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Authors

Withers, Mellissa
Sayegh, Philip
Rodriguez-Agudelo, Yaneth
et al.

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A mixed-methods study of cultural beliefs about dementia and genetic testing among Mexicans and Mexican-Americans at-risk for autosomal dominant Alzheimer's disease

Mellissa Withers[1], **Philip Sayegh**[2], **Yaneth Rodriguez-Agudelo**[3], **Karin Ernstrom**[6], **Rema Raman**[6], **Lucy Montoya**[4], **Angelica Zuno-Reyes**[5], **Chizoba Mosieri**[1], **Esmeralda Matute**[5], **John M. Ringman**[4]

[1]Keck School of Medicine, University of Southern California, Los Angeles, California, USA

[2]Department of Psychology, University of California, Los Angeles, Los Angeles, California, USA

[3]National Institute of Neurology and Neurosurgery, Mexico City, Mexico

[4]Department of Neurology, University of Southern California, Los Angeles, California, USA

[5]Institute of Neurosciences, University of Guadalajara, Guadalajara, Mexico

[6]Alzheimer's Therapeutic Research Institute, University of Southern California, Los Angeles, California, USA

Abstract

BACKGROUND: Trials to prevent autosomal dominantly inherited Alzheimer's Disease (ADAD) are critical and timely. However, cultural beliefs about AD and genetic testing may preclude informed consent and participation, especially among racial/ethnic minorities.

OBJECTIVE: This mixed-methods study examines cultural beliefs about AD and genetic screening among at-risk populations of Mexican heritage.

METHODS: We surveyed 86 Mexican and 37 Mexican-American family members of patients with ADAD, and interviewed 18 respondents in Mexico to explore perceptions and knowledge regarding AD and genetic testing.

AFFILIATED AUTHOR CONTACT: Mellissa Withers, 2001 N Soto Street SSB 318G, Los Angeles, CA 90089 USA, tel- (323) 865-0495, fax (323) 865-0127, mwithers@usc.edu.

AUTHORS' CONTRIBUTIONS STATEMENT: Mellissa Withers was involved in all elements of this study, including data collection, analysis, and writing this paper. Philip Sayegh was involved in the design of the study protocol, instruments, analysis, and writing of this paper. Yaneth Rodriguez Agudelo, Esmeralda Matute, and Angelica Zuno Reyes were all involved in the study design, data collection and analysis, and helped write this paper. Rema Raman and Karin Ernstrom did the statistical analyses of this study's data and helped write the final paper. Chizoba Mosieri helped with the data analysis of the qualitative data. Lucy Montoya was involved in the study's data collection phases, and helped write up the results. John Ringman was the PI on this study and was involved in all elements, including data collection, analysis, and writing this paper.

HUMAN STUDIES AND INFORMED CONSENT: All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

CONFLICT OF INTEREST STATEMENT: Drs. Mellissa Withers, Philip Sayegh, Yaneth Rodriguez Agudelo, Karin Ernstrom, Rema Raman, Lucy Montoya, Angelica Zuno Reyes, Chizoba Mosieri, Esmeralda Matute, and John Ringman declare that they have no conflicts of interest.

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RESULTS: While most respondents understood that AD is inherited in their families, they also had limited understanding of the genetic mechanisms behind AD. Many believed AD is a normal part of aging or that it is a mental illness caused by bad habits. However, beliefs that AD is caused by a curse or God's will were uncommon. The interviews demonstrated that very few at-risk respondents understood their own risk for harboring the mutation causing AD in their family. Once informed, most expressed a strong interest in genetic testing, largely motivated by the desire to be better prepared for the development of AD.

CONCLUSIONS: Health professionals treating and investigators enrolling members from families with ADAD cannot assume they fully understand the nature of the illness; therefore providers should provide comprehensive information about ADAD and genetic testing.

Keywords

Alzheimer's Disease; cultural beliefs; autosomal dominant; Mexican; Ethics; Genetics; Genetic Counseling; Clinical Genetics; Public Health; Qualitative Research; Quantitative Research

Introduction

Advances in genetics and diagnostic capabilities in preclinical Alzheimer's disease (AD) have opened up opportunities for research into prevention and treatment (Jack et al., 2018). With the global increase in longevity, AD is a growing problem worldwide. Dementia affects approximately 44 million people globally, and the worldwide total economic costs caused by dementia increased from US $279.6 billion in 2000 to $948 billion in 2016, with an annual growth rate of 15·94% (Zu, 2017). AD comprises 60–70% of all cases of dementia (Lalli et al., 2014); prevalence is expected to increase to over 80 million people worldwide by the year 2040 (Lalli et al., 2014).

In the US, the Administration on Aging projects that between 2008 and 2030 the Latino population aged 65 years and older will increase by 224% compared to a 65% increase for the non-Latino white population in the same age category. There are approximately four million Latinos over the age of 65 living in the US today, twice as many as in 2000. Some studies suggest that Hispanics are about one and one-half times as likely to develop AD or other dementias as non-Hispanic Whites (Wu et al., 2016; Mehta, et al., 2017; Alzheimer Association, 2018). According to a report published by the University of Southern California, the number of Latinos living with AD in the US could increase from 379,000 in 2012 to 1.1 million and to 3.5 million by 2060 —a growth of 832%—if modalities to prevent, cure, or slow the progression of the disease are not developed(Wu et al., 2016).

Autosomal dominantly inherited AD (ADAD) is a rare form of AD, accounting for less than 1% of all AD cases, that typically has a relatively young age of onset. At least 286 different mutations in three genes have been identified to cause ADAD in various families in several countries (AD&FTDMDB, 2018). In persons inheriting these mutations, the development of the disease can be predicted with essentially 100% certainty. Among these, a few mutations are represented by large numbers of superficially unrelated families that actually are distantly related, descending from a common affected person as a "founder effect". At least four different groups of families with ADAD due to this founder effect have been identified

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originating from Italy (Bruni et al., 2010), Mexico (Murrell et al., 2006; Yescas et al., 2006; Ringman et al., 2009), Puerto Rico (Athan et al., 2001), and Colombia (Lalli et al., 2014). More than 65 families have been identified by the research team in Mexico and the US. with the common A431E *PSEN1* mutation originating from a founder effect, apparently in Jalisco, Mexico (Murrell et al., 2006; Yescas et al., 2006).

In addition to contributing to advances in the basic scientific understanding of AD, families with this fully-penetrant genetic cause of AD represent an ideal population for preventative trials because the development and timing of symptom onset can be predicted in asymptomatic mutation-carrying individuals (Ryman et al., 2014), which would allow the initiation of sensitive therapeutic trials years or even decades before clinical onset (Bateman et al., 2010; Ringman et al., 2009). Prevention trials for ADAD are underway in Colombia, the US, and several other high-income countries (Reiman et al., 2011; Mills et al., 2013). Though clinical trials in preclinical persons inheriting ADAD mutations might initially appear to be straight-forward endeavors, there are many barriers to their implementation. Ringman et al. (2005) highlighted the practical and ethical challenges in research and clinical trials for this population. Lack of understanding of the causes of AD, the rationale for specific study designs, and an understanding of the nature of genetic risk are just some of the barriers to the meaningful informed consent required for such complex studies.

Cultural beliefs influence the way in which AD is recognized and understood, which may influence health-seeking behaviors and subsequent treatment. Furthermore, racial/ethnic minority groups' participation in research, including clinical trials, may also be impacted by prevalent cultural beliefs. To optimize capacity to perform clinical trials in ADAD, we must understand the prevalent beliefs and attitudes regarding the disease, its origins, and barriers to clinical research participation. In this mixed methods study, we investigated knowledge, beliefs and attitudes among families at-risk for ADAD in Mexico and among Mexican-Americans living in California regarding ADAD, genetics, genetic testing, and participation in research and clinical trials.

Literature

The literature demonstrates significant differences among racial/ethnic minority groups in the US regarding understanding of AD. Studies have documented lack of knowledge regarding the etiology and trajectory of AD among racial/ethnic minorities, suggesting a high prevalence of misconceptions (Ayalon & Arean, 2004; Sink et al, 2004; Connell et al., 2007; Chin et al., 2011; Sayegh & Knight, 2012). For example, Connell et al. (2007) assessed racial differences in knowledge and attitudes about AD among a national sample of 1176 adults aged 35 years and over (48.6% non-Hispanic White, 25.7% Black, and 25.8% Hispanic). Black and Hispanic respondents were significantly more likely to believe that AD is a normal part of aging. Sayegh & Knight (2012) also found in their literature review of cross-cultural differences in dementia that a number of studies indicate that caregivers from ethnic minority groups are more likely to view memory loss as a normal part of aging than Whites.

Research on attitudes towards genetic testing for AD also demonstrates differences between racial/ethnic minorities and non-Hispanic Whites in the US, although most of this work has

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been conducted among African-Americans (Hipps et al., 2004; Akinleye et al., 2011). Hipps et al. (2004) examined differences between 452 non-Hispanic Whites and African Americans with regard to testing for risk of late-onset AD. Both groups indicated general interest in predictive genetic testing for late-onset AD and believed it should be offered with few restrictions. However, in comparison to non-Hispanic Whites, African Americans showed significantly less interest in testing ($p<0.01$), endorsed fewer reasons for pursuing it ($p<0.01$), and anticipated fewer negative consequences from a positive test result ($p<0.001$). Akinleye et al. (2011) also examined differences in attitudes regarding genetic testing for AD between African Americans and non-Hispanic Whites. In comparison to non-Hispanic Whites, African Americans were less knowledgeable about genetics and AD risk and were less concerned about developing AD. However, they endorsed just as many reasons for pursuing genetic testing as non-Hispanic Whites.

Studies have also documented lower participation in clinical trials generally among Hispanics as compared with non-Hispanic Whites, although most of this work has focused on cancer trials. According to a national poll, when asked if they or someone in their family have ever participated in any clinical trial, only 17% of Hispanics said yes. Despite low levels of engagement, the poll also found that 56% of Hispanics said that the opportunity to improve the health of others is a very important reason to take part in a clinical trial and 81% said they would likely participate in a clinical trial if recommended by a doctor (Research! America, 2017). Lack of trust has been cited as a major factor in lack of participation in clinical trials among Hispanics (Byrne et al., 2014; Arevalo et al., 2016; Pariera et al., 2017). However, some researchers have found that low participation in cancer clinical trials among non-English speaking Hispanics may be related to lack of information and language barriers, not lack of willingness to participate in research (Nodora et al., 2010; Bryne et al., 2014; Arevalo et al., 2016; Pariera et al., 2017).

Methods

Respondents

Study respondents were all members of families living in Mexico or California in which ADAD mutations were known to run. Though a few respondents were in-laws, most had at least one, but often many, close relatives who have or have had the disease. All respondents gave written or verbal informed consent. This study was approved by the Institutional Review Board at the University of California, Los Angeles, the University of Southern California, the National Institute of Neurology and Neurosurgery in Mexico City, and the University of Guadalajara.

Quantitative Procedures

All survey respondents were part of a larger study in which they attended a 90-minute lay-oriented, educational presentation on basic genetics, ADAD, and participation in research, including clinical trials, given by one of the co-authors, a neurologist with a clinical and research focus in ADAD. The larger study included a total of four pre- and post-questionnaires. The presentations were designed to increase knowledge of the etiology of ADAD, genetics, genetic testing, and clinical research including interventional trials. A total

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of five presentations were conducted in health care centers or community halls between August 2015 and June 2016. All known family members of patients with ADAD being treated by the study team in Mexico or California were invited to attend the presentations.

Prior to the presentations, respondents were asked to complete four written, self-administered surveys, available in English or Spanish, including one assessing their beliefs about AD called the "Cultural Beliefs about AD" (CBAD) scale, which was developed by one of the co-investigators of this study based on a review of the relevant literature in this area (Sayegh & Knight, 2013). The CBAD scale is a 26-item questionnaire using a four-point Likert scale ranging from "strongly agree" to "strongly disagree" to rate the level of agreement or disagreement with statements such as, "Alzheimer's disease is a form of insanity" and "Alzheimer's disease results from a curse." The 26 questions can be divided into three main categories: 1) treatment and biomedical knowledge (11 questions), 2) stigma/blame (9 questions); and 3) curse/God (6 questions). After the presentation, respondents were asked to complete the surveys again to assess any changes in beliefs or knowledge. The CBAD scale was administered to a total of 123 respondents—86 Mexicans and 37 Mexican-Americans. Originally created in English, the CBAD survey was translated into Spanish by a fluently bilingual and bicultural research associate and the accuracy of translation verified independently by another fluently bilingual Spanish-speaker and adjustments made. All of the respondents in Mexico took the CBAD survey in Spanish. Of the respondents in the US, 73% preferred to take the survey in Spanish.

Quantitative Data Analysis

The data included in this paper are the pre-presentation CBAD survey results. Comparisons between countries for demographic characteristics of the respondents were performed using the Wilcoxon-rank sum test for continuous variables and the Fisher's exact test for categorical data. We also compared differences in agreement with the questions in the CBAD survey by country using the Fisher's exact test. We included the odds ratio and confidence intervals when there were at least five counts in each cell. Due to the exploratory nature of this study, we used an adjusted p-value of 0.01 to determine statistical significance. However, we have reported the odds ratios and 95% confidence intervals along with the p-values.

Qualitative Procedures

To further explore cultural beliefs about AD in Mexican populations, we conducted semi-structured, in-depth interviews with 18 family members of ADAD patients in Mexico. Most of the respondents attended one of the educational presentations; in these cases the interviews were conducted prior to the presentations. Five of the respondents did not attend any educational presentation but were identified by the local research team as being a family member of a current ADAD patient who could provide insights into the topics we were exploring. The interviews were conducted by the primary author, who is trained in medical anthropology, in Spanish in a private room at the health clinic or in the respondents' homes. The interviews lasted approximately 30–45 minutes each and were loosely structured, allowing for flexibility and responsiveness to the topics that are most salient to each respondent. The question guide was developed by the multi-disciplinary and multi-cultural

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research team based on the knowledge and experience of the study team and the existing literature. The following domains were explored during the interviews: perceptions and knowledge about AD, personal family history of AD; awareness of genetic testing and clinical trials; and potential barriers to genetic testing at the individual, community, and health-systems levels.

Qualitative Data Analysis

A continuous process of data collection and analysis of the interview data was undertaken simultaneously in the tradition of grounded theory (Glaser & Strauss, 1967). Field notes were also taken and debriefing sessions with research team members were conducted at the conclusion of each day of interviews in order to discuss the major themes and findings. The interview guide was further refined in order to fill any gaps that emerged during the data analysis process. The interviews were audiotaped and translated and transcribed by the study team. At least three members of the research team independently analyzed the transcripts to organize domains, develop primary broad thematic categories, and select illustrative quotes to represent these themes. Then, research team members in Mexico and the US assessed any discrepancies in coding until consensus was reached. The team reviewed the thematic categories and discussed the final results to ensure agreement amongst the team members. Verbatim quotes translated into English are used to illustrate the major findings. Pseudonyms are used in this paper.

Results

Quantitative

Demographic Characteristics—The demographic characteristics of the 123 respondents are seen in Table 1. Seventy (70%) percent of the total respondents resided in Mexico (in both rural and urban settings) and 61% of the respondents was female. The median age of respondents was 37 years (range 18–73 years). None of these characteristics was significantly different between the respondents from the US versus Mexico. However, the mean years of education among the US-based respondents was 13 (range 10–20 years) as compared to 11 (range 4–24 years) among the respondents in Mexico, which was a statistically significant difference (p=0.004).

Cultural Beliefs about AD—In the “biomedical and treatment knowledge” category, all the statements were false. However, about 72% of the total sample of respondents believed that losing your memory is a normal part of aging and about 58% believed that all elderly people will eventually suffer from serious memory loss. Less than one-quarter of respondents believed that AD is due to “bad blood” and 36% believed it was due to having a difficult life or traumatic experience. Only 11% of respondents agreed with the statement that “committing wrongs in one’s life can cause someone to have AD in later life.” However, nearly 60% of respondents believed that stress is associated with the development of AD. More than three-quarters of respondents believed that AD is a mental rather than a physical illness and more than one-third (37.76%) believed that AD is a psychological disorder rather than a biological disease. In terms of how to help patients with AD, about 57% of respondents believed that there is no treatment currently available to help these patients.

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In terms of questions about stigma, only about 3.0% believed that “people who have AD bring dishonor to their relatives” and only 4.7% agreed with the statement “having a relative who has AD is shameful for the family.” However, about 73% believed that “having a relative with AD was embarrassing”. About one-third (32.4%) believed AD is a form of insanity and 26.5% agreed with the statement “AD is a form of craziness.”

The results showed low levels of agreement with statements regarding AD in the category of “curse or God’s will”. For example, about 19% of the respondents agreed that “if someone develops AD, it is God’s will” but only about 5% believed that “AD is a punishment from God for one’s past sins.” In addition, only about 3% believed that “AD is the result of a curse being placed upon someone by another person” and only about 10% believed that “someone can develop AD because another person is jealous and wished him/her ill will.” However, 27% of respondents believed that “only God can change or cure a person who has AD.”

The results of the agreement with the CBAD scale statements, divided by country of residence of the respondents, can be seen in Table 2. When comparing between countries, agreement with “AD is embarrassing for the relatives of the person with the disease” ($p < 0.001$), “AD is a psychological disorder rather than a biological disease” ($p=0.003$), and “AD is a form of insanity” ($p = 0.002$) were found to be significantly different. Respondents based in the US tended to be less likely to agree with these statements. The other items were not statistically significant in terms of differences between countries. We also analyzed the differences in agreement with the questions by gender but no statistically significant differences were found.

Qualitative—The demographic characteristics of the interview respondents (n=18) are seen in Table 3. All of the respondents were Mexican, the majority of which were female (72.2%), married (77.8%) with a mean age of 44 years (range 24–74). The vast majority (88.9%) had at least one child. Most lived in rural areas (66.7%) and only four had education beyond high school.

The interview data analysis highlighted four overarching themes: 1) symptoms and causes; 2) myths; 3) stigma; and 4) genetic testing and clinical trials.

Symptoms & Cause—The first key theme was perceived symptoms and causes of ADAD. When asked to describe the symptoms of ADAD, most respondents reported that multiple members of their family suffered from ADAD so they were well aware of its most common symptoms. Most respondents were able to name at least three symptoms. The most commonly mentioned symptom was loss of memory, named by 14 respondents (77.8%), with moodiness or irritability named by 11 respondents (60%). Other common symptoms mentioned by at least one-half of respondents included lack of recognition of family members and lack of self-sufficiency in terms of daily personal tasks, such as being able to dress themselves. Other responses included: lack of motor skills (n=6), repetitive speech (n=5), getting lost (n=3), loss of speech (n=3), headaches (n=2), depression/anxiety (n=2), loss of appetite (n=1), and loss of senses (n=1). When asked to explain what caused them to first suspect AD in their affected family member(s), many mentioned forgetfulness first. For

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example, Lupita, a 55 year-old married mother with five children explained: "*Well for everyone they start forgetting about things as soon as they pick something up. Like my husband he would do that; he would ask "Where did I leave this?" even though he had it in his hands seconds ago. He would also go out on the streets to search for his cows but he does not have cows anymore."* Maricela, who was age 38 years and was married with three children, discussed the symptoms that her mother experienced: *"When she was here, she couldn't recognize people. She had a hard time holding conversations. There were small moments when she could recognize people but ever since she went to live with my sister, she has gotten worse. She likes to have conversations sometimes when nobody is there. She talks to the mirror; she thinks that her reflection is another person."* Consuelo, a 41-year old married mother of three from Mexico described it as: *"They start losing their short-term memory. They can be cooking something and wander off and I'd see smoke. Or they would wander off to the market and wouldn't know how to return. They recognized us; that part of memory was the last part that went. I lived with two of my aunts during the entirety of their illness. After two years, they forgot how to eat. My other aunt lasted a very long time because she was very well taken care of. She got home care when she was no longer able to take care of herself. After a while the brain forgets how to do things, like breathe. Her heart was barely beating. That is how she passed away."*

When asked what causes ADAD, the vast majority of respondents reported that it was hereditary, which was not surprising given their extensive family histories. In addition to genetics, the most commonly perceived primary causes of ADAD were related to an unhealthy lifestyle or "bad habits." This included having a poor diet, tobacco smoking, and the use of alcohol and illicit drugs. For example, Mario, a 31-year-old married father of two, said that ADAD was caused by *"bad habits, including smoking, drinking, and all of that. It contaminates the blood."* Juana, a 73-year old mother of eight, explained: *"With our family, some people start early especially if they drink a lot, take drugs or are womanizers. That's what we've noticed. If they live a fast-paced life they get it sooner."* Many also felt that stress was a contributing factor in the development of ADAD. About 45% of respondents did not believe that ADAD was inevitable in old age, while the other 55% said they were unsure.

A major theme relating to the development of ADAD was the widespread belief that it could be prevented, despite the fact that it is an autosomal dominantly inherited disease. For example, many respondents reported taking preventative measures that they believed would help them avoid developing the disease. This mostly related to health habits, such as taking vitamins, exercising, avoiding stress, having a healthy diet, and keeping their brains active. For example, Irene, a 42-year old single woman with no children explained what she most feared about developing the disease: *"I wonder who will take care of me. The affected person is no longer themselves, their mind is gone and they are no longer in charge of themselves. I do a lot to prevent this from happening; I take classes to learn new things to work my brain, I exercise and I work with children. I try to keep my brain stimulated as much as possible."*

Myths—The second theme related to myths about the cause of ADAD that were common in their grandparent's generations but had since been dispelled. This was seen in both the results of the survey as well as the interview data. For example, several mentioned that

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ADAD used to be associated with a curse on the family, and one that would last only a few generations. This coincided with low level of beliefs with the statement that AD was caused by a curse in the CBAD; only 4% of Mexican respondents and 2.9% of all respondents agreed with this statement. ADAD was also perceived to be a disease affecting only women (which was not included in the CBAD). For example, Andrea, a 52-year old mother of one, said "*Well… they used to say that the families had been bewitched and that the curse would be passed down through the family until the 7th generation. We began to see which of my grandmother's brothers carried the gene and during that time there were a lot of myths. It was a women's disease-not for men."* Consuelo explained that ADAD used to be associated with exposures to metals (which was also not explored in the CBAD), explaining: *"You shouldn't eat canned things. They said the aluminum was bad. My mother had aluminum pans; we had to throw everything away because they had properties that would affect us."*

Stigma—The third overarching theme was related to stigma. Contrary to our expectations, very few people reported experiencing stigma associated with ADAD in their community. While many previous myths and misconceptions about the disease were reported, it appeared that due to its high prevalence in their own communities, the vast majority of respondents felt that most people understood that ADAD is inherited, reducing its associated stigma. For example, Consuelo discussed how heightened awareness about ADAD had changed community perceptions: *"Well, I think it's not as bad as it used to be in my grandmother's time when people would just say that they had gone crazy. My uncles and my dad were the sons of 'the crazy woman.' It marked them pretty strongly. Now, people are aware of Alzheimer's and know that it is a family thing. Now it's almost a regular thing."*

Most respondents expressed a lack of clarity on whether it was related to physical or mental causes. When the discussions focused on beliefs about whether ADAD was related to mental or physical causes, six respondents (33.3%) believed that ADAD meant that the person had gone crazy, three respondents (16.7%) said it was not related to mental causes, and nine (50%) were not clear about the cause. Additionally, when asked whether ADAD is a physical or mental illness, five (27.8%) felt it was a mental illness and only one person (5.5%) firmly believed it was a physical illness.

Genetic Testing and Clinical Trials—Only one-half of respondents reported any knowledge about the possibility of genetic testing, despite having interacted on numerous occasions with healthcare providers who were treating their family members. None had received any genetic counseling and very few respondents who were at risk clearly understood their *own* risk for developing the disease. Once at-risk respondents were informed that they had a 50% chance of having the genetic mutation, almost three-quarters of respondents (72.2%) expressed a strong interest in genetic testing, even though they reported being aware that no effective treatment exists. Only two respondents (11.1%) said they would not want to know their genetic status and three respondents (16.7%) were unsure about whether they would want to know. Among those who wanted to know their status, their main motivations centered around preparing themselves and their families for the inevitable development of ADAD. Another commonly reported motivation was related to potentially not having more children. Several mentioned they would want to alert their

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children about their own risks so that they could decide whether to have children. For example, Consuelo explained, *"When I was 20, there was talk of genetic tests that could be done to show if you carried the gene. When we saw that my father wasn't getting it, I decided to have my first son and then the other two. If I were to have the disease, I would not have children; that would be the only way to stop it. I could adopt and I'd be happy. Luckily, my father did not fall ill."*

Knowledge about participation in research, such as clinical trials, was very low. In fact, no one reported understanding the concept of a clinical trial. After it was explained briefly, almost one-half of respondents said they would consider participating in a research study on ADAD. A few respondents also mentioned the desire to help others through research on ADAD. For example, Luis, a 39-year-old married father of two, said, *"If I could have the test done and have something done for a cure, to help find a cure, then yes. It wouldn't just be for me but for a lot of other people as well."*

Discussion

Our findings provide insight into the most prevalent beliefs regarding AD in Mexican and Mexican-American family members of patients with ADAD, many of whom were themselves at-risk for developing the disease. The findings from this mixed-methods study suggest several measures that ideally would be implemented before clinical trials among populations at-risk for ADAD are brought to Mexico and other countries. First, the findings suggest that knowledge regarding the disease is low. All of the respondents reported having close family members who have received diagnosis and care for ADAD and had various degrees of contact with the health care system. Therefore, a few may have received basic education and counseling about the trajectory of ADAD, including their own genetic risk, but many reported having received little or no information from the health care providers. This appeared to be especially true among the respondents in Mexico, who appeared to either have received little information about the disease or had difficulty assimilating it. The results from the CBAD surveys and the interviews both confirmed that there is a lack of scientific and medical information about AD and ADAD among the study participants. It is possible that family members of patients are not receiving information about the disease from providers or that there are educational, linguistic, and/or cultural barriers to the understanding of information that is presented.

The results also highlighted many erroneous beliefs about the cause of AD/ADAD. For example, a majority of our study respondents in Mexico perceived AD to be associated with lifestyle factors. This belief may contribute to increased stigma associated with development of AD. While most respondents did not believe that AD is due to a curse (either by God or a person known to them), they did associate it with bad habits. In the survey data, only about 11% of respondents agreed with the statement that "committing wrongs in one's life can cause someone to have AD in later life." However, from the interviews, it was clear that most respondents felt that people with unhealthy habits, such as substance abuse, were more likely to develop the disease or develop it a younger age. Therefore, the discrepancy between these findings might be associated with the definition of "committing wrongs" versus poor lifestyle choices. Most participants believed that AD was caused by stress, smoking,

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substance abuse, and poor diet. Other studies have found higher prevalence of similar beliefs about risk of AD among racial/ethnic minorities. For example, a 2013 study conducted by the National Hispanic Council on Aging (NHCOA) found Hispanics have several misconceptions when it comes to AD, including that some people get AD because “they think too much, are stressed, or have personality issues.” Connell et al. (2009) found among a sample of 301 participants (21.3% of whom were first-degree relatives of someone who had AD), compared with non-Hispanic Whites, African Americans were at least twice as likely as non-Hispanic Whites to report believing that other factors increase the risk of AD, including stress (60.3% vs. 28.8%), exposure to toxins (48.9% vs. 24.4%), mental illness (63.8% vs. 25.0%), God’s will (54.6% vs. 13.8%), drinking too much alcohol (37.6% vs. 14.4%), smoking too much (31.9% vs. 10.0%), head injury (53.2% vs. 33.1%), and old age (58.2% vs. 45.6%) increase a person’s risk of AD. However, in a similar study of 108 individuals from the general population in Chicago, Schrauf and Iris (2011) did not find high levels of agreement among Mexican-Americans regarding AD being associated with poor lifestyle choices, suggesting that Mexican and Mexican-Americans may have different prevailing cultural beliefs. This discrepancy highlights the need for further research in this area and for data to be disaggregated by different Hispanic groups in the US, instead of grouping all Hispanics into the same category (Vega et al., 2017). In future surveys of AD knowledge, it will be important to make clear the distinction between risk of cognitive decline in general and AD specifically.

We found significant differences among respondents based in Mexico and those in the US on three CBAD questions in the Stigma/Blame section, including “AD is embarrassing for the relatives of the person with the disease” ($p < 0.001$), “AD is a psychological disorder rather than a biological disease” ($p=0.003$), and “AD is a form of insanity” ($p = 0.002$). Respondents based in the Mexico were more likely to agree with these statements. This may be related to the fact that beliefs about AD being associated with bad habits were prevalent among Mexican respondents, which was demonstrated in both the qualitative and quantitative data. While about 73% of survey respondents believed that AD is embarrassing for the relatives of the person with the disease, this could be related to the behaviors of the person with AD instead of general stigma associated with having the disease or because of its perceived cause. In fact, our qualitative data suggest that the stigma associated with AD disappeared over generations, as people began to note the genetic nature of AD. Therefore, our findings may be different than in other communities without a high prevalence of AD or among individuals with other forms of AD that are not strongly inherited. Contrary to our expectations, most respondents did not report that family members of patients with AD experienced significant stigma. This contradicts the review by Mahoney et al. (2005) of three other studies (n=22) that have reported some level of fear of public disclosure among Latino, African American and Chinese family members of individuals with AD.

Most respondents believed that losing your memory is a normal part of aging; the belief that “all elderly people eventually suffer from serious memory loss” was held by the majority of respondents in both Mexico and the US. The qualitative results also demonstrated that a high proportion of respondents believed that ADAD is an expected part of aging, which is congruent with other studies that have found that racial/ethnic minorities have a greater likelihood of subscribing to the belief that memory impairment is a normal part of aging as

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compared to Whites (Roberts et al., 2003; Ayalon & Arean, 2004; Mahoney et al., 2005). For example, Mahoney et al. (2005) found a lack of knowledge about early signs of AD among Hispanics, Chinese and African-Americans in the US. The symptoms of AD, such as memory impairment, were attributed to normal aging and were not seen as alarming. Differing expectations with respect to cognition in normal aging may significantly negatively impact the time it takes for people experiencing symptoms of AD to seek healthcare and treatment. A systematic review of both quantitative and qualitative studies by Mukadam et al. (2011) revealed that a lack of knowledge about dementia was found to a barrier to seeking care among Hispanic and African Americans in several studies.

The desire for presymptomatic genetic testing in our study was higher than in some previous research in at-risk populations in the U.S. (e.g., Steinbart et al, 2001). One possible explanation for this discrepancy is that we presented the option as a theoretical possibility, whereas the study by Steinbart et al. (2001) was performed in a real-world genetics clinic among 251 persons at risk for ADAD in which they quantified how many persons actually followed through with such testing (only 8.4%). Singer et al. (2001) examined attitudes regarding genetic testing among African-Americans, Hispanics, and non-Hispanic Whites from a random sample stratified by ethnicity of 1763 adults in the general population with telephones in their households. They found that Hispanics and African-Americans were more likely to express preferences for both prenatal and adult genetic testing than non-Hispanic Whites. However, African-Americans and Hispanics were also less knowledgeable about genetic testing than non-Hispanic Whites. Respondents interviewed in Spanish were significantly less likely to follow news about health than those interviewed in English, and correspondingly scored significantly lower on genetic knowledge questions than those interviewed in English. Findings from Akinleye et al.'s study (2011) among 313 first-degree relatives of AD patients who were recruited prior to enrolling in an AD genetic testing research trial also suggested that the differences in attitudes towards genetic testing between African-Americans and non-Hispanic Whites were due in part to incomplete understanding regarding genetic testing.

Most interview respondents in Mexico reported a desire for genetic testing for the mutation that causes ADAD once they were informed of their own risk. Furthermore, many reported that they would be interested in participating in clinical trials in the future, even after becoming aware that no effective treatment currently exists. The primary motivation reported was to better prepare themselves and their families for the inevitable development of the disease. This finding is consistent with our previous work which demonstrated that a significant proportion of people at risk for AD (both in Mexico and in the US) report a desire to learn their genetic status, especially if participation in clinical trials is an option (Hooper et al., 2013). Other studies have had similar findings. For example, Roberts et al. (2003) examined attitudes toward testing through a randomized trial to evaluate genetic susceptibility testing (*APOE*) among 206 asymptomatic adult children of people with late-onset AD. In this sample, which largely consisted of non-Hispanic White females, 77.7% went on to seek such susceptibility testing. The best predictor of actual pursuit of testing was strong endorsement of the need to prepare family members for AD (odds ratio = 3.3, $p < 0.01$).

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Practice Implications

Community-wide educational campaigns on the early signs and symptoms of ADAD could encourage earlier help-seeking behavior and provide information to the public about available clinical trials options and new treatment options as they become available. These campaigns could also help address the misconceptions of the disease and reduce stigma.

A possible barrier to future work on ADAD in Mexico is that genetic testing and counseling is available only in tertiary centers in the country. Since genetic counseling does not exist as a career in Mexico (or most other Latin American countries), the responsibility of counseling patients and their families about genetics and genetic testing falls upon geneticists. We found that most families at-risk for ADAD lacked understanding regarding its genetic nature and, even when genetic testing was available, very few had accessed it. As a result, many at-risk individuals do not receive information about the heritable nature of the disease or their personal risks. This may result in delays in seeking medical care. Disparities in research participation among racial/ethnic minority groups may also be the result a lack of effective communication regarding the risks and expected benefits of participation (Vega et al., 2017). More training is needed to ensure that clinicians that see patients with ADAD and their families have the capacity to provide information in a way that can be understood. Training programs for clinicians may help meet the need for genetic counseling and improve communication between providers and patients and caregivers and family members. While this study focused on family members' perceptions, the need exists to explore these issues among clinicians in order to determine barriers to improving counseling skills among clinicians.

Research Recommendations

Our qualitative results also demonstrated that beliefs that ADAD is a disease that primarily affects women, that is disappears after a certain number of generations, and that it is associated with stress and unhealthy lifestyles are common. Additional research is needed to clarify whether these beliefs are prevalent in other populations, as well as how these beliefs may impact health-seeking behaviors. The diversity among the Latino community should also be taken into consideration in future AD and ADAD research; despite the fact that Latinos tend to be considered as one group, there are significant differences among its subgroups that should be further explored (Vega et al., 2017; Mehta & Yeo, 2017).

Participation of racial/ethnic minorities in AD and ADAD clinical research is essential to understanding the treatment options for the disease in all populations equally (Olin et al., 2002), and such research is not possible without the involvement of informed and willing subjects. It is possible that if the culture targeted for the research differs from that in which the research has been designed, e.g., in terms of sociodemographic traits such as literacy level and years of education, the full implications of clinical trial participation might not be well understood. This may help explain the high expressed interest in participation in clinical trials. More research is needed to understand and address barriers to participation in AD/ADAD research studies among racial and ethnic minority groups in the US and abroad.

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Study Limitations

This study has some limitations. It was conducted among at-risk populations in two communities in Mexico and two communities in the US using a convenience sample of family members of families with ADAD receiving care. Therefore, the results may not be generalizable to other populations outside of these areas or to those with family members of patients who have not sought care for ADAD. In addition, all interviews were conducted with respondents from Mexico and therefore cannot inform CBAD survey results from Mexican-Americans. In addition, we did not collect data on religious preferences of the respondents, which may have influenced the cultural perceptions of respondents. Finally, the validity and reliability of the CBAD survey is unproven and therefore the degree to which it measures the concepts in question has not been definitively demonstrated.

Conclusions

In order to ethically conduct clinical trials for AD/ADAD, it is critical that physicians and other healthcare providers ascertain that potential respondents understand the information provided about the biological nature of the disease and the potential options for medical interventions. Our study shows that misconceptions and myths about AD are prevalent, particularly in Mexico. Families at-risk for ADAD need additional information in order to make informed decisions about the potential impact of ADAD on their lives. In moving forward with clinical trials in ADAD in Mexico, there should be substantial effort devoted towards education about AD/ADAD, genetics, and clinical research in general prior to implementing any clinical trial.

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References

Alonso ME, Ochoa A, Sosa AL, Rodriguez Y, Chavez M, Boll C, Yescas P, Macias R, Rasmussen A (2009) Presymptomatic diagnosis in Huntington's Disease: The Mexican Experience. Genetic Testing and Molecular Biomarkers, 13(6): 717–720. [PubMed: 19810823]

Alzheimer's Association. (2018). Facts and Figures Accessed 17 April at: https://alz.org/documents_custom/2018-facts-and-figures.pdf

Alzheimer Disease and Frontotemporal Dementia Mutation Database (2018). Accessed 17 April 2018 at: http://www.molgen.ua.ac.be/admutations

Arevalo M, Heredia NI, Krasny S, Rangel ML, Gatus LA, McNeill LH, Fernandez ME (2016) Mexican-American perspectives on participation in clinical trials: A qualitative study. Contemp Clin Trials Commun, 15; 4: 52–57.

Athan ES, Williamson J, Ciappa A, Santana V, Romas SN, Lee JH, Rondon H, et al. (2001). A founder mutation in presenilin 1 causing early-onset Alzheimer disease in unrelated Caribbean Hispanic families. JAMA, 286(18):2257–2263. [PubMed: 11710891]

Avila J, Flowers A, Scott TM, Quilici J, Apostolova LG, Woo E, … Razani J. (2015). Daily Activity Abilities in MCI, Alzheimer's Disease, and Healthy Controls. GeroPsych, 28(4), 191–200. [PubMed: 27366145]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Ayalon L, Arean PA (2004) Knowledge of Alzheimer's disease in four ethnic groups. Int J Geriatr Psychiatry, 19:51–57. [PubMed: 14716699]

Bateman RJ, Aisen PS, Strooper BD, Fox NC, Lemere CA, Ringman JM, … Xiong C. (2010). Autosomal-dominant Alzheimer's disease: A review and proposal for the prevention of Alzheimer's disease. Alzheimer's Research & Therapy, 3(1), 1.

Bruni AC, Bernardi L, Colao R, Rubino E, Smirne N, Frangipane F, Terni B, et al. (2010). Worldwide distribution of PSEN1 Met146Leu mutation: a large variability for a founder mutation. Neurology, 74(10):798–806. [PubMed: 20164095]

Byrne MM, Tannenbaum SL, Glück S, Hurley J, Antoni M (2014) Participation in cancer clinical trials: why are patients not participating? Med Decis Making, 34(1):116–26. [PubMed: 23897588]

Chin AL, Negash S, Hamilton R (2011). Diversity and disparity in dementia: the impact of ethnoracial differences in Alzheimer disease. Alzheimer Dis Assoc Disord, 25(3):187–95. [PubMed: 21399486]

Connell CM, Shaw BA, Holmes SB, Foster NL (2001). Caregivers' attitudes toward their family members' participation in Alzheimer disease research: implications for recruitment and retention. Alzheimer Disease and Associated Disorders, 15(3):137–145. [PubMed: 11522931]

Connell CM, Scott Roberts J, McLaughlin SJ, Akinleye D (2009). Racial differences in knowledge and beliefs about Alzheimer disease. Alzheimer Dis Assoc Disord, 23:110–6. [PubMed: 19474569]

Cooper C, Tand y A.R., Balamurali TB, Livingston G (2010). A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. Am J Geriatr Psychiatry, 18:193–203. [PubMed: 20224516]

Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, … Scazufca M (2005). Global prevalence of dementia: A Delphi consensus study. The Lancet, 366(9503), 2112–2117.

Fiest KM, Roberts JI, Maxwell CJ, Hogan DB, Smith EE, Frolkis A, Cohen A,…. Jette N (2016). The Prevalence and Incidence of Dementia Due to Alzheimer's Disease: A Systematic Review and Meta-Analysis. Canadian Journal of Neurological Sciences, 43(S1).

Glaser BG, and Strauss AL. (1967). The Discovery of Grounded Theory: Strategies for Qualitative Research Transaction Publishers.

Grill JD, Bateman RJ, Buckles V, Oliver A, Morris JC, Masters CL, … D. (2015). A survey of attitudes toward clinical trials and genetic disclosure in autosomal dominant Alzheimer's disease. Alzheimer's Research & Therapy, 7(1).

Hayden MR, Bombasd Y (2005) Psychological effects of predictive testing for Huntington's disease. Adv Neurol, 96:226–238 [PubMed: 16383222]

Hensley Alford S, McBride CM, Reid RJ, Larson EB, Baxevanis AD, Brody LC (2011). Participation in genetic testing research varies by social group. Public Health Genomics, 14:85–93. [PubMed: 20299772]

Hipps YG, Roberts JS, Farrer LA, Green RC (2003). Differences between African Americans and Whites in their attitudes toward genetic testing for Alzheimer's disease. Genetic Testing, 7(1):39–44. [PubMed: 12820701]

Hooper M, Grill JD, Rodriguez-Agudelo Y, Medina LD, Fox M, Alvarez-Retuerto AI, Ringman JM (2013). The impact of the availability of prevention studies on the desire to undergo predictive testing in persons at risk for autosomal dominant Alzheimer's disease. Contemporary Clinical Trials, 36(1), 256–262. [PubMed: 23876673]

Jack CR Jr., Bennett DA, Blennow K, Carrillo MC, Dunn B, Haeberlein SB, Holtzman DM, et al. (2018).Toward a biological definition of Alzheimer's disease. Alzheimers Dement, 14(4):535–562. [PubMed: 29653606]

Korenman S, Finder SG, and Ringman JM (2015). Conceptualization and Assessment of Vulnerability in a Complex International Alzheimer's Research Study. The American Journal of Bioethics, 15(4), 87–89. [PubMed: 25856620]

Lalli MA, Cox HC, Arcila ML, Cadavid L, Moreno S, Garcia G, Madrigal L, et al. (2014). Origin of the PSEN1 E280A mutation causing early-onset Alzheimer's disease. Alzheimers Dement, 10(5 Suppl):S277–S283 e210. [PubMed: 24239249]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Mahoney DF, Cloutterbuck J, Neary S, Zhan. L (2005). Africa American, Chinese, and Latino Caregivers' Impressions of the Onset and Diagnosis of Dementia: Cross-Cultural Similarities and Differences. Gerontologist, 45(6): 783–792. [PubMed: 16326660]

Masters CL, Mayeux RP, RIngman JM, Rossor MN, Salloway SP, Schofield PRD (2016). Neurological manifestations of autosomal dominant familial Alzheimer's disease: A comparison of the published literature with the Dominantly Inherited Alzheimer Network observational study (DIAN-OBS). The Lancet Neurology, 15(13), 1317–1325. [PubMed: 27777020]

Mehta KM, Yeo GW (2017) Systematic review of dementia prevalence and incidence in United States race/ethnic populations. Alzheimers Dement 13(1):72–83. [PubMed: 27599209]

Mills SM, Mallmann J, Santacruz AM, Fuqua A, Carril M, Aisen PS, Althage MC, et al. (2013). Preclinical trials in autosomal dominant AD: implementation of the DIAN-TU trial. Rev Neurol (Paris) 169(10):737–743. [PubMed: 24016464]

Morris JC, Aisen PS, Bateman RJ, Benzinger TL, Cairns NJ, Fagan AM, … Buckles VD (2012). Developing an international network for Alzheimer's research: The Dominantly Inherited Alzheimer Network. Clinical Investigation, 2(10), 975–984. [PubMed: 23139856]

Mukadam N, Cooper C, Livingston G (2011). A systematic review of ethnicity and pathways to care in dementia, 26(1):12–20.

Murrell J, Ghetti B, Cochran E, Macias-Islas MA, Medina L, Varpetian A, Cummings JL, et al. (2006). The A431E mutation in PSEN1 causing familial Alzheimer's disease originating in Jalisco State, Mexico: an additional fifteen families. Neurogenetics, 7(4):277–279. [PubMed: 16897084]

Neumann PJ, Hammitt JK, Mueller C, Fillit HM, Hill J, Tetteh NA, et al. (2001) Public attitudes about genetic testing for Alzheimer's disease. Health Affairs, 20:252–264. [PubMed: 11558711]

Nodora J, O'Day K, Yrun V, Garcia F Barriers and facilitators to mexican-american participation in clinical trials: physician and patient focus group perspectives. Health 2010;2:742.

Pariera KL, Murphy ST, Meng J, McLaughlin ML (2017) Exploring Willingness to Participate in Clinical Trials by Ethnicity. J Racial Ethn Health Disparities, 4(4):763–769. [PubMed: 27604379]

Peters N, Rose A, Armstrong K (2004). The association between race and attitudes about predictive genetic testing. Cancer Epidemiology, Biomarkers & Prevention, 13(3):361–365.

Research!America. (2017). Lack of Trust Less of a Barrier to Clinical Trial Participaton, According to Minority Populations; Other Factors Contribute to Low Participation Rates Accessed on 17 April 2018 at: https://www.researchamerica.org/news-events/news/lack-trust-less-barrier-clinical-trial-participation-according-minority-populations

Reiman EM, Langbaum JB, Fleisher AS, Caselli RJ, Chen K, Ayutyanont N, Quiroz YT, et al. (2011). Alzheimer's Prevention Initiative: a plan to accelerate the evaluation of presymptomatic treatments. J Alzheimers Dis, 26 Suppl 3:321–329. [PubMed: 21971471]

Ringman JM, and Flores DL (2005). Earlier Alzheimer onset in Latino persons: ethnic difference vs selection bias. Arch Neurol, 62(11):1786–1787. [PubMed: 16286560]

Ringman JM, Goate A, Masters CL, Cairns NJ, Danek A, Graff-Radford N, Ghetti B, Morris JC, ….. Network, D.I. (2014). Genetic Heterogeneity in Alzheimer Disease and Implications for Treatment Strategies. Curr Neurol Neurosci Rep, 4(11):499.

Roberts JS, and Tersegno S (2010). Estimating and disclosing the risk of developing Alzheimer's disease: challenges, controversies and future directions. Future Neurology, 5:501–517. [PubMed: 20856693]

Roberts JS, Connell CM, Cisewski D, Hipps YG, Demissie S, Green RC (2003). Differences between African Americans and whites in their perceptions of Alzheimer disease. Alzheimer Dis Assoc Disord, 17:19–26. [PubMed: 12621316]

Roberts JS, LaRusse SA, Katzen H, Whitehouse PJ, Barber M, Post SG, et al. (2003). Reasons for seeking genetic susceptibility testing among first-degree relatives of people with Alzheimer's Disease. Alzheimer Disease and Associated Disorders, 17(2):86–93. [PubMed: 12794385]

Ringman JM, Grill J, Rodriguez-Agudelo Y, Chavez M, Xiong C (2009). Commentary on "a roadmap for the prevention of dementia II: Leon Thal Symposium 2008." Prevention trials in persons at risk for dominantly inherited Alzheimer's disease: opportunities and challenges. Alzheimers Dement, 5(2):166–171. [PubMed: 19328453]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Ryman DC, Acosta-Baena N, Aisen PS, Bird T, Danek A, Fox NC, Goate A, et al. (2014). Symptom onset in autosomal dominant Alzheimer disease: A systematic review and meta-analysis. Neurology 2014;83(3):253–260. [PubMed: 24928124]

Sayegh P, and Knight BG (2013). Cross-cultural differences in dementia: the Sociocultural Health Belief Model. Int Psychogeriatr, 25(4):517–30. [PubMed: 23237243]

Schrauf RW, Iris M (2011). A direct comparison of popular models of normal memory loss and Alzheimer's disease in samples of African Americans, Mexican Americans, and refugees and immigrants from the former Soviet Union. J Am Geriatr Soc 59(4):628–36. [PubMed: 21480837]

Sink KM, Covinsky KE, Newcomer R and Yaffe K (2004). Ethnic differences in the prevalence and pattern of dementia-related behaviors. Journal of the American Geriatrics Society, 52, 1277–1283. [PubMed: 15271114]

Steinbart EJ, Smith CO, Poorkaj P, Bird TD (2001). Impact of DNA testing for early-onset familial Alzheimer disease and frontotemporal dementia. Arch Neurol, 58(11):1828–1831. [PubMed: 11708991]

Vega IE, Cabrera LY, Wygant CM, Zelez-Ortiz D, Counts SE (2017) Alzheimer's Disease in the Latino Community: Intersection of Genetics and Social Determinants of Health. J Alzheimers Dis, 58(4): 979–992. [PubMed: 28527211]

Wimo A, Guerchet M, Ali G, Wu Y, Prina AM, Winblad B, … Prince M (2017). The worldwide costs of dementia 2015 and comparisons with 2010. Alzheimer's & Dementia, 13(1), 1–7.

World Health Organization (WHO). (2016). Dementia Fact Sheet Retrieved December 3, 2016, from http://www.who.int/mediacentre/factsheets/fs362/en/

Wu SW, Vega WA, Resendez J, Jin H (2016) Latinos and Alzheimer's Disease: New Numbers Behind the Crisis. (2016). USC Edward R. Roybal Institute on Aging and the LatinosAgainstAlzheimer's Network

Yescas P, Huertas-Vazquez A, Villarreal-Molina MT, Rasmussen A, Tusie-Luna MT, Lopez M, … Alonso ME (2006). Founder effect for the Ala431Glu mutation of the presenilin 1 gene causing early-onset Alzheimer's disease in Mexican families. Neurogenetics, 7(3), 195–200. [PubMed: 16628450]

Zu JX, Zhang Y, Qiu C, Cheng F (2017). Global and regional economic costs of dementia: a systematic review. The Lancet, 390(S47).

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Table 1:

Demographic Characteristics of Survey Respondents

Indicator	US (n=37)	Mexico (n=86)	Total	Fisher.pval or Wilcoxon.pval
Gender				
Male	12 (34.3%)	34 (40.5%)	46 (38.7%)	0.68
Female	23 (65.7%)	50 (59.5%)	73 (61.3%	
Location of Residence				
Urban/Suburban	37 (100%)	30 (34.9%)	67 (54.5%)	<0.001
Rural	0 (0%)	56 (65.1%)	56 (45.2%)	
Age (continuous)				
Median	36	37	37	0.884
Range	(20–73 years)	(18–71 years)	(18–73 years)	
Years of Education				
Median	13	11	12	0.004
Range	10–20	4–24		

* discrepancies in sample size is due to missing data.

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Table 2:

Agree/Strongly Agree by CBAD survey questions

Item	US n & %	Mexico n & %	Total n & %	Fisher (p-value)	Odds Ratio* (C.I.)
Treatment and Biomedical Knowledge (11 questions)					
Losing your memory as you grow older is a normal part of aging.	25/32 78.1%	53/76 69.7%	76/108 72.2%	0.482	1.54 (0.55,4.84)
Sometimes the brain dries up as people grow older, which causes AD.	10/29 34.5%	15/73 20.6%	25/102 24.5%	0.20	2.02 (0.69,5.79)
All elderly people eventually suffer from serious memory loss.	16/27 59.3%	43/74 58.1%	59/101 58.4%	>0.999	1.05 (0.39,2.87)
There are currently no medical treatments such as medications for AD.	10/23 43.5%	46/75 60.5%	56/99 56.6%	0.16	0.51 (0.17,1.43)
AD is the same thing as senility.	3/18 16.7%	13/70 18.6%	16/88 18.2%	>0.999	
All people with AD exhibit childlike behaviors.	13/26 50.0%	53/76 69.7%	66/102 64.7%	0.096	0.44 (0.16,1.2)
People with AD should be cared for by family members rather than outside of the home such as in nursing homes.	12/25 48%	39/76 51.3%	51/101 50.5%	0.821	0.88 (0.32,2.39)
There is no reason to bring someone with AD to a doctor because they cannot do anything to help.	1/31 3.2%	13/76 17.1%	14/107 13.1%	0.062	
AD is due to having bad blood.	4/30 13.33%	20/76 26.32%	24/106 22.64%	0.2	
AD can be caused by having experienced a difficult life, such as traumatic events or the death of loved ones.	6/30 20%	32/75 42.6%	38/105 36.19%	0.042	0.34 (0.1,0.98)
A stressful life can cause someone to develop AD in later life.	15/26 57.69%	45/75 60.0%	60/101 59.41%	>0.999	0.91 (0.34,2.51)
Stigma/Blame (9 questions)					
Family members of people with AD should not tell others that their relative has AD.	0/26 0%	11/75 14.67%	11/101 10.89%	0.062	
People who have AD bring dishonor to their relatives.	0/26 0%	3/75 4%	3/101 2.97%	0.567	
Having a relative who has AD is shameful for the family.	0/30 0%	5/76 6.58%	5/106 4.72%	0.318	
AD is embarrassing for the relatives of the person with the disease.	13/32 40.62%	65/75 86.67%	78/107 72.9%	<0.001	0.11 (0.04,0.31)

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Item	US n & %	Mexico n & %	Total n & %	Fisher (p-value)	Odds Ratio* (C.I.)
Committing wrongs in one's life can cause someone to have AD in later life.	0/27 0%	11/76 14.47%	11/103 10.68%	0.063	
AD is a mental illness rather than a physical illness.	17/26 65.38%	62/75 82.67%	79/101 78.22%	0.096	0.4 (0.13,1.25)
AD is a form of insanity.	3/29 10.34%	30/73 41.1%	33/102 32.35%	0.002	
AD is a form of craziness.	4/30 13.33%	23/72 31.94%	27/102 26.47%	0.083	
AD is a psychological disorder rather than a biological disease.	3/24 12.5%	34/74 45.95%	37/98 37.76%	0.003	
Curse/God (6 questions)					
AD is a punishment from God for one's past sins.	0/25 0%	5/73 6.85%	5/98 5.1%	0.325	
Only God can change or cure a person who has AD.	10/26 38.46%	17/74 22.97%	27/100 27%	0.134	2.08 (0.71,6)
A person can curse someone with AD if they dislike that person.	3/29 10.34%	14/74 18.92%	17/103 16.5%	0.384	
If someone develops AD, it is because it is God's will.	9/27 33.33%	10/75 13.33%	19/102 18.63%	0.04	3.21 (0.99,10.36)
AD is due to a curse being place on a person by someone else, of "the evil eye" (mal de ojo).	0/28 0%	3/75 4%	3/103 2.91%	0.561	
If someone is jealous of another person, he or she can wish ill will on the other person so that they will develop AD.	0/26 0%	10/75 13.33%	10/101 9.9%	0.06	

*Odds ratios and respective confidence intervals are included for variables where there are at least 5 counts in each cell.

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Table 3:

Demographic Characteristics of Interview Respondents

Indicator	Percentage (n=18)
Sex	
--female	72.2% (13)
Mean Age	44 (range 24–74)
Education	
--high school or beyond	22.2% (4)
--less than high school	77.8% (14)
Residence	
--rural	66.7% (12)
--urban	23.3% (6)
Marital Status*	
--married	77.8% (14)
--single	22.2% (4)
Children*	
--none	11.1% (2)
--one	33.3% (6)
--two	16.7% (3)
--three	11.1% (2)
--four or more	22.2% (4)