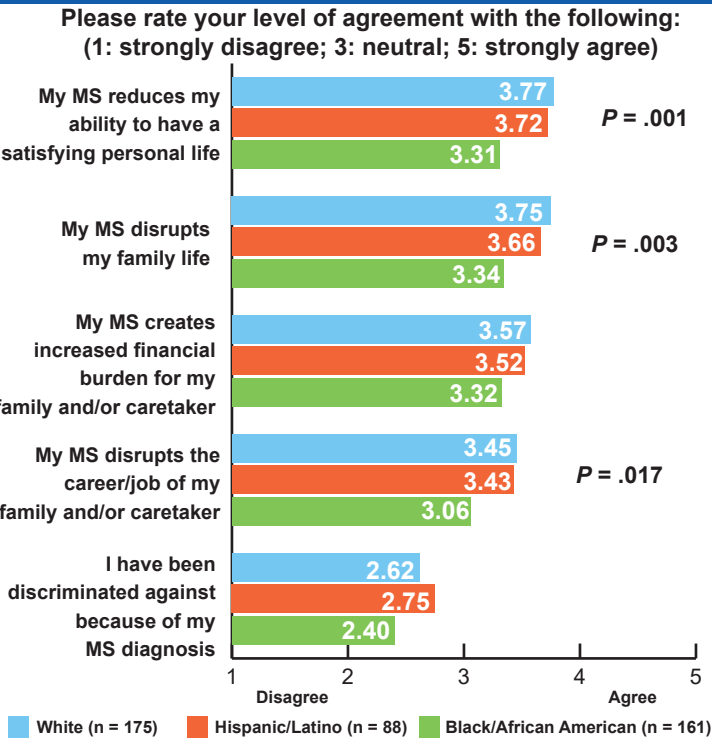
Table 1. Demographics of sample

	White (n = 175)	Black (n = 161)	Hispanic (n = 88)
Age, mean (range)	45 (21-65)	42 (23-68)	40 (21-68)
Years since diagnosis, mean (range)	10 (0-46)	8 (0-39)	8 (0-24)
Gender (% female)	70%	83%	74%
Insurance status			
Private	62%	47%	50%
Government	35%	47%	42%
No insurance coverage	2%	4%	6%
Current course of MS (patient reported)			
Relapsing-remitting	69%	77%	65%
Primary-progressive	18%	11%	23%
Secondary-progressive	7%	6%	6%
Not sure	6%	6%	7%



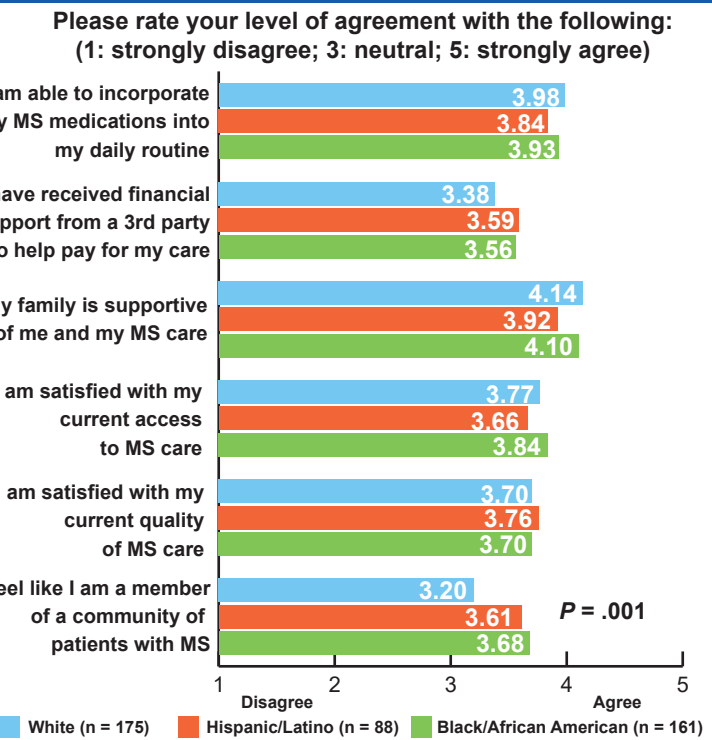
RESULTS

Figure 1. Barriers to optimal patient care



Minority and white patients experience similar barriers to living with MS. White and Hispanic patients are more likely than black patients to believe that MS reduces their ability to have a satisfying personal life, disrupts the career/job of their family, and disrupts their family life.

Figure 2. Facilitators of optimal patient care

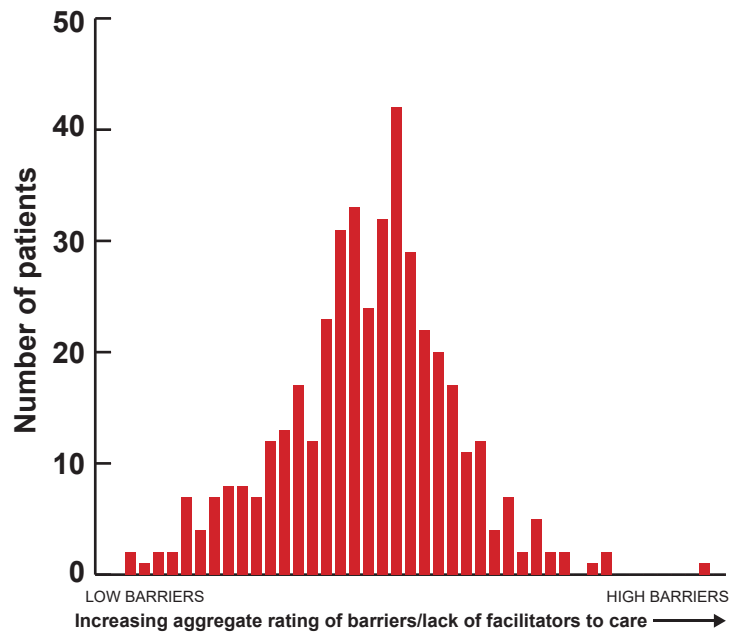


White patients are less likely than Hispanic or black patients to believe that they feel like a member of a community of MS patients.

Figure 3. Predicting barriers to care

In order to predict the patients most likely to experience barriers to care, a new variable was created. All barrier and facilitator variables (facilitator values were reversed) were added together to show the amount of trouble/frustration a specific patient with MS is experiencing. The higher the number, the greater the individual barriers to care.

Histogram of distribution of barriers/lack of facilitators



This new variable was normally distributed and used as a dependent variable in a multiple linear regression.

Multiple linear regression model

	B	Std error	P-value
Had symptoms of dizziness	1.44	0.67	.032
Not currently taking treatment	4.21	0.85	< .001
Family understands MS	-0.95	0.36	.008
Know where to go to find MS information	-1.03	0.43	.017
Would benefit from info on clinical trials	1.00	0.32	.002
Number of children	0.55	0.22	.014
Government insurance (vs. private)	1.20	0.57	.034
Adjusted R-squared = .528; P < .001			

Items with little influence on barriers include other symptoms, current treatments, familiarity with specific patient advocacy groups/websites, perceptions of value of different educational formats, gender, use of websites, or race/ethnicity.

Patients who presented with dizziness, are not currently taking treatment, feel that they would benefit from information regarding clinical trials, have more children, and who are on government insurance experience more barriers and less facilitators. Patients who feel that their family understands MS, and know where to go to find MS information experience fewer barriers.

Figure 4. Minority patient educational needs

What one informational or educational topic related to MS would be most valuable to you? (open-ended)



*Minority patients were significantly more likely than white patients to want education related to progression/stages (7.6% vs 1.7%, P = .021).

CONCLUSIONS

- The regression model shows that the major influencer on barriers to care is whether or not a patient is currently taking treatment, no matter what that treatment is.
- The regression model also shows that patients less likely to have issues with MS are those with knowledge of where to get information. Support for patients should include education on where to go for help with their MS, including materials distributed by a healthcare provider and accurate online resources.
- Further, race/ethnicity was not found to be an influencer on MS barriers in this study. Disparities seen in previous MS studies may have less to do with race/ethnicity and more to do with socioeconomic status, as seen by the role of government versus private insurance in predicting barriers. Future research should continue to elucidate the role of race and economic status in MS patient outcomes.
- Families are important. The more children a patient has, the more barriers they experience. Also, patients report fewer barriers if they feel their family understands MS. Education, as well as patient management, should consider the role of families in patient support.
- While all patients with MS want information on symptoms and therapies, minority patients are specifically interested in topics related to progression and stages of the disease.

References

- Forbes A, et al. *J Adv Nurs*. 2007; 58(1):11-22.
- Buchanan RJ, et al. *Ethn Dis*. 2010; 20(4):451-457.
- Cree BA, et al. *Neurology* 2004; 63(11):2039-2045.
- Langer-Gould A, et al. *Neurology* 2013; 80(19):1734-1739.
- Wallin MT, et al. *Brain* 2012; 135(6):1778-1785.
- Avsarala J. *JAMA Neurol*. 2014; 71(8):943-944.
- Durant RW, et al. *J Natl Med Assoc*. 2011; 103(2):123-130.

Disclosures

EH, JS, JR, LM, and TL are employees of Biogen and hold stock/options in Biogen. Other authors have nothing to disclose.

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