

Revealing attitudes about epilepsy in the Hispanic community

In the US:⁴

Epilepsy (*eh-puh-lep-see*) is a complex neurological disease. It can have a huge impact on the individual and those around them by:¹⁻³

- Reducing quality of life
- Negatively impacting mental and physical health

3.4m
people are living with epilepsy

~1 in 5

people diagnosed with epilepsy are Hispanic

There are around **710,000** Hispanic people living with epilepsy (HPwE)



The Hispanic Cultural Attitudes Regarding Epilepsy (CARE) study⁵ revealed the challenges faced by those living with epilepsy in US Mexican-Hispanic communities.

WHAT MAY AFFECT THE EXPERIENCE OF HISPANIC PEOPLE LIVING WITH EPILEPSY (HPwE)?

SOCIO-ECONOMIC SITUATION

HPwE and their caregivers may struggle to access healthcare due to social and economic factors:

Language barriers

- Scarcity of information available in Spanish

"Almost all information is in English. Very few neurologists speak Spanish."

– Patient

- Interpreters, who are not experts in epilepsy, may be unable to express nuanced patient experiences and feelings to doctors

Cultural misalignment

- Most information is not tailored to Hispanic culture and experiences
- Doctors are viewed as authority figures, so some HPwE may be less likely to raise questions

Finances



- 2 in 5** HPwE delay or avoid seeking healthcare due to costs



- 3 in 5** HPwE are worried about their ability to pay medical bills

"My mom found a doctor who spoke Spanish. We felt more confident with him, but my insurance didn't cover it."

– Patient

Visas

- Undocumented persons fear seeking care



CULTURE^{6,7}

HPwE and their caregivers have multifaceted cultural factors to consider when accessing healthcare:

STIGMA AND MISCONCEPTIONS

- Some HPwE are often fearful of disclosing their condition and feel embarrassed about having seizures in public

"Hispanics have to be strong, macho. Not weak. I feel weak. My mom didn't talk about it; didn't want people to see me as weak."

– Patient

- HPwE may feel they have brought shame upon the family
- Cultural belief that seizures may be due to "being possessed"
- HPwE can feel ostracized from their culture, family, work and society

"In our family, it's like a taboo. Autism or epilepsy - we don't talk about it. I never understood why because better communication means better results."

– Caregiver

PASSIVITY WHEN PRACTICING SELF-CARE IS COMMON WITHIN THE HISPANIC COMMUNITY

- Some people may deflect seeking preventative or proactive healthcare unless they are visibly sick, or illness involves their children
- Some people may associate good and bad experiences in life with their faith, reducing the urgency to seek care

CONFLICTED FEELINGS ABOUT "CONTROL"

- Some HPwE do not want epilepsy or medication to control their lives, but acknowledge control partly comes from adherence to medication
- HPwE may use their faith to find balance so they regain control and positivity

MULTI-GENERATIONAL FAMILY INVOLVEMENT IS TYPICAL

- Hispanic communities generally approach life through a collective lens. Epilepsy is front and center for the whole family
- Caregivers are primarily family members who take personal responsibility and feel guilt for the well-being and quality of life of the patient

"My sister is anxious [for her daughter]. We help her: with medication for my niece, [to] be there for her, go with her, always taking turns, always with her, always alert."

– Caregiver

OPTIMIZING THE CARE EXPERIENCE FOR HISPANIC PEOPLE WITH EPILEPSY

Recognize the diversity of HPwE and what cultural values are important to them



To deliver care that aligns with their beliefs, lifestyle and customs

Change the narrative



To debunk cultural misconceptions to empower HPwE and their caregivers

Assign a Spanish speaking doctor or other HCP, when possible



To build trust and vital connection, while avoiding misinterpretation

Ensure interpreters are aware of Hispanic culture, language, dialect and condition-related nuances



To improve the effectiveness of conversations both ways

Develop culturally relevant materials in Spanish, rather than translating from English



To increase health literacy. "Knowledge is power, not fear."

Use highly visual or video formats for sharing information



To make information more accessible

Use text messages and the QuestionBuilder app to help HPwE prepare for their appointment



To promote health equity by using accessible technology

A successful relationship between a doctor, their patient and the patient's family is highly reliant on the environment created by the doctor. Consider:



- Building trust by inviting and asking questions
- Listening without judgment and showing respect
- Being warm and maintaining eye contact
- Learning more about the healthcare experiences of HPwE
- Getting to know the patient, their family and their journey
- Helping the patient and family feel at ease
- Involving the family in decision-making

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