

## Qué es la Epilepsia? Attitudes and knowledge of epilepsy by Spanish-speaking adults in the United States

Joseph I. Sirven<sup>a,\*</sup>, Ricardo A. Lopez<sup>b</sup>, Blanca Vazquez<sup>c</sup>, Peter Van Haverbeke<sup>d</sup>

<sup>a</sup> Department of Neurology, Mayo Clinic, Mayo Clinic College of Medicine, Scottsdale, AZ, USA

<sup>b</sup> Hispanic Research, East Brunswick, NJ, USA

<sup>c</sup> Department of Neurology, New York University College of Medicine, New York, NY, USA

<sup>d</sup> Peter Van Haverbeke, Epilepsy Foundation, Landover, MD, USA

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### Abstract

**Background.** Spanish-speaking adults are the largest minority population group in the United States and are disproportionately afflicted by epilepsy.

**Methods.** A unique 78-item survey instrument conducted entirely in Spanish and devoted to the topic of epilepsy was administered to 760 Spanish-speaking adults in seven large U.S. Hispanic metropolitan areas representing a cross section of the U.S. Hispanic community. The answers were compared with those of 272 non-Hispanic controls administered the same survey in English in June 2004.

**Results.** The Hispanic sample correlated well with U.S. Census data. Spanish-speaking adults are mostly unaware about epilepsy, with 21% reporting no familiarity with the condition ( $P = 0.0001$ ). The vast majority of Hispanics use the term *convulsiones* or *ataque* to describe a seizure. Thirteen percent of Hispanics with less than high school education believe that epilepsy is contagious ( $P = 0.0001$ ); 8% see “sins” as a cause of seizures ( $P = 0.0001$ ); and 10% agree that “exorcism” would be a good remedy ( $P = 0.002$ ).

**Conclusions.** There is considerable misinformation about epilepsy in the U.S. Hispanic community. Neurologists must be made aware of U.S. Hispanic attitudes and beliefs regarding epilepsy to provide culturally competent care.

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**Keywords:** Hispanics; Seizures; Epilepsy; Stigma; Healthcare disparities

### 1. Introduction

The U.S. Hispanic population has surpassed African-Americans as the largest minority group [1]. This population has witnessed tremendous growth over the past 30 years, accounting for 6% of the U.S. population in 1960 to 12.6% in 2000; it is projected to account for 25% of the population by 2050 [1]. Yet, despite their increasing numbers, the group remains an enigma to many Americans. One reason is the heterogeneity of the cultures

and the countries of origin of U.S. Hispanics. Many Americans often mistakenly view Hispanics as a single entity when the only common bond between many of the major subgroups of Hispanic Americans is the Spanish language, which can effectively stop assimilation into the greater English-speaking population.

For neurological conditions that rely on accurate clinical histories for diagnosis and treatment, caring for Hispanics with limited English proficiency may be especially challenging and may lead to poor health outcomes. Because of communication and economic barriers, many Hispanics are not able to access health care systems [2,3]. The Institute of Medicine (IOM) warned

\* Corresponding author. Fax: +1 480 342 2544.

E-mail address: [Sirven.Joseph@mayo.edu](mailto:Sirven.Joseph@mayo.edu) (J.I. Sirven).

of this “unequal treatment” minorities face when attempting to enter the health system [4].

Seizures are a common condition found in all populations but have a twofold higher incidence in Spanish-speaking adults in the United States (Hispanics) [5]. This is explained by the high prevalence of epileptogenic conditions such as cysticercosis, birth trauma, head trauma, and stroke in U.S. Hispanics [2]. Moreover, Hispanics with epilepsy often carry a larger burden of disease because of the considerable social ostracism that seizures invoke. Because there is no literature investigating the attitudes and beliefs of Hispanic Americans toward epilepsy or any neurological condition, the objective of this study was to identify, document, and quantify specific culturally based attitudes, beliefs, fears, and understanding regarding seizures and epilepsy by conducting a national telephone survey. The results can then be used for public education campaigns, as well as by clinicians who require insight into how best to deliver neurological care for Spanish-speaking adults in the United States with seizures.

## 2. Methods

A 78-item Spanish-language telephone survey devoted to the topic of epilepsy was conducted in June 2004 with 760 Spanish-speaking adults living in the United States drawn from a Hispanic marketing research database in seven of the largest U.S. Hispanic metropolitan areas, including: Chicago (109), New York (108), Miami (108), San Antonio (109), Phoenix (108), San Diego (108), and Los Angeles (110). These seven metropolitan areas are representative of the U.S. Spanish-speaking population. The survey respondents were chosen at random. The sample was equally divided between male and female heads of household. All respondents were 18 years of age or older. Survey respondents identified themselves as Hispanic, and all interviews were conducted in Spanish. The survey was written by two Spanish-speaking neurologists (J.S., B.V.).

A separate sample of 272 non-Hispanic respondents was used as the control group. The identical English version of the survey was administered to the control group sample drawn from a national list of random telephone numbers and was geographically divided as follows: Northeast (16%), Midwest (17%), South (31%), Mountain (13%), Pacific (23%).

Demographic variables including age, gender, country of birth, income level, and education were noted. Demographic characteristics and survey responses were compared between the Hispanic group and the controls using a two-tailed *t* test. In this report, the term *Hispanic* refers to Spanish-speaking adults in the United States.

## 3. Results

### 3.1. Demographic variables

The demographic characteristics of our survey correlate well with U.S. Census data [1] in that they show the Hispanic population as younger and with lower income and lower education levels. Of the 760 respondents, 41% spoke only Spanish. As can be seen in Table 1, a significantly larger number of Hispanics fell between the ages of 18 and 34 (42%) than did non-Hispanics (27%,  $P = 0.0001$ ). The majority of the Hispanics surveyed (73%) had household incomes below \$40,000. In contrast, significantly less than half (41%) of the non-Hispanic respondents indicated a household income level below \$40,000 ( $P = 0.0001$ ). The education levels also exhibit great disparity. More than two-thirds (69%) of Hispanics had no more than a high school education. The reverse is true for non-Hispanics; the same number (69%) had *more* than a high school education ( $P < 0.0001$ ).

Overall, the distribution of the Hispanic survey sample based on the Hispanic country of origin mirrored the U.S. Census data [1]. Fourteen percent of respondents were born in the United States, 18% had lived in the United States less than 5 years, and 45% had been in this

Table 1  
Summary of demographic characteristics

	Hispanic ( <i>N</i> = 760)	Non-Hispanic ( <i>N</i> = 272)	Significance, <i>P</i>
Age <sup>a</sup>			
18–24	13%	9%	0.1056
25–34 <sup>a</sup>	29%	18%	0.0002
35–49	36%	31%	0.1509
50–64 <sup>a</sup>	16%	23%	0.0243
≥65 <sup>a</sup>	6%	20%	0.0001
Gender <sup>a</sup>			
Male	50%	59%	0.0389
Female	50%	41%	0.0389
Born in the United States <sup>a</sup>	14%	93%	0.0001
Income <sup>a</sup>			
<\$25,000 <sup>a</sup>	51%	19%	0.0001
\$25,000–39,000	22%	22%	0.8483
\$40,000–64,000 <sup>a</sup>	9%	24%	0.0001
\$65,000–79,000 <sup>a</sup>	2%	9%	0.0007
≥\$80,000 <sup>a</sup>	3%	18%	0.0001
Refused	13%	8%	0.0943
Education <sup>a</sup>			
Less than high school <sup>a</sup>	26%	6%	0.0001
High school <sup>a</sup>	43%	25%	0.0001
Some college <sup>a</sup>	14%	27%	0.0002
Trade or technical school	6%	6%	0.6888
College graduate <sup>a</sup>	6%	25%	0.0001
Postgraduate work <sup>a</sup>	3%	11%	0.0003
Refused	1%	1%	0.7011

<sup>a</sup> Denotes significant difference.

country longer than 10 years. In general, the survey sample can be categorized as arising from the following Hispanic world regions: Mexico—62%, Caribbean—11%, Central America—10%, and other—17%.

### 3.2. Knowledge of epilepsy

Epilepsy does not seem to have a defined image by U.S. Hispanics. Close to one-fifth (21%) are not at all familiar with the disorder as compared with our non-Hispanic sample ( $P = 0.0001$ ). Overall, 49% of all Hispanics said that they know someone with epilepsy. This is no different from the non-Hispanic response (47%). When asked about their relationship to the person with epilepsy, there was no difference between the Hispanic and non-Hispanic surveys. The proportions were also similar to those found in prior research commissioned by the Epilepsy Foundation [6,7]. One percent of the respondents in our survey had epilepsy themselves.

### 3.3. Perceptions of epilepsy

The vast majority of Hispanics use the term *convulsiones* (77%) or *ataque* (60%) to describe a seizure. Seizures are often perceived as a result of bad behavior or contagious illnesses. *Sobredosis*, which translates as an “overdose,” was the third most common term for seizures at 37%, suggesting a connection to drug or alcohol abuse. Twenty percent of the Hispanics surveyed thought that young individuals with generalized tonic-clonic seizures were drunk or on drugs ( $P = 0.0001$ ). In the same vein, 16% of the Hispanic respondents thought that individuals experiencing a complex partial seizure were drunk or on drugs, while only 9% of the non-Hispanics agreed that individuals were drunk or on drugs ( $P = 0.0001$ ). Interestingly, although there is no difference in their death perception of the convulsive seizure type, more Hispanics (25%,  $P = 0.0001$ ) perceived the complex partial seizure as related to dying than did non-Hispanics (8%).

Figs. 1 and 2 detail the main responses from Hispanics and non-Hispanic controls. Hispanics were significantly more likely than non-Hispanics to attribute epilepsy to common etiologies such as brain tumors (63%,  $P = 0.0002$ ), lack of oxygen at birth (56%,  $P = 0.0001$ ), a head injury as an infant (54%,  $P = 0.0007$ ), meningitis (31%,  $P = 0.0001$ ), and eating undercooked pork (30%,  $P = 0.0001$ ). However, 8% ( $P = 0.0001$ ) of Hispanics interviewed agreed that “sins” are a cause of epilepsy. Along the same lines, 9% of all Hispanic respondents agreed that “lack of spiritual faith” causes epilepsy. Finally, 6% ( $P = 0.0003$ ) of the Hispanics surveyed agreed that “epilepsy can be contagious” or is caused by lack of intelligence (9%,  $P = 0.0001$ ). While these numbers are relatively small,

the opinions do seem to prevail among the less educated Hispanics. For example, among Spanish-speaking adults with less than a high school education, the proportion agreeing that epilepsy can be contagious more than doubles from 6 to 13% ( $P = 0.0001$ ).

A person with epilepsy was perceived as “dangerous to others” by 31% of the Hispanic respondents (see Fig. 1). Only 17% of the non-Hispanics interviewed agreed ( $P = 0.0001$ ). Fear of the supernatural and diabolical was a factor in the perception of seizures. Eight percent ( $P = 0.0007$ ) of all Hispanics interviewed agreed that being possessed by an evil spirit is one of the causes of epilepsy. Moreover, among the segment of Hispanics with less than a high school education, these figures go up to 15% ( $P = 0.0001$ ) for being possessed by an evil spirit, and 10% ( $P = 0.002$ ) agreed that exorcism would be a good remedy for seizures.

### 3.4. The hispanic family and epilepsy

Fig. 2 demonstrates the differences between Hispanics and non-Hispanics with respect to overprotection. The majority of the Hispanics responding to our survey (68%,  $P = 0.0001$ ) agreed that a person with epilepsy needs total supervision. Only 1 of 10 (11%) non-Hispanics agreed. Overall, many Hispanics feel that a person with epilepsy is unlikely to get married (32%,  $P = 0.0001$ ), cannot hold a steady job (31%,  $P = 0.0001$ ), and would not be allowed to drive a car (36%,  $P = 0.019$ ). These proportions are significantly higher than those of non-Hispanics (3, 4, and 27%, respectively). Moreover, the majority of Hispanics (53%) agreed that a family is likely to hide that a member has epilepsy ( $P = 0.0001$ ).

### 3.5. Epilepsy treatments

Hispanics seem to place a lot of emphasis on taking care of the mind and body as a treatment for epilepsy Fig. 3. They were significantly more likely to agree with treating epilepsy by avoiding stress (75%,  $P = 0.0058$ ), maintaining a healthy diet (65%,  $P = 0.0001$ ), sleeping well (65%,  $P = 0.0001$ ), exercising (63%,  $P = 0.0001$ ), taking vitamins (62%,  $P = 0.0001$ ), and using herbal remedies (30%,  $P = 0.0001$ ).

### 3.6. Response to a seizure

While both the vast majority of Hispanic and non-Hispanic controls agreed that they would call 911, the police, or other emergency help in response to witnessing a seizure, Hispanics were also significantly more likely than non-Hispanics to scream for help (83% vs 57%,  $P = 0.0001$ ), pray quietly (55% vs 39%,  $P = 0.0003$ ), restrain the person (50% vs 36%,  $P = 0.0017$ ), or perform a religious ritual (14% vs 3%,  $P = 0.0001$ ).

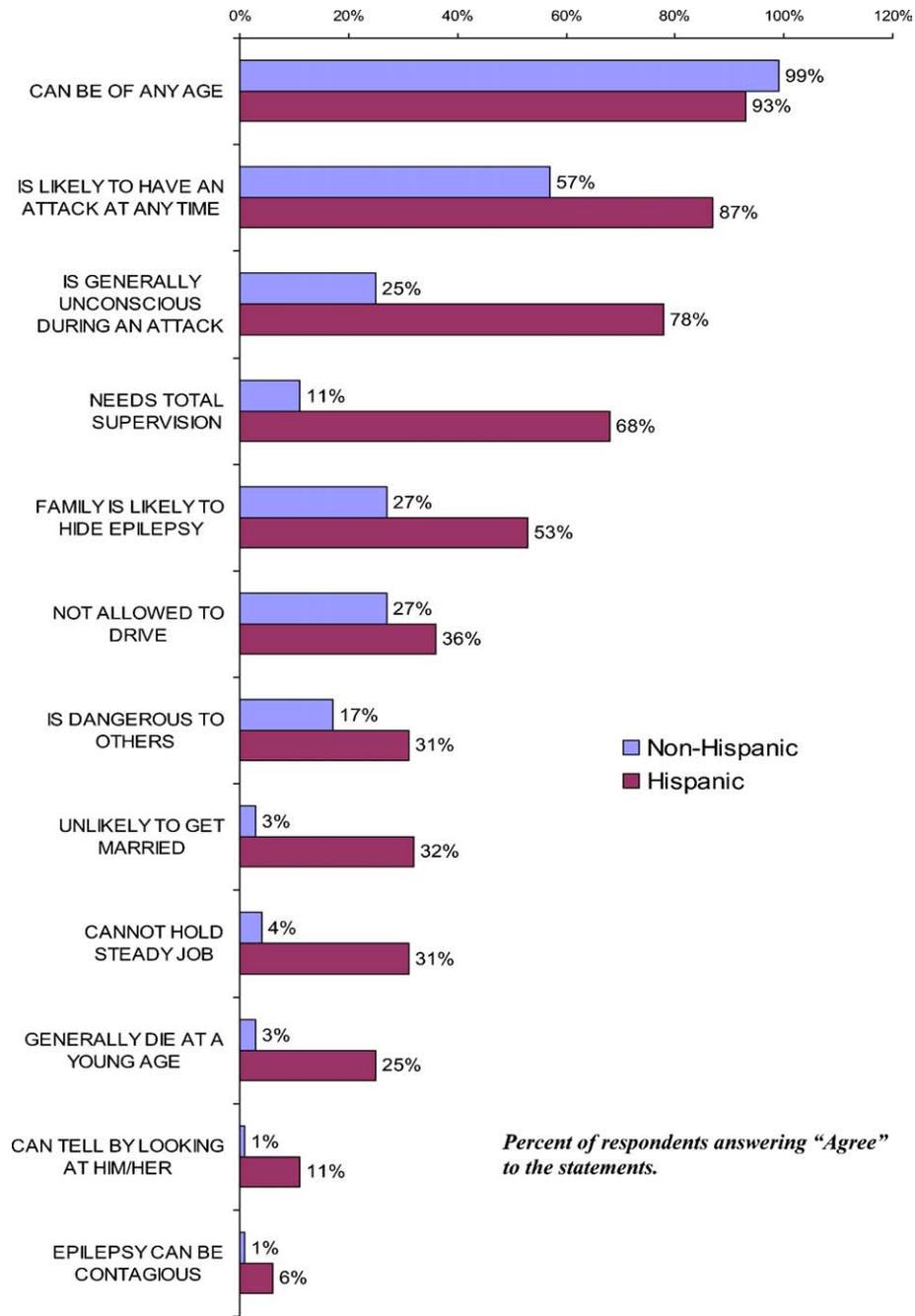


Fig. 1. What do you know about epilepsy? Responses of the Hispanic group differed significantly from those of non-Hispanic controls.

**4. Discussion**

This study is the first to address the attitudes and perceptions of seizures and epilepsy by the Hispanic population in the United States. Although Spanish-speaking adults in the United States are a heterogeneous group, our sample demographics compare well with U.S. Census Bureau statistics [1]. According to the 2004 Census, 67% of American Hispanics are of Mexican descent; in our survey, 62% were of Mexican origin. The proportion of Puerto Ricans participating in this survey was lower

(3.3%) than the figure quoted by the Census Bureau (8.6%) [1], whereas the proportion of Cubans was higher in our sample (5.1%) than the proportion in the Census Bureau (3.7%) [1]. It should be noted that 5% of Hispanics surveyed chose the United States as their country of origin. This is not unusual as many Hispanics whose family history in the United States goes back more than two generations do not identify with a different country as their origin.

Many Hispanics are unaware about epilepsy and there appears to be no defined image of the condition

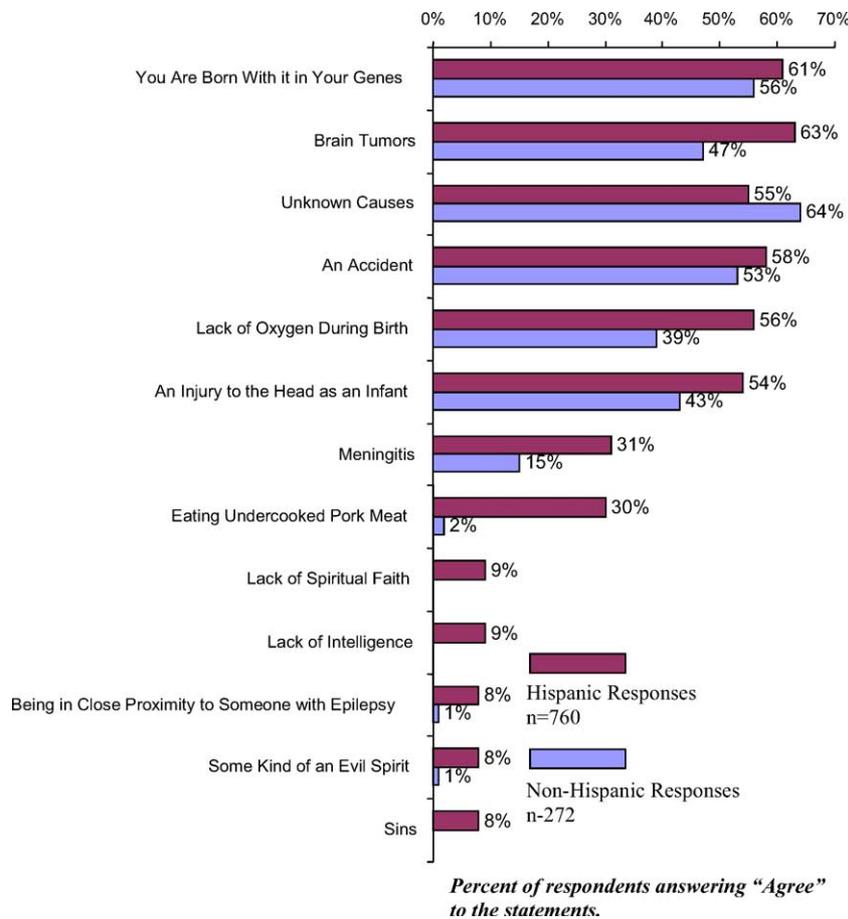


Fig. 2. Perceived causes of epilepsy. Please note that all responses were statistically different except for “you are born with it in your genes” and “lack of oxygen during birth.”

in the Hispanic community, which can result in misguided assumptions. The limited knowledge that Hispanics have of epilepsy is based largely on their experience with witnessing a seizure.

One of the misguided assumptions regarding epilepsy is the relationship of seizures to death. Our survey found that Spanish-speaking people in the United States were more likely to relate complex partial and convulsive seizures to dying. Diseases and conditions that are perceived as leading to death not only are the most feared in Hispanic communities but are also the ones that create the highest levels of social stigma [8]. Thus, any clinical or public health education about epilepsy must address the misconception that epilepsy generally leads to death.

Social stigmas are commonly identified as one of the greatest burdens of epilepsy and as the burdens with the most impact on quality of life. U.S. Hispanics surveyed had several misperceptions that can easily create stigma. The misperceptions revolved around the idea that seizures were a result of either bad behavior, an infectious condition, a fear of the individual as dangerous, or the thought that supernatural forces were somehow at work. These opinions seem to prevail among the less educated Hispanics. Given that most of the growth in

the Hispanic population is due to newly arrived immigrants, with lower education levels [1], and a language information barrier impeding education, most Hispanics seem to rely on word-of-mouth as their primary source of knowledge. Therefore, it is important to dedicate resources in disbanding seizure myths either directly within the context of a clinical visit or via Spanish-language mass media.

U.S. Hispanics are more likely to overprotect individuals with seizures and epilepsy. When a family member has a physical or mental handicap, Hispanics increase their overprotection [9]. A person with epilepsy is often considered by Hispanics to require total supervision. This was clearly illustrated by the results. Because of the interdependence of the family unit, Hispanics are not only protecting the person with epilepsy, but also sheltering the family against possible social stigmas. This helps to explain why the majority of Hispanics were likely to hide a member of the family with epilepsy.

There were several heartening findings to note. Hispanics attributed epilepsy to several common preventable etiologies such as cysticercosis, head trauma, and birth trauma. Also encouraging was the emphasis on taking care of the mind and body as a treatment for epi-

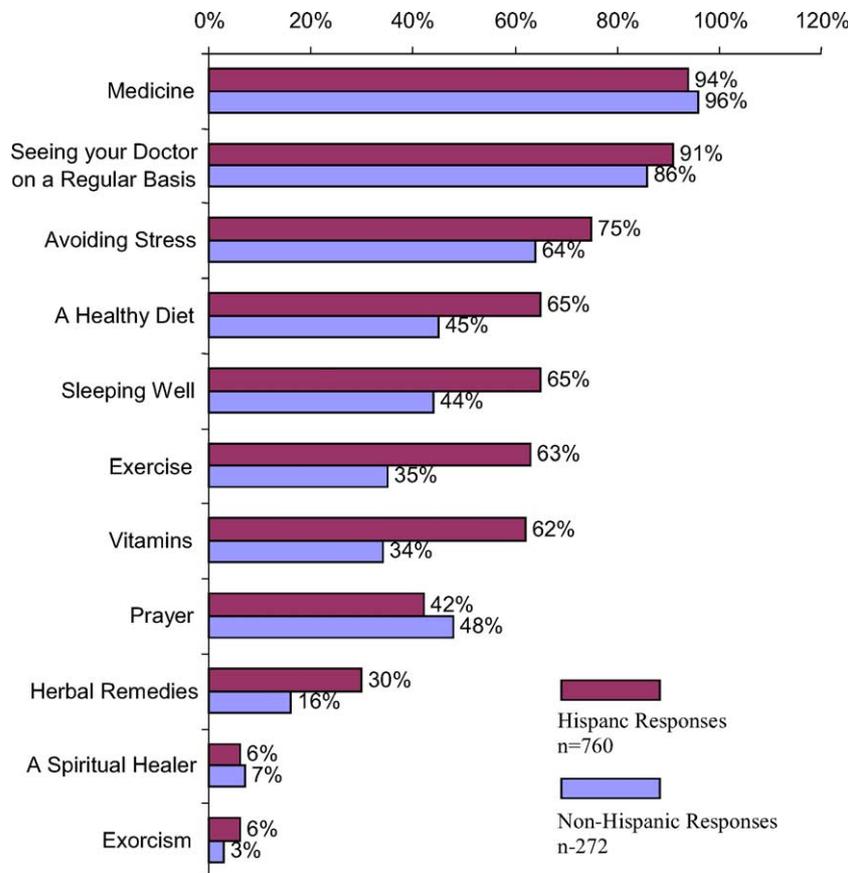


Fig. 3. Percent that agree with the treatment. Statistically different responses included: avoiding stress, diet, sleeping well, exercise, vitamins, and herbals. Exorcism was statistically different only for Hispanics with less than a high school education.

lepsy such as avoiding stress, maintaining a healthy diet, sleeping well, exercising, and taking vitamins. Importantly, Spanish-speaking adults in the United States were more willing to get involved in helping a person experiencing a seizure. These hopeful results can serve as a starting point for public health educational initiatives. Information in Spanish is needed to address the preventable causes of epilepsy and improve awareness of the various medical and surgical therapies available for the condition.

This survey has a number of limitations. First, Hispanics of Mexican origin constituted the majority of survey respondents. Thus, the survey is more representative of Hispanics of Mexican origin who are new to the United States and have a limited education and lower income. Yet, it is this group that is the largest segment of U.S. Hispanics and the most vulnerable to the medical and psychosocial burden of epilepsy that many neurologists commonly encounter and struggle to help. Consequently, the results of this survey do not necessarily translate to all Spanish-speaking populations in the United States. Lastly, there were several demographic variables on which Hispanics significantly differed from non-Hispanic controls. However, our Hispanic sample is an accurate snapshot of a changing U.S. Hispanic pop-

ulation as described by recent U.S. Census Bureau data. Our results can serve as a starting point for further exploration of the topic.

This survey has important implications for practicing neurologists, primary care and emergency room physicians, nurses, and all health practitioners who commonly deal with Hispanic patients with acute and chronic seizures. It is important to know that the terms *convulsiones* and *ataque* are the most commonly used for seizures. More time needs to be devoted to education and counseling during clinic visits with Hispanics to debunk the myriad of myths associated with the condition so as to lessen the burden of disease. One must be prepared to bridge the cultural and language barriers that typify this patient encounter to provide culturally competent care. Seizure education should be delivered in a factually direct manner using Spanish-language audiovisual media as opposed to books or pamphlets that rely on literacy. This is an important issue because cultural barriers can lead to underutilization of effective therapies [10,11]. The only certainty we have is that Spanish-speaking patients with epilepsy or any neurological condition will be increasingly more commonplace regardless of the location of one's practice in the United States, and we must be prepared to care for them.

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## Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at [doi:10.1016/j.yebeh.2005.04.015](https://doi.org/10.1016/j.yebeh.2005.04.015).

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