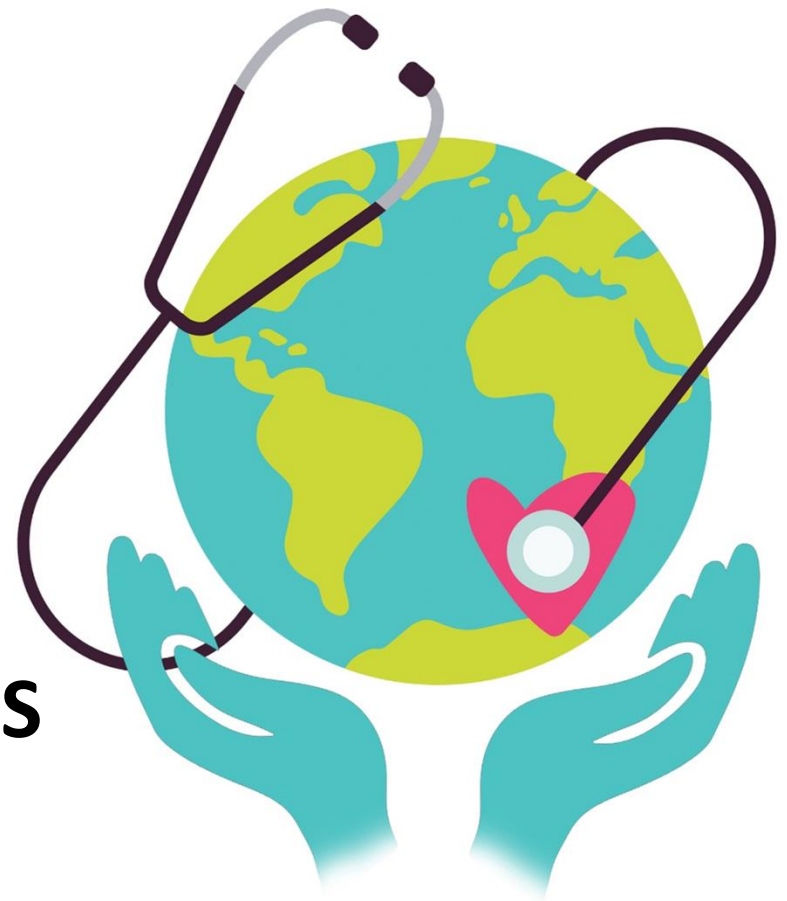


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# International Organization of MS Nurses

## Cultural Diversity in MS



Supported by Novartis Pharmaceuticals Corporation

# Culturally Competent Care

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- “Cultural competence in health care means delivering effective, quality care to patients who have diverse beliefs, attitudes, values, and behaviors.”
- “While cultural competence in health care initially referred to meeting the needs of people from distinctive ethnic and racial groups, it now also refers to meeting the needs of people with disabilities, those from diverse socioeconomic backgrounds, and members of the LGBTQ community.”

# Cross-Cultural Competency

- Cross-cultural competency is an essential skill for MS nurses as US and MS populations become more diverse
- IOMSN, Consortium of MS Centers, American Academy of Neurology, American Nurse's Association, American Association of Nurse Practitioners, American Association of Colleges of Nursing, and other groups are engaging in activities to improve cultural competency among health professionals



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# Unconscious Biases and Cultural Differences

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- Implicit biases are unconscious associations about a person based on their race, ethnicity, sex, age, place of origin, religion, socioeconomic status, education level, sexual orientation, gender identity, or disability status that lead to negative evaluations
- Implicit biases are common among healthcare professionals
- Biases influence diagnosis, treatment decisions, and levels of care
  - Example: Black and Hispanic children are (18% and 13%, respectively) are less likely to undergo imaging during healthcare visits vs their White peers<sup>4</sup>
  - Example: Women of minority race or ethnicity and lower socioeconomic status experience lower digital breast tomosynthesis, screening access and/or use, especially during the early technology adoption period<sup>5</sup>

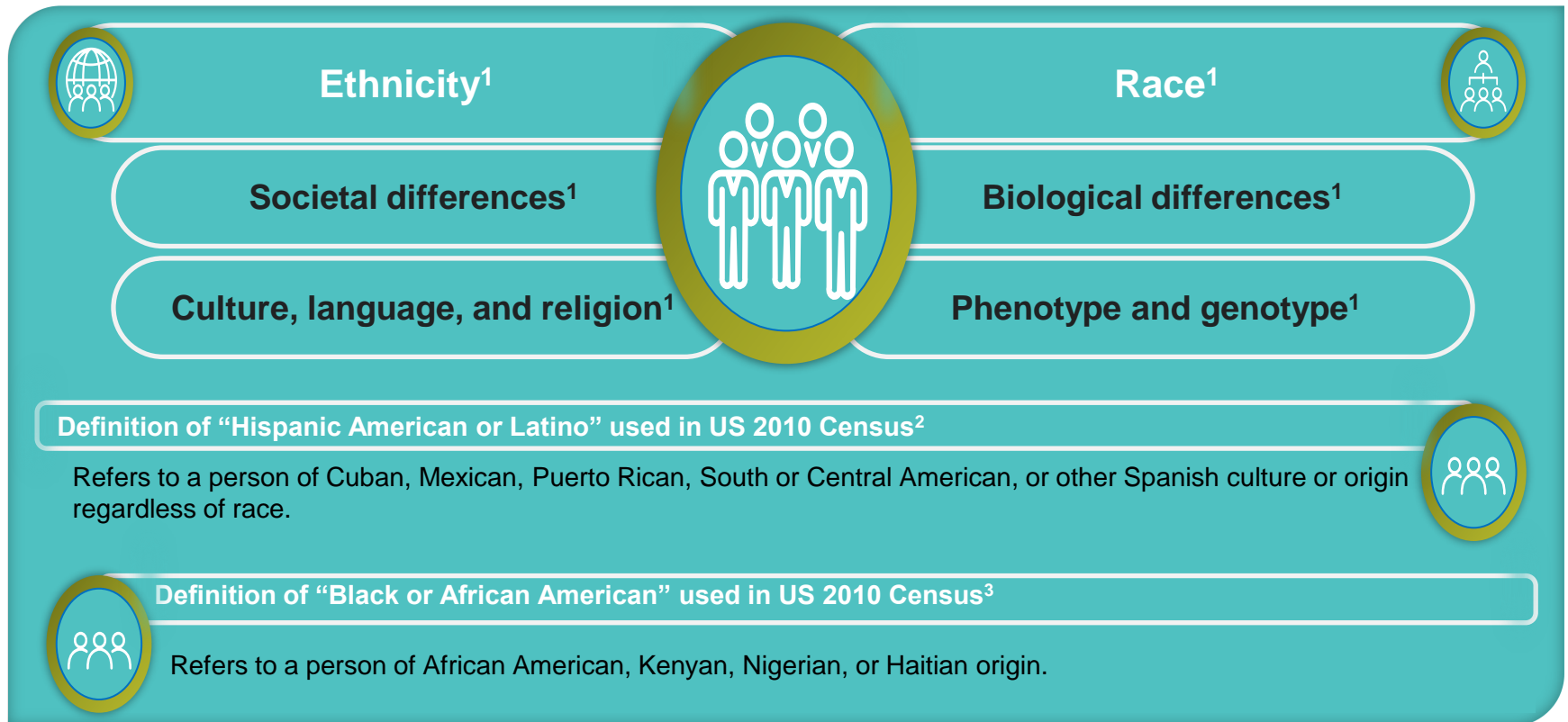
1. FitzGerald C, Hurst S. *BMC Medical Ethics*. 2017;19; 2. Sloane A. Improving cultural competency of MS healthcare professionals. CMSC Annual Meeting, 2021, Orlando, FL.; 3. Tulane University School of Public Health and Tropical Medicine, 2021; 4. Innovate Healthcare. Health Imaging. Insights in imaging and informatics; 5. Lee CI et al. *JAMA Network Open*. 2021;4:e2037546.



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# RACE VERSUS ETHNICITY

# Nomenclature Used to Gather Census Data: Ethnicity vs Race



1. Santos D et al. *Dental Press J Orthod*. 2010;15:121-124;
2. US FDA Website. About Hispanic origin;
3. US Census website. Quick facts about race.

# Minority Populations with MS



## Susceptibility to MS

- Compared with White Americans:
  - African Americans have a 47% increased risk of MS
  - Hispanic Americans and Asian Americans had a 50% and 80% lower risk of MS, respectively

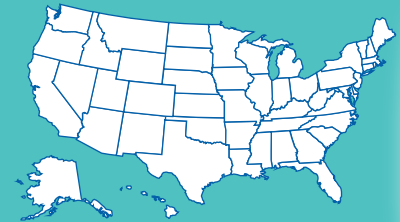


## Onset

- Percentage of Hispanic patients has increased among pediatric MS cohorts, with an overall younger age of onset noted among Hispanic adult cohorts
- African Americans have been reported to develop MS both at a younger and an older age vs White patients
- Hispanic Americans were reported to develop MS at an earlier age vs White Americans

# US Minority Populations Are Underrepresented in Literature and Clinical Trials

- African Americans represent 12% of the US population but only 5% of clinical trial participants<sup>1</sup>
- Hispanics make up 16% of the US population but only 1% of clinical trial participants<sup>1</sup>



A PubMed review (January 2014) revealed that there were **~60,000 published articles on MS<sup>2</sup>**



Only **113 studies** out of these focused on African Americans (or Blacks), and **23** focused on Hispanic Americans (or Latino)<sup>2</sup>

1. US FDA Website: Clinical Trials Shed Light on Minority Health;  
2. Khan O et al. *Neurol Clin Pract.* 2015;5:132-142.





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# **PREVALENCE AND PRESENTATION OF MS IN BLACK AND HISPANIC POPULATIONS**

# Incidence of MS Varies by Race/Ethnicity in US



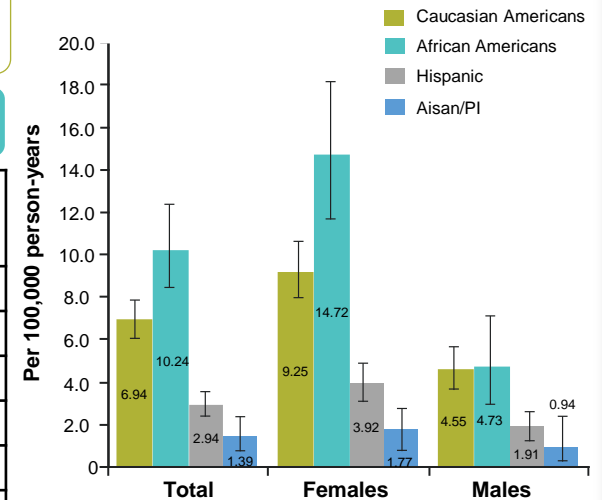
## Risk of MS

- Black females have higher risk of MS vs White females<sup>1</sup>
  - Higher incidence of MS in Blacks is probably due to higher percentage of hormonal,<sup>2</sup> environmental,<sup>3</sup> and genetic risk factors<sup>1</sup>
- Hispanic people have half the risk of MS vs White people<sup>1</sup>

## Standardized incidence rates and estimated number of newly diagnosed individuals with MS annually in the US by race/ethnicity<sup>1,a</sup>

Race/ethnicity	Incident MS cases	Active KPSC members	Incidence per 100,000 PYs	Standardized incidence rates <sup>b</sup>	2000 US census population	Expected newly diagnosed MS cases annually
White	258	3,715,433	6.9	7.28	194,552,600	14,169
Hispanic	116	3,952,122	2.9	2.94	35,305,400	1061
Black	106	1,035,406	10.2	10.24	33,947,400	3575
Asian/PI	13	934,255	1.4	1.45	10,476,700	153
Other	3	276,744	1.1	0.78	7,139,400	56
Total	496	9,913,959	5.0	-	281,421,500	19,014

## Incidence of MS by race/ethnicity and sex<sup>1</sup>



Adapted with permission from Langer-Gould et al.<sup>1</sup>

KPSC=Kaiser Permanente Southern California; PI=Pacific Islander; PY=person-year.

<sup>a</sup>Retrospective cohort study of >9 million PY of KPSC health plan from January 1, 2008, to December 31, 2010.

<sup>b</sup>Standardized to 2000 US Census; adjusted for age and sex.

1. Langer-Gould A et al. *Neurology*. 2013;80:1734-1739;

2. Ponsonby A-L et al. *Neurology*. 2012;78:867-874;

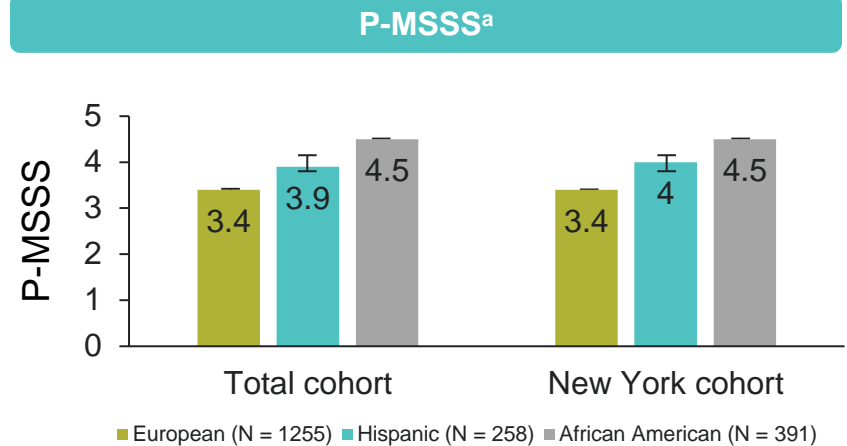
3. Palacios N et al. *Ann Epidemiol*. 2011;21:536-542.

# US Minority Populations Experience More Severe Disease Course Compared with Caucasians



## Disease severity

- The age- and gender-adjusted disease severity score (P-MSSS) was significantly higher in Hispanic Americans and African Americans vs Caucasian Americans ( $P < .0001$  for both)\*
- Hispanic Americans and African Americans both were found to have a more rapid disability accumulation than Caucasian Americans



Data were derived from Ventura et al.

ANCOVA=analysis of covariance; P-MSSS=Patient-Derived Multiple Sclerosis Severity Score.  
Ventura RE et al. *Mult Scler*. 2017;23(11):1554-1557.



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# **INCIDENCE AND CLINICAL PHENOTYPES IN BLACK AND HISPANIC POPULATIONS**

# MS in African American vs Caucasian Populations: Clinical Phenotype



## Disease type\*

- No significant differences were observed for the proportion of RRMS, SPMS, PPMS, and PRMS between African Americans and Caucasian Americans



## Onset

- Median time to diagnosis after disease onset was 1 year for African Americans and 2 years for Caucasian Americans



## Age of onset

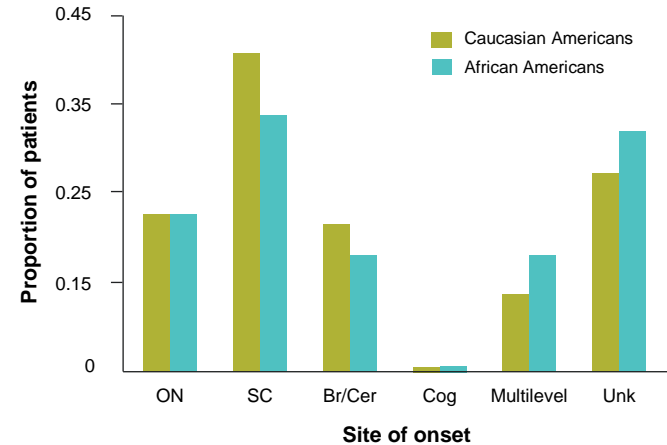
- Age at onset was ~2.5 years later in African Americans vs Caucasian American (33.7 vs 31.1 years, respectively;  $P < 0.0001$ )



## Site of onset

- African Americans presented with multisite signs and symptoms at disease onset more often than Caucasian Americans ( $P < 0.018$ )

## Anatomic site of disease onset deduced from initial clinical presentation



Adapted with permission from Cree et al.

Br/Cer=brainstem/cerebellar; Cog=cognitive; ON=optic neuritis; PPMS=primary progressive MS; PRMS=progressive relapsing MS; RRMS=relapsing-remitting MS; SC=spinal cord; SPMS=secondary progressive MS; Unk=unknown.

Cree BAC et al. *Neurology*. 2004;63:2039-45.

# MS in African American vs Caucasian Populations: Clinical Phenotype (Cont.)



## Optic nerve and spinal cord

- In a retrospective study of patients with MS (N = 802), optic nerve and spinal cord issues (opticospinal MS) occurred in 16.8% of African Americans vs 7.9% of Caucasian Americans ( $P < 0.001$ )



## Transverse myelitis

- Transverse myelitis was more frequent in African Americans (28%) vs Caucasian Americans (18%)



## Disability

- African American subjects were at higher risk for development of ambulatory disability than Caucasian Americans
  - African Americans were at 1.67-fold greater risk of requiring a cane to ambulate vs Caucasian Americans (even after adjusting for ethnicity, gender, age at onset, and DMTs;  $P < 0.001$ )
  - African Americans were also at greater risk for development of wheelchair dependency ( $P = 0.099$ )

DMT=disease modifying therapy.

Cree BAC et al. *Neurology*. 2004;63:2039-2045.

# MS in African American vs Caucasian Populations: Clinical Phenotype (Cont.)



## Disease severity

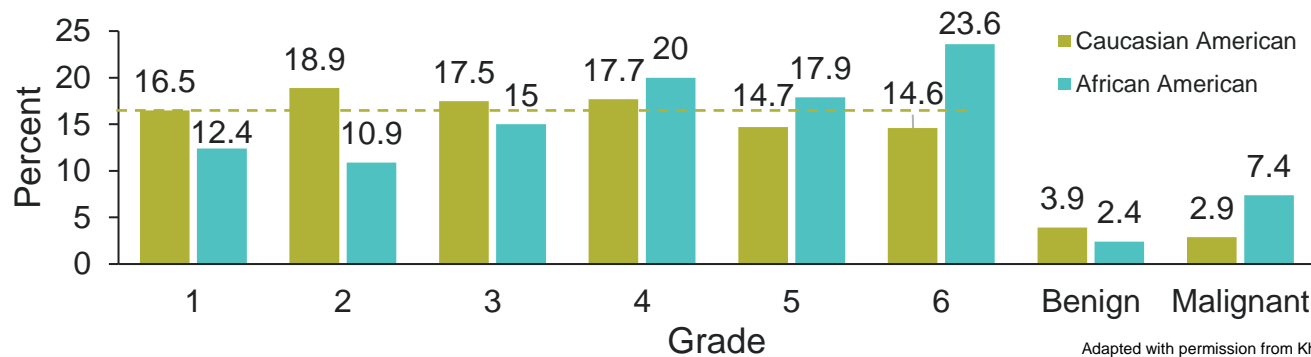
- A retrospective study investigating the utility of an MSSS-based classification comparing African Americans (n = 419) and White patients (n = 5809) with MS reported African Americans having higher tendency to transition to a more severe grade of MS (malignant)<sup>1,2</sup>



## Opticospinal MS

- African Americans have a higher risk of opticospinal MS, transverse myelitis, and a motor onset. This retrospective multicenter cohort study of African Americans (n = 673) and White patients (n = 717) with MS, investigated the influence of genetic variation on clinical MS patterns<sup>1,3</sup>
  - African Americans experience symptoms restricted to the spinal cord and optic nerves more often and are at a higher risk of ambulatory disability vs Caucasian Americans
  - In African Americans, DRB1\*15 alleles are more often associated with a classic/multifocal rather than an opticospinal disease type

Distribution of African American and Caucasian American patients with MS across EDSS grades and benign/malignant categories<sup>1,2,a,b</sup>



Adapted with permission from Khan et al.<sup>1</sup>

EDSS=Expanded Disability Status Scale; MSSS=MS Severity Score.

1. Khan O et al. *Neurol Clin Pract.* 2015;5:132-142;
2. Kister I et al. *Neurology.* 2010;75:217-223;
3. Cree BAC et al. *Arch Neurol.* 2009;66:226-233.

# MS in African American vs Caucasian Populations: Neuroimaging Outcomes (Brain Atrophy)



## Brain atrophy

- African Americans with MS had: higher inflammatory disease activity, faster disability accumulation, greater visual dysfunction, more brain tissue damage, higher lesion volume vs Caucasian Americans\*
  - Gray matter ( $P=0.02$ ), white matter ( $P=0.04$ ), and nuclear thalamic ( $P=0.02$ ) atrophy rates were ~2 times faster in African Americans vs Caucasian Americans

Comparisons of regional (substructure) atrophy (percentage change/year)<sup>a</sup> of the brain<sup>b</sup>

	Substructure atrophy (percentage of change/year)							
	African Americans		Caucasian Americans		African Americans vs Caucasian Americans			
	(n = 22)		(n = 60)		P value			
	%/year	95% CI	%/year	95% CI	Model 1 <sup>c</sup>	Model 2 <sup>d</sup>	Model 3 <sup>e</sup>	Model 4 <sup>f</sup>
Whole brain	-0.53	(-0.76 to -0.30)	-0.30	(-0.39 to -0.21)	0.086	0.083	0.080	0.084
<b>Cortical gray matter</b>	<b>-0.87</b>	<b>(-1.16 to -0.58)</b>	<b>-0.46</b>	<b>(-0.58 to -0.34)</b>	<b>0.013</b>	<b>0.012</b>	<b>0.012</b>	<b>0.012</b>
<b>Cerebral white matter</b>	<b>-0.69</b>	<b>(-0.96 to -0.41)</b>	<b>-0.34</b>	<b>(-0.46 to -0.22)</b>	<b>0.039</b>	<b>0.038</b>	<b>0.039</b>	<b>0.038</b>
Whole thalamus	-1.08	(-1.59 to -0.57)	-0.71	(0.96 to -0.45)	0.293	0.292	0.283	0.292
<b>Nucleus thalamus</b>	<b>-1.50</b>	<b>(-2.03 to -0.97)</b>	<b>-0.66</b>	<b>(-0.91 to -0.41)</b>	<b>0.021</b>	<b>0.021</b>	<b>0.020</b>	<b>0.021</b>
Deep gray matter	-0.95	(-1.27 to -0.63)	-0.62	(-0.77 to -0.48)	0.104	0.104	0.120	0.104
<b>T<sub>2</sub> lesion</b>	<b>10.97</b>	<b>(4.04 to 18.37)</b>	<b>4.65</b>	<b>(1.64 to 7.75)</b>	<b>0.006</b>	<b>0.006</b>	<b>NA</b>	<b>0.006</b>

Adapted with permission from Caldito et al.

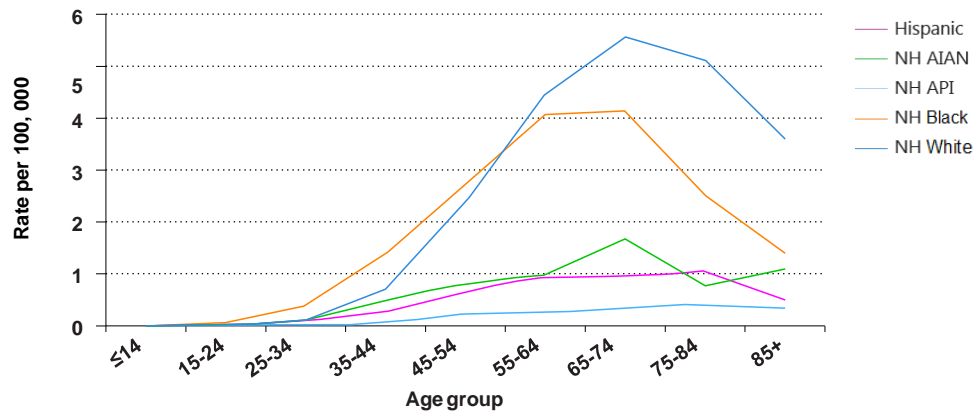
MRI=magnetic resonance imaging; NA=not applicable.

Caldito NG et al. *Brain*. 2018;141:3115-3129.



# MS in Black vs White Populations: Mortality

Age-specific MS mortality by race/ethnicity in US females, 1999-2015



Adapted with permission from Amezcua et al.



## Mortality

- Black patients die at an earlier age and have more substantially increasing mortality trends than White patients; this indicates that MS burden weighs unequally by race\*

AIAN=American Indian or Alaska Native; API=Asian or Pacific Islander; NH=non-Hispanic.  
Amezcua L et al. *Neuroepidemiology*. 2018;50:35-40.

# MS in Hispanic vs White Populations: Clinical Phenotype



## Onset

- MS age of onset can be as long as 7 years younger in Hispanic vs White populations<sup>1,2</sup>

MS clinical characteristics in Hispanic vs White patients by region in US<sup>1-4,a</sup>

	South-East coast <sup>2,3</sup>		West coast <sup>2,4</sup>		West coast <sup>1,2</sup>	
	Hispanic, n = 312	White, n = 312	Hispanic, n = 119	White, n = 76	Hispanic, n = 116	White, n = 258
First symptom, mean age	33.6	35.2	28.5	32.6	33.2	40.7
Diagnosis, mean age	38.1	40.9	29.7	32.9	35.1	44.5
Diagnosis lag, years	4.4	5.6	1.2	0.3	NA	NA
Disease duration, years	12.4	16.7	8.8	11.4	10.7	13.5
Gender, female (%)	80	77	58	75	78	71
Initial presentation, %						
Sensory	47	49	13.9	27.9	NA	NA
ON <sup>b</sup>	<25	<25	31.5	19.7	NA	NA
Spinal cord <sup>c</sup>	35	30	25.1	13.1	NA	NA

Adapted with permission from Amezcua et al.<sup>2</sup>

1. Langer Gould A et al. *Neurology*. 2013;80:1734-1739;
2. Amezcua L et al. *Mult Scler J Exp Transl Clin*. 2017;3:1-12;
3. Hadjixenofontos A et al. *Neuroepidemiology*. 2015;44:262-268;
4. Amezcua L et al. *Mult Scler*. 2011;17:1010-1016.

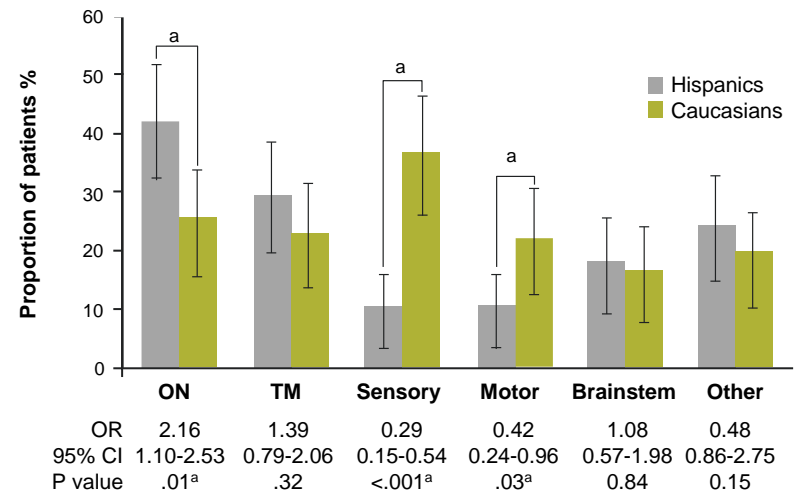
# MS in Hispanic vs White Populations: Clinical Phenotype (Cont.)



## ON and TM

- Hispanics are more likely to present with ON and transverse myelitis vs Whites<sup>1,\*</sup>
  - Genetic ancestry influences the likelihood of presenting with ON<sup>2,†</sup>

## Presenting symptoms at onset in Hispanic and Caucasian patients with MS<sup>1</sup>



Adapted with permission from Perez et al.<sup>1</sup>

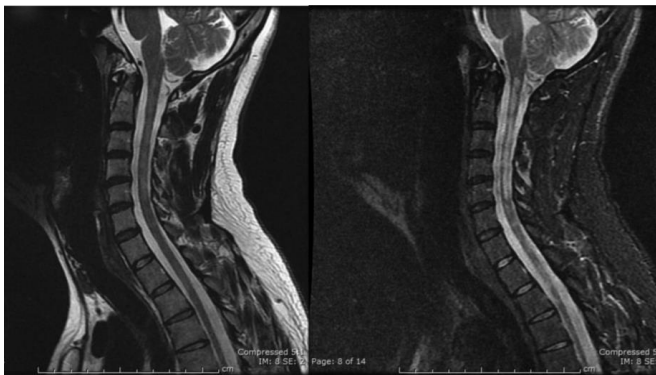
OR=odds ratio; TM=transverse myelitis.

1. Perez CA et al. *J Neuroimaging*. 2021; 31:115-123:

2. Amezcua L et al. *Ann Clin Transl Neurol*. 2018; 5:1362-1371.

# MS in Hispanic Population: Neuroimaging Outcomes

A Hispanic patient with LESCL



The association between type of spinal cord lesion and disability (n = 164)

Possible factors	Disability EDSS (≥4) OR (95% CI; unadjusted)	P value	Disability EDSS (≥4) OR (95% CI; adjusted)	P value
Age (years)	1.07 (1.04–1.11)	<0.0001	1.07 (1.03–1.11)	0.0004
Sex (female)	1.43 (0.75–2.71)	0.28	1.23 (0.57–2.62)	0.60
Disease duration (years)	1.17 (1.09–1.25)	<0.0001	1.12 (1.04–1.21)	0.004
nSCLs	0 (ref)		0 (ref)	
sSCLs	3.12 (1.19–8.19)	0.02	2.48 (0.87–7.06)	0.09
LESCLs	11.55 (3.66–36.39)	<0.0001	7.28 (2.00–26.54)	0.003

Adapted with permission from Amezcua et al.



LESCL

- Prevalence of LESCLs in the Hispanic American cohort (19%) was higher than those in Caucasians (2%–3%)\*
- Presence of LESCLs was associated with a 7-fold increased risk of disability (after adjusting for age, gender, and disease duration;  $P=0.003$ ) compared with not having spinal cord lesions in the Hispanic population

EDSS=Expanded Disability Status Scale; LESCL=longitudinally extensive spinal cord lesions; nSCL=no spinal cord lesions; sSCL=scattered spinal cord lesions.

Amezcua L et al. *J Neurol.* 2013;260:2770-2776.

# Summary: Clinical Phenotypes



## Blacks

- Highest MS mortality rate before the age of 45 years (for males only)<sup>1</sup>
- Higher incidence rates of MS vs Whites<sup>2</sup>
- Present more often with transverse myelitis (spinal cord syndrome) and ON<sup>3</sup>
- More frequent relapses (adult and pediatric); worse recovery from relapse and faster time to second relapse<sup>4,5</sup>
- Faster rate to ambulatory impairment<sup>5,6</sup>
- Higher rates of disability at any stage<sup>5,7</sup>
- Greater visual dysfunction, more brain tissue damage, and higher lesion volume<sup>8</sup>



## Hispanics

- Younger age of onset than general MS population (higher pediatric MS) – more pronounced in US born<sup>9</sup>
- Get MS less often, but when they do it is younger and more severe<sup>2,7,9,10</sup>
- More likely to present with ON and transverse myelitis<sup>11,12</sup>
- Higher baseline EDSS score<sup>12</sup>
- Increased risk of requiring ambulatory assistance<sup>12</sup>
- Presence of LESCLs is higher (~19%) than those in White patients (2–3%)<sup>13</sup>

1. Amezcua L et al. *Neuroepidemiology*. 2018;50:35-40;
2. Langer-Gould A et al. *Neurology*. 2013;80:1734-1739;
3. Cree BAC et al. *Neurology*. 2004;63):2039-2045;
4. Boster AL et al. *Pediatr Neurol*. 2009;40:31-33;
5. Khan O et al. *Neurol Clin Pract*. 2015;5:132-142;
6. Cree BAC et al. *Arch Neurol*. 2009;66:226-233;
7. Ventura RE et al. *Mult Scler*. 2017;23:1554-1557;
8. Caldito NG et al. *Brain*. 2018;141:3115-3129;
9. Amezcua L et al. *Mult Scler J Exp Transl Clin*. 2017;3:1-12;
10. Amezcua L et al. *Mult Scler*. 2011;17:1010-1016;
11. Amezcua L et al. *Ann Clin Transl Neurol*. 2018; 5:1362-1371;
12. Perez CA et al. *J Neuroimaging*. 2021;31:115-123;
13. Amezcua L et al. *J Neurol*. 2013;260:2770-2776.

# Influence of Genetic Ancestry: Hispanic Americans

## Average Hispanic American mixture<sup>1,a</sup>



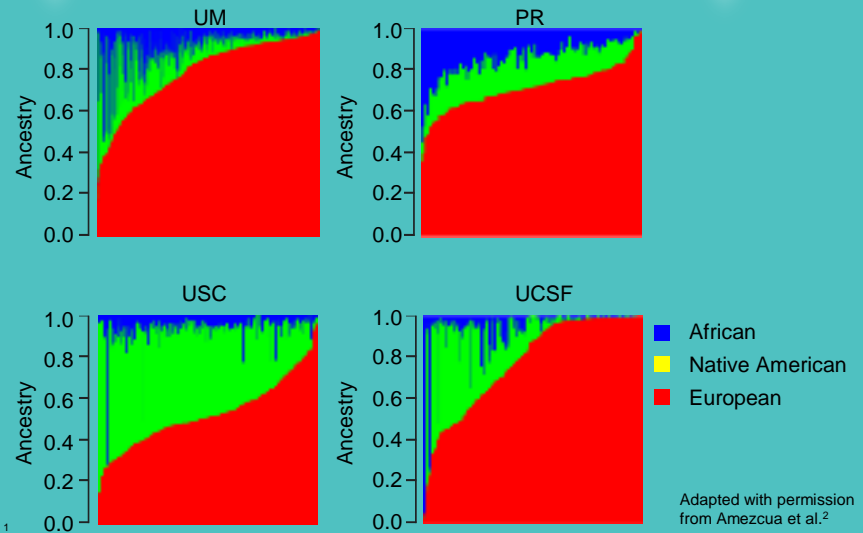
15% African ancestry

30%-40% Native ancestry

40%-60% European ancestry

Adapted with permission from Amezcua et al.<sup>1</sup>

## Distribution of genetic ancestry proportions in Hispanics with MS across different sites<sup>2,a,b</sup>



PR=San Juan MS Center in Puerto Rico; UCSF=University of California, San Francisco;  
USC=University of Southern California; UM=University of Miami.

1. Amezcua L. Paper presented at: The 2nd Annual MS Symposium. September 29, 2018. Phoenix, AZ;
2. Amezcua L et al. *Ann Clin Transl Neurol.* 2018;5:1362-1371.

# Influence of Genetic Ancestry: Hispanic Americans (Cont.)

## Likelihood of ON presentation by quartiles of Native American ancestry

Variables in model	OR (95% CI)	<i>P</i> value
Native American ancestry		
2nd vs 1st quartile	1.27 (0.77–2.10)	$3.49 \times 10^{-01}$
3rd vs 1st quartile	1.29 (0.76–2.19)	$3.44 \times 10^{-01}$
4th vs 1st quartile	<b>2.35 (1.35–4.10)<sup>a</sup></b>	$2.60 \times 10^{-03}$
African ancestry	0.48 (0.10–2.41)	$3.74 \times 10^{-01}$
Sex (female vs male)	1.20 (0.82–1.77)	$3.46 \times 10^{-01}$
Age at first symptom	0.98 (0.96–0.99)	$7.80 \times 10^{-03}$
Site		
PR vs UM	1.98 (1.11–3.53)	$2.00 \times 10^{-02}$
USC vs UM	1.65 (1.00–2.71)	$4.88 \times 10^{-02}$
UCSF vs UM	1.33 (0.79–2.25)	$2.83 \times 10^{-01}$

Adapted with permission from Amezcua et al.



### Genetics

- Hispanic American ancestry varies across different regions in the US
- Native American ancestry increases the likelihood of ON presentation 2-fold



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# MS IN ASIAN AND OTHER POPULATIONS



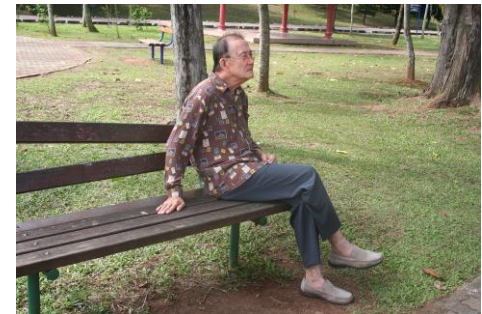
# MS in US Asian Groups

- Research is sparse in regard to prevalence of MS among Asians
- Most of Asian population in US is comprised of six origin groups: Chinese, Indian, Filipino, Vietnamese, Korean, Japanese
  - Culturally diverse from one group to next
- Close to 60% of Asian Americans are foreign born
- US Asian population is expected to exceed 6 million by 2060

Jiang Y. *IOMNews*. Fall 2020;5-8;  
Henson L. CMSC Annual Meeting, Orlando, FL. October 26, 2021;  
Pew Research Center data.



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# MS in Asian Groups: Statistics

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- Asian population has:
  - 80% lower risk of developing MS than Caucasians<sup>1</sup>
  - Incidence rate 1.4–1.3 per 100,000<sup>1-2</sup>
  - Increasing prevalence<sup>3</sup>
- Sex ratio, presentation, DMT efficacy similar to Caucasians<sup>4,5</sup>
- Opticospinal type of MS affects 15%–40% of Japanese patients with MS<sup>6</sup>
- Lower serum vitamin D levels than Caucasians<sup>7</sup>

1. Langer-Gould A et al. *Neurology*; 2013;1734-1739; 2. Wallin MT et al. *Brain*. 2012;135:1778-1785;  
3. Yoshimura S et al. *PLoS One*. 2012;7:e48592; 4. Henson L. CMSC Annual Meeting, Orlando, FL. October 26, 2021;  
5. Robers MV et al. *Practical Neurology*; 2020; 6. Kira J. *Lancet Neurol*. 2003;2:117-127;  
7. Niino M et al. *Clin Experim Neuroimmunol*. 2013;4(Suppl 1):59-67.

# MS in LGBTQIA+ Patients

- Beyond race and ethnicity, lesbian, gay, bisexual, transgender, queer intersex, asexual, and all sexual and gender minority (LGBTQIA+) patients face many healthcare barriers:
  - May be stigmatized and rejected by families and communities
  - May lack health insurance
  - Often change providers due to negative attitude and homophobia of staff and providers toward them
- Knowledge of a patient's sexuality contributes to appropriate care



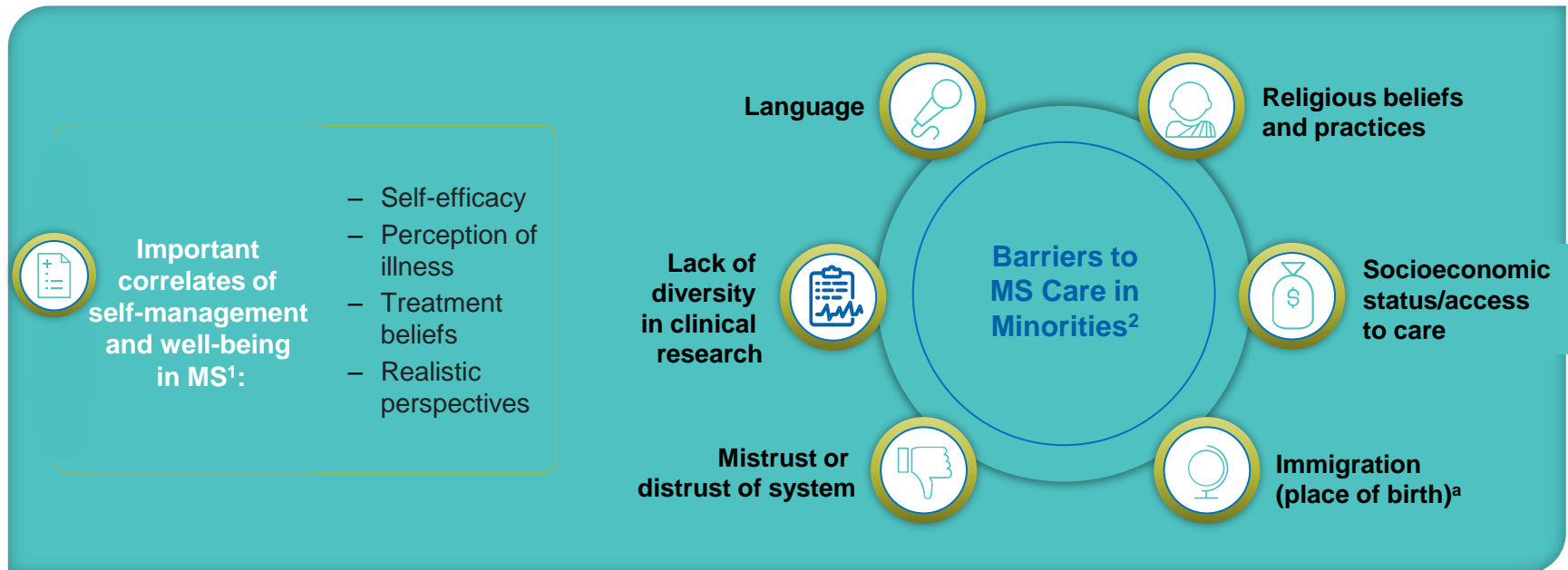
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# **BARRIERS TO ACCESS AND CARE**

# Barriers to Care in Minorities



<sup>a</sup>Does not apply to Puerto Ricans (US citizens).

1. Wilski M, Tasiemski T. *Acta Neurol Scand.* 2016;133:338-345;

2. Khan O et al. *Neurol Clin Pract.* 2015;5:132-142.

# Mistrust in Clinicians and Clinical Research



## Mistrust

- Deeply religious patients may have a direct conflict between their faith and the treatments required by a study<sup>1,\*</sup>
- Blacks have greater distrust in healthcare providers due to prior experiences of racism and discrimination<sup>2,†</sup>

Types of distrust in clinical research in Caucasian Americans vs African Americans<sup>3,a</sup>

	Survey responders		
	Caucasian American (n = 5481)	African American (n = 5295)	P value
<b>Sociodemographics</b>			
Mean age, years (SD)	76.0 (9.0)	69 (10.0)	<0.001
Education: college graduate or higher, %	56	34	<0.001
Has current health insurance, %	98	98	0.5
Has personal doctor or nurse, %	95	93	0.2
<b>Experimental factors, %</b>			
History of discrimination in healthcare	15	43	<0.001
Awareness of Tuskegee Syphilis study	41	64	<0.001
Previous trial participation	59	52	0.07
Trust in physician, n (SD) PCAS trust subscale <sup>b</sup>	77.1 (15.3)	77.6 (14.9)	0.07
<b>Individual distrust index items, %</b>			
Likelihood that you/people like you will be used as guinea pigs without permission	27.7	54.2	≤0.05
Frequency that doctors, in general, prescribe medications to experiment on people without their knowledge	40.6	60.0	≤0.05

Adapted with permission from Khan et al.<sup>3</sup>

PCAS=Primary Care Assessment Survey.

1. Daverio-Zanetti S et al. *J Cancer Educ.* 2015; 30: 220-224;
2. Armstrong K et al. *Med Care.* 2013;51:144-150;
3. Khan O et al. *Neurol Clin Pract.* 2015;5:132-142.



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# ADDRESSING DISPARITIES IN HEALTHCARE

# Ongoing Studies About MS in Minorities

Study/Registry	Objective
Determining Enhanced Inflammatory B-cell Function in African Americans with MS <sup>1</sup>	To see if MS patients of African ancestry possess greater T-dependent inflammatory B-cell function relative to those of Caucasian ancestry.
ARHMS (Alliance for Research in Hispanic MS) <sup>2</sup>	To collaborate and expand the knowledge of MS in Hispanic communities.
NAAMS Registry (National African Americans with MS Registry) <sup>3</sup>	To accurately estimate the number and geographic distribution of African American people with MS in the United States, the existence of barriers to access to care, and strategies required to fix inequities of access.
MS Genetic Susceptibility Project <sup>4</sup>	To find the genetic factors underlying the development of MS and affecting disease progression.

1. Grantome-NIH. Determining Enhanced Inflammatory B cell Function in African Americans with MS;
2. ARHMS Website; 3. NAAMS MS Registry Website; 4. UCSF MS Genetics Project.



# Resources for Addressing Disparities in MS

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MS Minority Health Hub

MS Minority Research Network (with HCP and research toolkits to increase diversity in trials)

Achieving Diversity, Inclusion, and Equity in Clinical Research Toolkit (MRCT Center Website)

Programs to Train Clinical Investigators Who Are Ethnic Minorities or Have Demonstrated a Commitment to Heightening Diversity in Clinical Trials

# Providing Culturally Competent Care

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- Lifelong process requiring:
  - Cultural awareness
  - Self-awareness
  - Cultural humility
  - Understanding of important concepts and terms
- As provider, be a guide—not the authority or fixer
- Directly engage in cross-cultural interactions with patients of different backgrounds
- Participate in online chats and networks

# How to Boost Cultural Competency

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- Perform a cultural competence self-assessment
- Enroll in a cultural competence training program or workshop
- Minimize communication and language barriers
- Directly engage in cross-cultural interactions with patients of different backgrounds
- Participate in online chats and networks

# MS in Black Americans: Takeaways

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- Despite higher risk of MS, African Americans tend to be diagnosed later, have more severe disease, and may be less responsive to first-line disease-modifying treatments than White Americans
- Black Americans often distrust healthcare providers and researchers, may not have a primary care provider, and may lack access to healthcare
- Religious beliefs may lead them to rely on prayer for healing rather than medicine, delaying care



# MS in Black Americans: Communication Tips

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- Encourage patients to participate in support groups
- Identify a network of African-American providers to refer patients to
- Educate patients about their disease and how to manage it, including medication adherence
- Encourage patients to bring family and friends to medical appointments
- Talk about cultural concerns
- Encourage patients to take part in clinical trial



# MS in Hispanic Americans: Takeaways and Communication Tips

- Hispanic people have a much lower risk of MS than Caucasians
- Tend to have low health literacy and language barriers
- Strong cultural beliefs: They may attribute health issues to emotions, which can undermine diagnosis, prognosis, and treatment
- Hispanic people are responsive to caring treatment
- Include whole family in patient visits, as they make treatment decisions as a unit



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# MS in Asian Groups: Takeaways and Communication Tips

- Chinese culture values stoicism, productivity, family
  - Believe they should be able to handle pain and that illness leading to disability is shameful and should be hidden
  - *Example:* Silence from a patient may be interpreted as disinterest when it is really due to a lack of understanding or is intended as a sign of respect
- Language barriers may be an issue
- May distrust Western medicine
- Important to educate and normalize MS for Asian patients



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# MS in LGBTQIA+ Patients: Takeaways and Communication Tips

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- Don't assume a patient's sexuality without asking about it
- Ask open-ended questions
- Refer to other providers if you are uncomfortable with patients' sexuality—just as you would for heterosexuals
- Give out LGBTQIA+-inclusive information—not just brochures featuring photos of heterosexuals



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# Resources to Expand Knowledge About LGBTQIA+ Patients

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- National LGBTQIA+ Health Education Center  
Provides educational programs, resources, and consultation to healthcare organizations to optimize quality, cost-effective healthcare for lesbian, gay, bisexual, transgender, queer, intersex, asexual, and all sexual and gender minority (LGBTQIA+) people.  
<https://www.lgbtqiahealtheducation.org/>
- “How to Care for LGBTQIA+ Patients” by Shari Berg  
<https://www.incrediblehealth.com/blog/how-to-care-for-lgbtqia-patients/>

# Nursing Implications

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- Providing culturally competent care takes extra effort but is essential to optimal care of the diverse MS population in the United States
- Additional education to serve diverse populations is advisable
- Have an interpreter on hand and visual aids for visits with patients with whom you don't share a language, including brochures featuring LGBTQIA+ couples