

Ethno-cultural diversity in MS care: the Hispanic experience

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Disclosures

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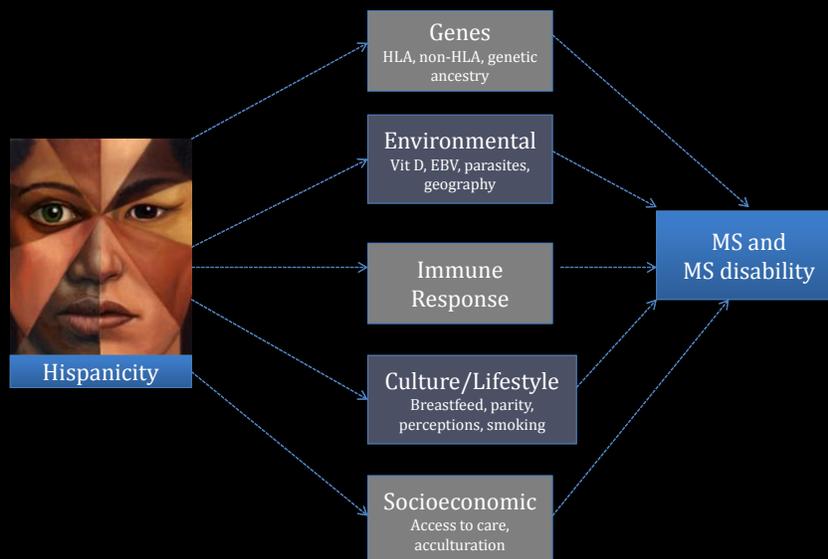
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- ✧ Race to Erase MS –Young Investigator Award

Goals of Today

- To provide a review on the current literature supporting clinical differences between Hispanics and whites
- To provide information on common barriers to health care in Hispanics
- To inform about current and innovative tools being investigated targeting disease awareness in Hispanics

Race/Ethnicity in MS



USC Hispanic Registry

Table 1: Productivity in building the Hispanic MS Registry

Hispanic USC Registry	Recruited	Data collected						Blood Sampling	
		Phase	n	Demographics	Ethnicity	Clinical Disease Measures	MRI	Migration History	Lab Values
Phase 1 (2008)	142*	X	Hispanic, plus whites (n=100)	X	X	X	X	0	0
Phase 2 (2011)	206	X	Hispanic only	X	n=206*	X	Vitamin D (n=160)*	n=60*	n=140
Phase 3 (2014)	400	X	Hispanic only	X	X	n=304*	X	n=260	n=260
Current Application	430+	X	Hispanic only	X	X	X	X	X	n=20; IL-6, sIL-6R, IL-17
Future		X	Multi-site	X	X	X	X	X	IL-6 SNPs and function

**indicates manuscripts/abstracts published (see References 3,7,8,39, web2), X indicates ongoing collection*

USC Hispanic MS Registry

Age of onset is younger compared to whites¹

- US born earlier age of onset²
- Late migrants at greater risk of ambulatory disability²

Clinical Presentation:

- Twice or more the risk of optic neuritis and transverse myelitis compared to whites¹
- Lower Vitamin D compared to whites³
- Spinal cord involvement is common, including LESCLs⁴
- **GENETIC:** Non-European genetic background (Asian and Amerindian) is associated with Asian features (spinal cord involvement) and disability in Hispanics⁵

1. Amezcua L, et al. Mult Scler. Aug 2011;17(8):1010-1016.
2. Amezcua, L., et al. Multiple Sclerosis and Related Disorders 2015 (4): 25-30
3. Amezcua, L, et al Journal of neurology. Dec 2012;259(12):2565-2570.
4. Amezcua L, et al Journal of neurology. 2013;260(11):2770-6.
5. Amezcua, L, et al. Ancestry: Marking its Impact in Hispanics with Multiple Sclerosis. AAN, April 2012.

Studies of Latinos With Multiple Sclerosis

- Two studies by Buchanan, et al. (2011 and 2012)
 - 99 Latinos recruited from Registry of North American Research Committee on Multiple Sclerosis (NARCOMS)
 - Recruitment letters in English with call back number for interview
 - 25 minute computer-assisted telephone survey in English
 - Interview assessed HRQOL using SF-8 Health Survey
 - S-F 8 assesses eight dimensions of HRQOL
 - Physical and mental health, overall well-being & emotional health
 - Qualitative/Quantitative Scale
 - 0 (no interference) to 10 (significant affect on daily activities)
 - Screenings for MS patients with depression

Study Results

- Mental Component Summary Model
 - Marital status significantly associated with MCS
 - Married Latinos with MS had lower mental dimensions of HRQOL
 - Employed Latinos with MS had lower mental dimensions of HRQOL
 - No significant association between age, gender, income, U.S. birthplace or parent's birthplace
 - Satisfaction with access to MS-focused care linked to higher mental dimensions
- General Conclusions on access to MS-focused care
 - “Latinos with MS from all points along the continuum of acculturation could benefit from a culturally specific focus on experiences of other Latinos with MS”

Discussion/Conclusions

- Mental health and social services play important role in comprehensive care needed by Latinos with MS
- Disparity in access to care
 - Need to improve availability of mental health services even among Latinos with excellent access to MS-focused care
- Culturally competent care
 - Vulnerability: low-income, underserved, less assimilated Latinos with MS
- Focus groups will be helpful in identifying health care needs
- Low response rate
 - 14% of of 2012 NARCOMS Project Registry Latinos completed survey

Multiple Sclerosis and Related Disorders (2015) 4, 25–30

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Journal homepage: www.elsevier.com/locate/msard

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Place of birth, age of immigration, and disability in Hispanics with multiple sclerosis

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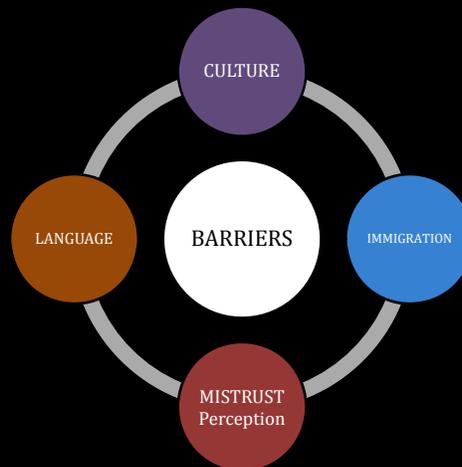
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KEYWORDS
Multiple sclerosis;
Hispanic;
Immigration;
Acculturation;
Disability

Abstract
Background: Hispanics in the US are a diverse community where their knowledge and risk for developing disability in multiple sclerosis (MS) may relate to their level of acculturation.
Objective: To compare the risk of disability in Hispanics with MS in the US by place of birth and age of immigration.
Methods: We conducted a cross-sectional study of 304 Hispanics with MS residing in Southern California. Place of birth and age of immigration were used as proxies to acculturation. Individuals were classified as US-born, early and late-immigrant (<15 and ≥15 years at immigration to the US, respectively). Risk of disability (expanded disability status scale ≥6) was adjusted for age at symptom onset, sex, socioeconomic status, and disease duration, using logistic regression.
Results: Late-immigrants were older at symptom onset (34.2 ± 11.9 vs. 31.9 ± 12.9 vs. 28.5 ± 9.7 years, p < 0.001) and had more disability (28% vs. 9% vs. 18%, p = 0.04) compared to early-immigrant and US-born respectively. There was no difference between groups by female sex, type of MS, ethnicity, chronic medical conditions, and disease duration while differences were noted by socioeconomic status. Being late-immigrant was independently associated with increased disability (adjusted OR 2.3 95% CIs 1.07–4.82; p = 0.03) compared to US-born.
Conclusion: Later immigration to the US in Hispanics with MS is associated with greater disability. These findings may reflect differences in social, environmental and cultural factors

Hispanics/Latinos in US



About 23 percent of Latinos in the United States live in poverty

(US Census/accessed 4/30/15)

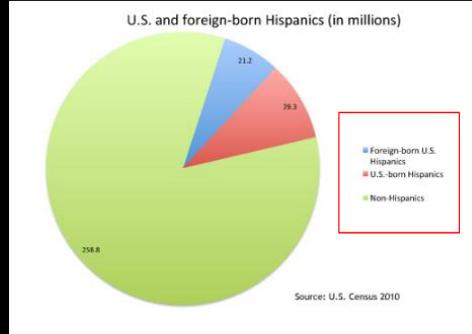
Barriers

- Cost/Expense
- Competing Priorities (i.e. work)
- Transportation
- Immigration Status
- Education
- Mistrust/Stereotypes
 - Patient view of provider
 - Provider view of patient

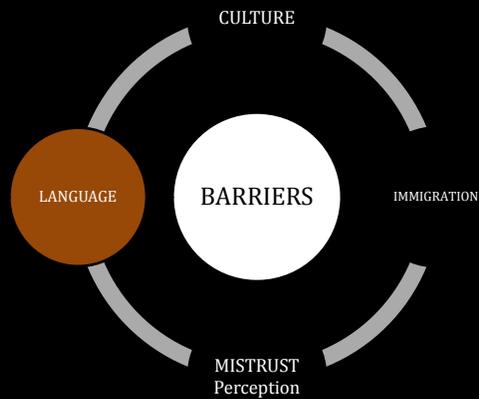
Marsella, Anthony J. *Ethnocultural Perspectives on Disaster and Trauma: Foundations, Issues, and Applications*. 1st ed. New York, NY: Springer, 2008. Springer-Verlag New York. Web. 1 May 2015.

Immigration and Acculturation

- Hispanics: A complex population of *US-born and foreign-born* immigrants
- Age of immigration and nativity are social factors.
- Acculturation: process of cultural and psychological change that results following meeting between cultures



Torres JM, Wallace SP. *American journal of public health*. Sep 2013;103(9):1619-1627. Lara M, et al. Acculturation and Latino health in the United States: *Annual review of public health*. 2005;26:367-397.



Language Barrier

- Many hospitals and offices lack trained interpreters
 - Rely on ad hoc interpretation by bilingual staff
 - Children of patients or family members
- False Fluency
 - When physicians mistake the meaning of a Spanish word because of unfamiliarity with cultural or linguistic subtleties

NMSS: Hispanic Focus Groups & Online Survey

- Focus Groups
- Conducted in 6 markets (65 participants)
 - Chicago, IL
 - El Paso, TX
 - Los Angeles, CA
 - Miami, FL
 - New York, NY
 - San Antonio, TX
- Online Survey
- Disseminated to over 2,000 individuals
 - 126 Total respondents
 - 109 (English survey)
 - 17 (Spanish survey)
 - 6% response rate

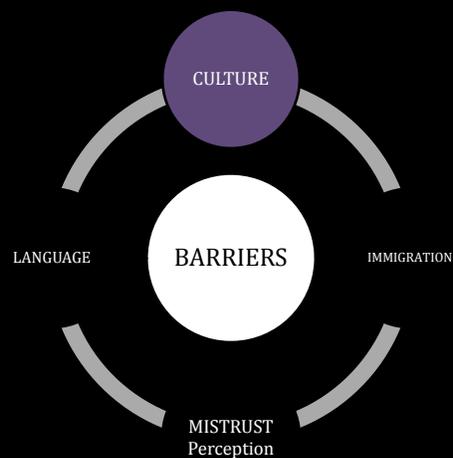
* Courtesy of Craig Wesley
(NMSS)

Preliminary results

- Bilingual content has the greatest reach
- Family members require educational resources and support
- There was a noted lack of access to educational materials in Spanish
- Priority content was identified
- Variety of access points and media identified

* Courtesy of Craig Wesley
(NMSS)

17



Culturally Competent

Culturally Sensitive

Culturally Sensible

The Concept of Culture

- “A dynamic shared system of beliefs, Values and learned patterns of behavior that are shaped by factors such as proximity, education, gender, age, and sexual preference.”
- Manifests as:
 - Language
 - Levels of Acculturation
 - SES
 - Unique health and disease models

Cultural Competence

Health care providers must:

- Be aware of social and cultural factors on health beliefs and behaviors
- Assess how these factors affect families and have tools and skills to manage these factors
- Empower patients to be active partners and to negotiate ethno-cultural beliefs and practices of the patient and those of the culture of biomedicine.

Betancourt JR, Green, AR, Carillo, JE, 2002

American Academy of Pediatrics Committee on Pediatric Workforce, 1999

Cultural Sensitivity (passive)

- “...being *aware* that cultural differences and similarities exist and have an effect on values, learning and behavior.”

Hispanic Culture

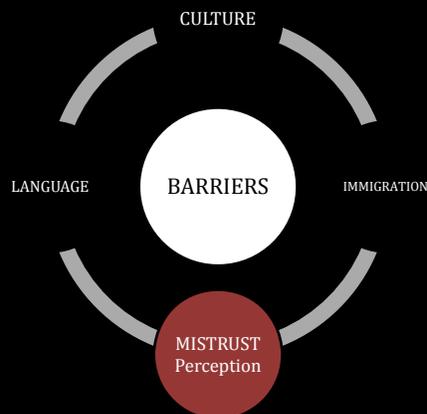
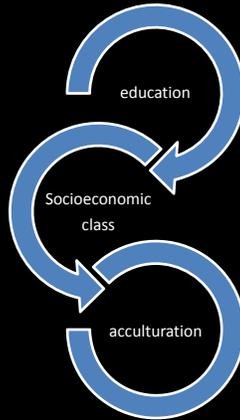
- *“Familismo”* (family ties)
 - Extended kinship system
 - Collectivistic ideals
- *“Personalismo”* (warm personal relationships)
 - Building rapport and trust
- *“Caridad”* (caring)
- *“Tener valor y Fortaleza”*
 - Idea of being brave in difficult situations
- *“Fe”*
 - Recognition of Religion
 - » Prayers and folk remedies first choice

Healthcare Beliefs and Folk Illnesses

- Non-Latino physicians may be perplexed by references to folk healing and illness
 - Latino healing traditions include:
 - Mexico: Curanderismo
 - Brazil, Cuba, Puerto Rico: Santeria and Espiritismo
- Other healing specialties include yerberas (herbalists), hueseros (bone setters), and sobadores (similar to physical therapists)

Healthcare Beliefs and Folk Illnesses

- Patients should be asked if they use alternative therapies
- Latinos do not volunteer this information



General Hispanic Perceptions

- Eye Care
 - Glasses not “well accepted”
 - Analogous to poor health and environment
 - When eye exam is necessary
 - No concept of “prevention”
 - Children’s eyes are “new” and should not have any problems
 - » Only old people need glasses
 - Tendency to use home remedies before seeking medical attention
 - Rinsing eyes with chamomile (manzanilla)
 - Confusion between vision screening and full eye exam
 - » Belief school eye exam is enough

General Hispanic Perceptions

- Mental Health
 - Evaluation of Hispanic psychopathology tainted with bias
 - Based on Caucasian model of mental health
 - Adapt personality tests for assessment of Hispanic patients
 - Create valid testing procedures for personality assessment in Hispanics
 - Surveys in Spanish as well as interpreters in Spanish
 - Communication and Understanding is key in diagnosing mental illness in Latinos

Common Culturally Patterned Mental Illnesses in Latinos

- “**espiritismo**”
 - People are surrounded by good and bad spirits
 - » Bad spirits can create mental illness
- “**Ataque nervioso**”
 - Acute hysterical reaction to an extremely stressful situation
 - » Fainting, screaming, falling, etc.
 - » Out of cultural context misdiagnosed as psychosis/schizophrenia
- “**Mal de ojo**”
 - Belief someone has cast a curse/spell on another individual
- “**Susto**” (fright)
 - State of unhappiness and/or sickness brought about by a frightful event (trauma)
 - » Belief that soul leaves the body

Perceptions about MS among Hispanic Americans: need for targeted messaging.

L. Amezcua¹, A. Polemanco¹, J. Aparicio¹, L. Tarlow¹, A. Langer-Gould²

- Using data from two focus group responses and questionnaires
- We characterized perceptions about the causes of MS into environmental, biological, and sociocultural using the following sample question:
 - “Are there any significant events you would like to report that led to your MS onset?”

Perceptions of MS

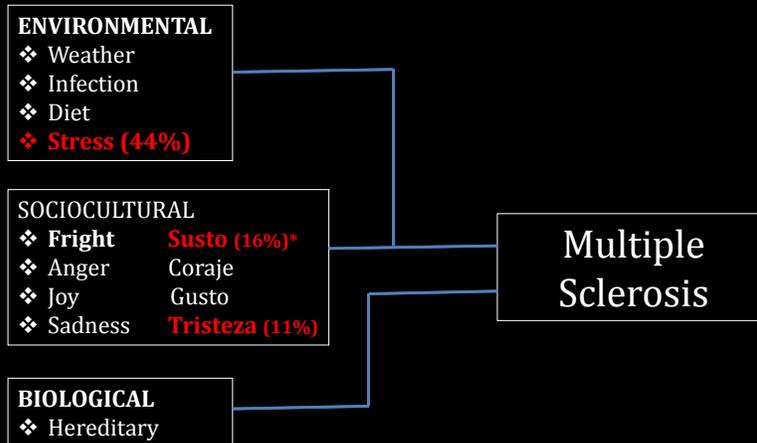


Perceptions about MS among Hispanic Americans: need for targeted messaging.

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- Out of the 97 responders
 - female (63%) with relapsing MS (89%),
 - US-Born (70%)
 - disease duration of 5.7 years (SD: 6.7)
 - college education (61%)

Perceptions of MS-prelim results



*Susto was significantly more commonly reported in individuals with low levels of acculturation (30% vs 9%, $p=0.04$)

Preliminary Conclusions

- Stress and cultural related factors were found to be commonly perceived causes of MS in Hispanics, even among more acculturated.
- These findings may have important implications for the clinical care and self-management of MS in Hispanics.
- Tailored health education interventions will be needed to reduce the misconceptions and increase awareness of MS in Hispanics.

Recommendations

- Physicians must be sensitive to Latino cultural values
- Language services

Recommendations

- Explore the use of alternative therapies and belief in traditional folk illnesses
- Recognize that health beliefs are dependent on
 - Education
 - Socioeconomic status
 - Acculturation
 - Cultural beliefs

Successful Interventions in Hispanic Patient Populations

- Cervical Cancer Screening
 - *Tamale Lesson*
 - Narrative short film (telenovela) stronger than the informational video in changing attitudes about HPV vaccine
- Diabetes Prevention
 - Utilized principles of social cognitive theory and patient-centered counseling
 - Targeted cultural beliefs/attitudes (i.e. videotape *novella*)

Teach Back and Patient Activation

- “Teach Back” or “Show Me”
 - have patients repeat their care instructions until they do it correctly
 - active dialogue and discussion

The extra time necessary for this technique is justified by the prospect of much better understanding and adherence.

Addressing the Hispanic MS Community

"Capacity building for multiple sclerosis education in Hispanic communities"

- *Promotores or Promoters* -known as community health workers, peer leaders, patient navigators or health advocates, who are recognized to play an important role in promoting community-based health education and prevention in a manner that is culturally and linguistically appropriate, particularly in communities and for populations that been historically underserved and uninsured.

Illustrate the health challenges among Hispanics with MS

- Health promoters can serve to reinforce provider's recommendations and education.
- Such measures may improve medication adherence and intensify the educational experience provided down the line.
- By educating health care community workers we have a potential of improving wellness and care among Hispanics with MS, which could also readily extend to other minority communities affected with MS.

*working together with the local chapter of the NMSS, Biogen, immigration health initiative of USC

Useful Websites

- A Physician's Practical Guide to Culturally Competent Care
 - <https://cccm.thinkculturalhealth.hhs.gov>
- Office of Minority Health: Cultural Competency
 - <http://minorityhealth.hhs.gov>

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