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MS
CONSORTIUM OF THE MULTIPLE SCLEROSIS CENTERS

MS in the Latin American Patient

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Disclosures



- None that may influence this presentation except perhaps:

"I am Mexican"



Latin America



- Area over 25 m sq km
- 36 countries and 6 Territories
- Latitudes: 32° N – 56° S
- Climate: tropical to sub-Antarctic
- Population over 550 m
- Ethnic groups: Caucasian, Mestizo, A/A black, Mulattoes, Amerindian
- Languages: Spanish, Portuguese, English, French, Dutch, indigenous dialects and others..



Definitions



RACE

- KIND OR CLASS of INDIVIDUALS with
- ▶ COMMON GENETIC CHARACTERISTICS
 - ▶ COMMON GEOGRAPHIC DISTRIBUTION
 - ENVIRONMENT DETERMINES BEHAVIOR

ETHNICITY

- MAY INVOLVE SEVERAL RACES (LARGE GROUPS OF PEOPLE) with
- ▶ COMMON TRAITS and CUSTOMS
 - ▶ COMMON or SIMILAR LANGUAGE
 - ENVIRONMENT DETERMINES BEHAVIOR



The Changing Faces of USA



- US proportion of "non-Hispanic Whites":
 - 90% in 1950
 - 69% in 2000
 - 50% in 2050
- US "Hispanics (any race)"
 - 25% in 2050 (one of each 4 people)

Mexican Office of Human Statistics:

Each family in Mexico may have a relative living in the U.S.

One of each four Mexicans resides in the U.S .



Hispanic VS Latino



Hispanic? "PERSON THAT SPEAKS SPANISH OR CLAIMS SPANISH HERITAGE"

Latino? "PERSON THAT SPEAKS A LANGUAGE DERIVED FROM LATIN" (OR A ROMANCE LANGUAGE): SPANISH, FRENCH, ITALIAN, PORTUGUESE, RUMANIAN

LATIN AMERICAN? TERM COINED IN THE XIX CENTURY



Hispanic



- Term first used in the U.S. Census forms in 1980 to replace the denomination “*persons of Spanish surname (Mexicans, Puerto Ricans, Central and South Americans or other Spanish descent)*”
- Inaccurate : excludes Brazilians, Portuguese, many African Americans, Caribbean and Caucasians of European ancestry (not Spain) from Latin American countries



Hispanic



- Convenient term widely used by politicians and influential Spanish-speaking media
- Preferred by many Mexican Americans:
 - *Naturalized citizens*
 - *Ethnic Mexican Americans* (born of Mexican ancestry)
- Also favored by Puerto Ricans
- Cubans prefer the term *Cuban American*



2000 US CENSUS DIFFICULTIES



Self-identification

- **Black Caribbean** (people of African ancestry): tend to identify themselves as ✓
“*non black, non white... other*”
- **Cuban Mulattos** : identify themselves as ✓
“*Whites*”
- **Latin Americans** : **48%** as “White”
 2% as “Black”
 6% as “other”
 42% as “Latino”



LATIN AMERICANS and MS



- **LACTRIMS**: ↑ prevalence from better diagnostic ascertainment, MRI advent,
- Brazil, Cuba and Colombia: commonly describe *Opticospinal disease* resembling more “Asiatic-Japanese” and “African” forms than “Western” MS types
- *Devic’s Disease* higher than expected prevalence in Argentina



MS Incidence/Prevalence in LATAM



- The estimated annual incidence of MS in Latin America is 0.3 to 1.9 cases per 100,000 person-years, with prevalence rates ranging from 0.75 to 21.5 per 100,000 population
- **Lowest prevalence: Ecuador**
- **Highest prevalence: Argentina and Uruguay**
- The estimated number of people diagnosed with MS in LATAM is 50,000.



US Prevalence: 100/100,000

Correale et al., Journal of the Neurological Sciences, 339 (2014) 196–206

MS Prevalence in Mexico



- Based on a population of 107,449,525 and a prevalence of 10/100,000 total estimated # of cases is 15,000
- Considering the total number of neurologists (about 500) and their ratio 1/180,000, MS is most likely under diagnosed and underestimated.
- Sources: Academia Mexicana de Neurología, Consejo Mexicano de Neurología, Asociación Médica Mexicana para el Estudio de la Esclerosis Múltiple (AMMEEM), Comité Latinoamericano para la Investigación y Tratamiento de la Esclerosis Múltiple (LACTRIMS), Comité Mexicano de Investigación y Tratamiento de EM (MEXCTRIMS), Esclerosis Múltiple de México (EMMEX).



Incidence of MS in LATAM



- Reasons for the low incidence of MS have not been determined
- May be due to genetic and/or environmental factors.
- The Latin America population is very heterogeneous and comprises a multiethnic population of approximately 600 million people of Caucasian, Amerindian and African ancestry.
- In addition, numerous Latin American inhabitants are mestizos, a complex admixture of Caucasian and Amerindian (mongoloid) genes.



LATIN AMERICANS and *Multiple Sclerosis*



• SEX RATIO

- ▶ While "Caucasian" (Eur, Can, USA) MS has a 2-3♀: 1♂ ratio:
- ▶ Houston (Mexican Americans) 4.6♀: 1♂
- ▶ Monterrey (Mexicans) 6♀: 1♂
- ▶ Chihuahua (Mexicans) 4♀: 1♂
- ▶ Central American Countries 4♀: 1♂
- ▶ São Paulo (Brazilians) 4♀: 1♂



MS experts in LATAM: Consensus



• Management of relapsing–remitting multiple sclerosis in Latin America:

Practical recommendations for treatment optimization

- Jorge Correale, Edgardo Cristiano : Buenos Aires, Argentina
- Patricio Abad: Quito, Ecuador
- Regina Alvarenga, Soniza Alves-Leon : Rio de Janeiro, Brazil
- Elizabeth Armas, Arnoldo Soto : Caracas, Venezuela
- Jorge Barahona: Santiago, Chile
- Ricardo Buzó: Montevideo, Uruguay
- Teresa Corona: Mexico City, Mexico
- Fernando Gracia: Panama, Panama
- Juan García Bonitto: Bogota, Colombia
- Miguel Angel Macías: Guadalajara, Mexico
- Darwin Vizcarra: Lima, Peru



Correale et al., Journal of the Neurological Sciences, 339 (2014) 196–206

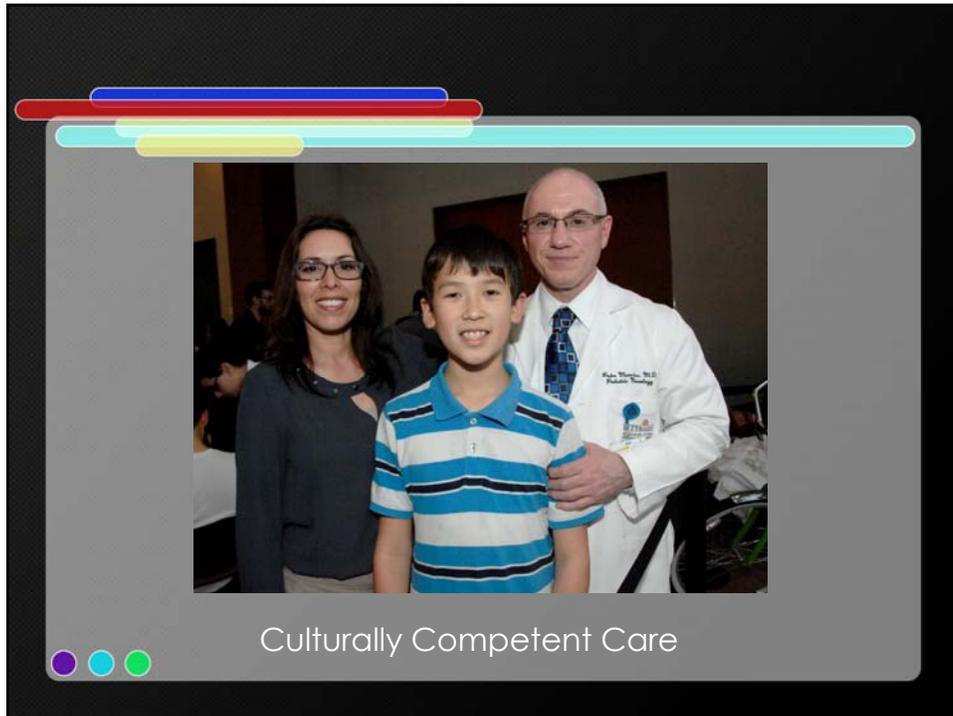
Summary of core recommendations for treatment optimization by the Latin American MS Experts' Forum



1. Patients with suspected RRMS should be referred to a specialist with expertise in demyelinating disorders for evaluation, treatment initiation and follow-up, if local conditions permit.
2. Clinicians should consider the long-term treatment plan prior to initiating therapy.
3. The initial treatment will be influenced by clinical and patient-specific factors, and guided by patient preferences that will influence adherence and persistence. A more aggressive approach is advised or patients presenting with more active disease from onset.
4. The decision as to the optimal starting therapy will be influenced by patient circumstances, drug availability and regulatory restrictions.
5. Treatment response should be based on relapse frequency/severity, disease progression and MRI findings .
6. Clinical and radiological assessments should be every 6 months; annual evaluations may be sufficient for patients with stable disease.



Correale et al., Journal of the Neurological Sciences, 339 (2014) 196–206



Culturally Competent Care ?



- A complex integration of knowledge, skills and attitudes that allow healthcare providers to understand and take care of people from cultures that are not their own
- Compassion and real communication are essential ingredients for success

Culturally Competent Tips:



- LATAM patients hold physicians in great respect (paternalistic medicine)
 - If patient was born in the US, the parents may not speak English proficiently
 - At a typical encounter you will find one to three family members:
 - Practice last name pronunciation
 - Consider greeting them in Spanish
 - Ask if they would like a translator
 - Acknowledge everyone in the room
 - Direct the conversation to the patient but
- also address the father and mother

Cultural issues



- LATAM patients tend to be sensitive and can be easily offended
- They like to be proper and use “thank you, please, excuse me and after you”
- They like to be addressed by their last name if they are adults
- Members of the opposite sex prefer to leave the room during physical exam

Cultural issues



- Depending on their level of education they may not ask any questions
- Confirm they understood the plan
- Ask them to explain what they understood
- Ask them to bring questions written for next visit.
- Referred them to proper websites



NMSS Website in Spanish



<http://www.nationalmssociety.org/Resources-Support/Library-Education-Programs/Informacion-en-Espanol>

EXAMPLES

- [La esclerosis múltiple](#)
- [Diagnóstico y tratamientos](#)
- [Manejo de síntomas](#)
- [Asuntos laborales](#)
- [Información para cuidadores](#)
- [Para niños](#)
- [Libros, Webcasts, Podcasts, y Vídeos](#)



More resources in the website



"Saber es Poder" ([Knowledge is Power - KIP en inglés](#)), por favor llame al 1-800-344-4867.

[WATCH VIDEO](#)

- **Rehabilitación en Esclerosis Múltiple**

[WATCH VIDEO](#)

- **Asuntos laborales**
- **¿Debo Trabajar? Información para Empleados que tienen EM (.pdf)**



Summary

- Hispanics will become the largest minority in the US by 2050
- Although most speak English to some degree, cultural issues are likely to be maintained
- It is our responsibility to ensure that these patients have access to the highest quality of care possible.



THANK YOU



TEXAS MEDICAL CENTER

UT Houston

