


RESEARCH ARTICLE

The words community dwelling, Spanish-preferring Mexican/Mexican American adults use to talk about Alzheimer's disease and genetic testing: Implications for education and outreach

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Abstract

INTRODUCTION: Hispanic/Latino (H/L) adults are more likely than non-Hispanic White individuals to have Alzheimer's disease (AD), yet fewer than one in five H/L adults has apolipoprotein E (APOE) $\epsilon 4$, underscoring gaps in understanding genetic risk across H/L heritage groups. H/L adults remain underrepresented in AD research that uses genetic data for participant stratification. To inform culturally appropriate educational materials for 16 million U.S. Spanish speakers, we identified culturally salient words Spanish-preferring H/L adults use to describe AD and genetic testing beyond APOE.

METHODS: Community-residing, Spanish-preferring Mexican/Mexican American adults ($n = 14$) completed freelist interviews, a method eliciting group-level concepts by identifying culturally salient words. Participant responses were analyzed using inductive thematic analysis and frequency calculations.

RESULTS: Participants recognized AD as a memory disorder influenced by aging and genes but were largely unfamiliar with AD genetic testing. Testing was viewed as useful for diagnosis rather than future risk prediction, with limited perceived value for cognitively normal individuals without a family history. Despite this limited familiarity, participants expressed interest in AD research involving genetic testing.

DISCUSSION: Findings suggested a perceived responsibility to use AD genetic testing despite limited awareness of its purposes, applications, and clinical implications. Participants' responses reflected a present-oriented health disposition: Genetic testing was viewed as appropriate once symptoms emerge rather than as a proactive tool for anticipating future decline, consistent with current clinical practice outside autosomal dominant AD. Educational materials co-created by community members and

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researchers may address these gaps by explaining both limitations of genetic testing in isolation and its potential future applications, including how genetic and multimodal biomarker data may inform risk estimation and prevention-focused decision-making. This approach may foster a future-oriented health disposition while remaining responsive to social and structural contexts. Future work is needed among other H/L heritage groups with differing social and structural experiences, migration histories, and language primacy.

KEYWORDS

Alzheimer's disease, APOE, community dwelling, education or outreach, genetic testing, Hispanic or Latino, preclinical testing, secondary findings, Spanish language

Highlights

- Spanish-preferring Mexican/Mexican American participants acknowledged genes contribute to Alzheimer's disease (AD).
- Many participants were unfamiliar with AD genetic testing but were interested in participating in clinical research that involved it.
- Materials co-created by community members and researchers about primary and secondary findings and use of AD genetic results to inform future-oriented health decisions may help education and outreach.

1 | INTRODUCTION

Alzheimer's disease (AD) disproportionately affects older individuals. Comprising the fastest growing population in the United States, Hispanic/Latino (H/L) individuals face accelerating rates of AD. Compared to non-Hispanic White (NHW) individuals, older H/L adults are 1.5 times more likely to have AD.¹⁻³ This increased AD risk may be influenced by medical factors⁴⁻⁶ and non-medical factors.^{7,8}

Knowledge of the genetic contribution to AD among H/L adults is incomplete. Highly penetrant, deterministic gene variants are a rare cause of autosomal dominant AD. By contrast, the $\epsilon 4$ allele of the *apolipoprotein E* (APOE) gene is a common AD risk factor across populations, but is present in fewer than one in five H/L adults.⁹ Current practice guidelines recommend testing high penetrance AD gene only in selected scenarios, such as early-onset disease or suggestive family history.¹⁰ Recently, APOE genotyping has gained relevance for anti-amyloid therapy decisions due to risk of amyloid-related imaging abnormalities (ARIA),^{11,12} but remains otherwise not recommended for diagnostic evaluation.¹⁰ Nevertheless, APOE genotyping is frequently used in research to stratify participants alongside other biomarkers.

Most AD research studies and trials have included predominantly NHW adults,^{13,14} and national AD research programs have not yet achieved H/L representation reflective of the U.S. population.¹⁵

Addressing this gap will require culturally and linguistically appropriate outreach and educational materials about AD and genetic testing (see [Supplemental Introduction](#)). Spanish language materials are particularly critical for H/L engagement, as nearly 40% of 41.4 million Spanish speakers in the U.S. have limited English proficiency.¹⁶ Although some culturally tailored content exists,¹⁷ Spanish language educational materials about AD genetic testing remain limited and largely focused on APOE. By contrast, Spanish language materials about cancer gene panels are more widely available, yet adoption of cancer genetic testing among H/L adults remains lower than among NHW adults, even when expertly designed Spanish language materials are used.^{18,19} Together these findings highlight the importance of community-defined, rather than expert-driven, educational content.

In this study, we interviewed Spanish-preferring Mexican/Mexican American adults in Houston, using a freelisting technique to identify AD cultural concepts relevant for educational materials. Prior freelisting research among Puerto Rican and NHW adults found AD widely recognized as memory loss, with variation in perceptions of other symptoms and causes,²⁰ and noted awareness of genes as an AD cause without examining views on genetic testing. Our findings provide a framework for developing community-tailored AD and genetic testing education beyond APOE—including return of primary and secondary findings, polygenic risk scores, and pharmacogenetic results—for research and clinical care.

RESEARCH IN CONTEXT

- Systematic review:** The authors reviewed the literature using traditional (e.g. PubMed, MEDLINE/OVID) sources. Spanish language educational materials about Alzheimer's disease (AD) genetic testing are scarce despite their importance for recruitment and retention in AD clinical research involving diverse populations, including Hispanic/Latino (H/L) adults. Although many H/L adults recognize that genetics influences AD risk, published data suggest limited awareness of genetic testing and its clinical implications, highlighting a gap between general genetic knowledge and understanding of testing applications.
- Interpretation:** Participants expressed a perceived responsibility to pursue AD genetic testing despite limited understanding of its purposes and clinical implications, reflecting a present-oriented health disposition in which testing is viewed as appropriate after symptom onset rather than as a proactive risk assessment tool.
- Future directions:** Community co-created educational materials that clarify both the limitations and emerging applications of genetic and multimodal biomarker testing may promote more informed, future-oriented decision-making. Additional research is needed across diverse H/L heritage groups with varying social, structural, migration, and language contexts.

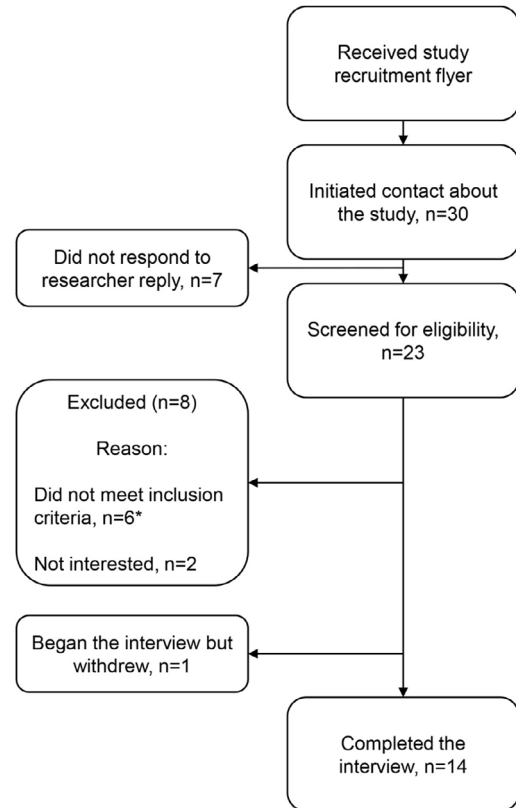


FIGURE 1 Recruitment of study population. *Six were ineligible, because they did not endorse H/L self-identification or Spanish as their primary language during screening. H/L, Hispanic/Latino.

Supplemental Methods), two declined, and one withdrew due to discomfort completing the interview in Spanish. Fourteen Mexican/Mexican American adults completed interviews (Figure 1).

2 | METHODS

2.1 | Eligibility criteria

Adults (≥ 18 years) in Houston, Texas, who self-identified as Spanish-preferring (comfortable conversing entirely in Spanish) and H/L were screened. The Baylor College of Medicine Institutional Review Board approved the study (see Supplemental Methods).

2.2 | Recruitment and enrollment

Using a community-engaged approach,^{21–23} we recruited participants through partnerships with H/L organizations, health fairs, clinics, social media, and snowball sampling. Responding to a flyer, interested individuals contacted the team directly or via an online survey. Spanish–English bilingual–bicultural H/L coordinators followed up by phone or email to describe the study, confirm eligibility, and conduct interviews (see Supplemental Methods). Recruitment continued until thematic saturation was achieved—no new themes or deeper insights emerged from additional interviews.²⁴ Thirty individuals contacted the team; seven did not respond to follow-up, six were ineligible (see

2.3 | Procedures

From May to September 2021, bilingual–bicultural H/L coordinators (F.C., G.C.) conducted recorded phone or videoconference interviews due to coronavirus disease 2019 (COVID-19) restrictions about in-person encounters (see Supplemental Methods). Coordinators conducted 1- to 2-hour long interviews comprising nine word-cluster prompts (Table S1) and four narrative vignettes with a prompt (Table S2)—all read aloud to participants. Word-cluster prompts focused on words for AD, dementia, genes, and reasons for genetic testing. Vignettes described disclosure of AD genetic testing results to a fictional H/L man whose demographics, cognition, function, and genetic result varied. Each vignette was followed by a prompt to elicit words describing the man's reaction to the result. Participants answered demographic, cultural identity, and subjective understanding, and knowledge questions (see Supplemental Methods and Table S3). Participants also responded to a question about interest in participating in clinical research about AD and involving AD genetic testing. Validated measures assessed acculturation,²⁵ cultural values,²⁶ and subjective health literacy^{27,28} (see Supplemental Methods). We used

established freelisting methods²⁹ with supplementary techniques³⁰ to maximize output.

Freelisting is a semi-structured interviewing technique that elicits word lists reflecting culturally salient knowledge, attitudes, and discourse about a topic.^{29,31} In this study, prompts and vignettes were developed collaboratively by experts in AD genetic counseling, neurology, cultural neuropsychology, and H/L cognitive aging outreach. Interviewers asked participants to list all words evoked by each word-cluster prompt and each vignette prompt about the man's reaction to genetic results (see [Supplemental Methods](#)).

2.4 | Data analysis

Interview recordings were transcribed in Spanish and translated into English by a professional service (Landmark Associates, Inc). Transcripts in both languages facilitated team discussion, which included non-Hispanic/non-Spanish speakers and bilingual-bicultural H/L members.

Although freelist analysis²⁹ was initially planned, participants frequently provided narrative rather than single-word responses. We therefore organized responses into word-phrase lists and applied inductive thematic analysis. Two bilingual-bicultural H/L coordinators (F.C., K.S.) coded transcripts in Spanish, adhering to participants' language and meaning without preconceived assumptions. After jointly coding an initial subset and resolving differences, coders analyzed remaining transcripts independently, meeting regularly to ensure consistency. Coding results were translated into English for further coding by the full team. The same process was applied to vignette responses. Results were analyzed for unifying or related codes, which were subsequently organized into superordinate thematic categories. During analysis, we monitored for thematic saturation to guide recruitment closure. Percent frequency for each theme was summarized as the number of times a thematic category appeared divided by the total number of codes yielded by a prompt.

3 | RESULTS

3.1 | Participants

As shown in [Table 1](#), respondents varied in age (mean = 49.3 ± 16.8). All respondents identified as Mexican, Chicano, or Mexican/Chicano American, and 11 of 14 were born in Mexico. On average, participants had higher engagement with Spanish than English (Bidimensional Acculturation Scale, mean Δ = -2.6 ± 4.1; [Table 2](#)). In addition, language preferences for music, radio, and television varied, with responses distributed across a preference for Spanish, English, or no preference ([Table 1](#)). Subjective health literacy varied widely (3-Brief Screening Questionnaire, mean = 6.1 ± 3.2; [Table 1](#)). Participants endorsed familism as an important cultural value (Pan-Hispanic Familism Scale, mean = 23.4 ± 2.6; [Table 1](#)). Subjective understanding of genetics and AD also varied widely, though each topic's mean rating was similar, falling

TABLE 1 Respondent characteristics.

Demographics	Number (%)	
Total enrolled	14	
Female	12 (86%)	
Interview platform		
Zoom	7 (50%)	
Phone	7 (50%)	
Nativity		
Mexico born	11 (78.6)	
U.S. born	3 (21.4)	
Age, years		
40 or younger	4 (28.6)	
41–49	3 (21.4)	
50–63	4 (28.6)	
64 or older	3 (21.4)	
Duration living in U.S., years		
20 or fewer	3 (21.4)	
21–40	8 (57.1)	
41–60	3 (21.4)	
Highest level of education		
Less than or at most high school	5 (35.7)	
Some college or vocational training	3 (21.4)	
Bachelor's degree	3 (21.4)	
Graduate or professional degree	3 (21.4)	
Marital status		
Married	8 (57.1)	
Divorced	2 (14.3)	
Never married	4 (28.6)	
Household income		
Less than \$25K	2 (14.3)	
\$25K to \$74,999	4 (28.6)	
\$75K or greater	3 (21.4)	
Don't know/No response	5 (35.7)	
Number of relatives with AD		
None	9 (64.3)	
1 or more first-degree	2 (14.3)	
1 or more second-degree	4 (28.6)	
Preferences for media^a	Prefers Spanish	Prefers English
Music	6 (42.9)	4 (28.6)
Radio	6 (42.9)	5 (35.7)
Television	4 (28.6)	5 (35.7)
Subjective health literacy^b	Score	SD
Mean	6.1	3.2
Range	3–12	

(Continues)

TABLE 1 (Continued)

Subjective health literacy ^b	Score	SD
Familism cultural value ^c	Score	SD
Mean	23.4	2.6
Range	15-25	
Likelihood to participate in clinical research ^d	Rating	SD
About AD		
Mean	8.9	1.0
Range	7-10	
Involving AD genetic testing		
Mean	8.4	2.1
Range	3-10	
Clinical research knowledge ^e	Percent correct	SD
Mean	63	19
Range	20-80	

Abbreviations: AD, Alzheimer's disease; SD, standard deviation.

^aMeasure of preferences for media. Three statements assessed preference for language of 3 forms of media—music, radio, and television—each with choice of “prefer Spanish”, “prefer English”, or “no preference”. Proportion of “no preference” responses is not shown, but is the difference between total enrolled and sum of proportion of other preferences.

^b3-Brief Screening Questionnaire.^{33,34} Responses to 3 individual questions were based on a rating scale from 1 to 5. Scores ranged from 3 to 15, with larger scores reflecting worse self-reported health literacy.

^cPan-Hispanic Familism Scale.³² Responses to 5 individual questions were based on a rating scale of 1-5. Scores ranged from 5 to 25, with larger scores reflecting greater alignment with H/L cultural value of *familismo*.

^dRating scale, with 1 = not at all, 10 = extremely likely.

^eMeasure of clinical research knowledge. Five true-false statements assessed knowledge of clinical research, including its distinction from medical care, its voluntary nature, and other features of the informed consent process. Percent correct scores ranged from 0% to 100%.

near the midpoint of the scale spanning from “not at all” to “extremely well” understood (Figure 2). Although participants reported a high level of understanding of clinical research (mean = 8.1 ± 2.0; Figure 2), their performance on a measure assessing knowledge of informed consent topics suggested only a partial grasp of key concepts (mean score = 64 ± 19%; Table 1). Participants reported high interest in clinical research about AD (mean = 8.9 ± 1.0; Table 1) and involving AD genetic testing (mean = 8.4 ± 2.1; Table 1) (see [Supplemental Results](#)).

3.2 | Participants have limited familiarity with AD genetic testing

Interviews began by prompting participants with words and phrases about AD, dementia; genes; and reasons for genetic testing, and we analyzed responses to identify dominant themes. Detailed results are shown in Table 3, and we focus here on excerpts of potential importance. Respondents believed AD was a serious illness. When asked

TABLE 2 Bidimensional acculturation scale for Hispanics individuals.³¹

English			Spanish			Delta (Δ)			
Mean	SD	Range	Mean	SD	Range	Mean	SD	Min	Max
Subscale score									
8.1	2.9	3-12	10.8	1.7	6-12	-2.6	4.1	-9	6

Note: For each language subscale (English, Spanish), responses to three individual questions were based on a rating scale of 1–5. Scores ranged from 3 to 12, with larger scores reflecting high engagement with the subscale language. Delta (Δ) represents the difference between English and Spanish subscale scores, with a greater negative value associated with greater Spanish than English language engagement, and Δ = 0 suggesting bicultural, bilingual engagement.

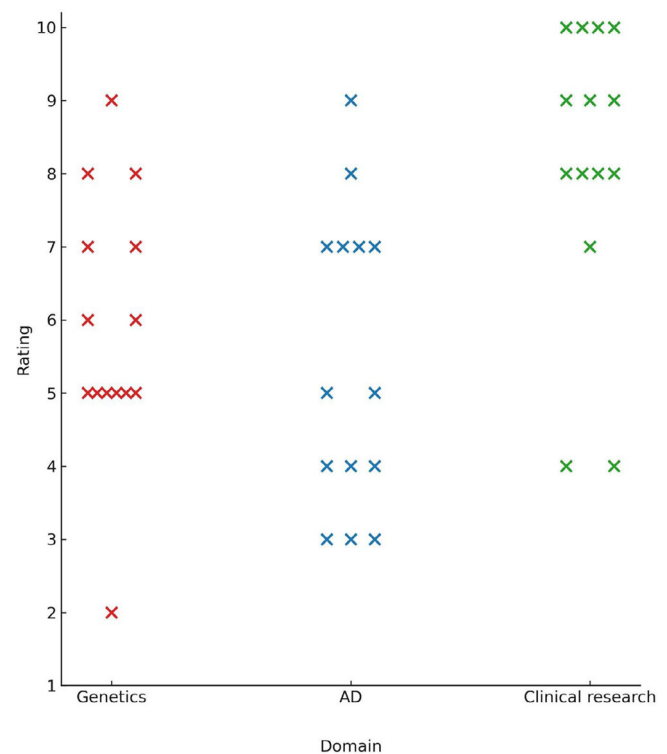


FIGURE 2 Subjective understanding. Responses to rating scales measured self-reported understanding of different domains: genetics, AD, and clinical research, plotted on the x-axis. Each rating, ranging from 1 = not at all to 10 = extremely well understood, is plotted on the y-axis. Each X represents a participant. Higher ratings reflected greater perceived understanding. Red = genetics (mean = 5.9 ± 1.8, range = 2–9), blue = AD (mean = 5.4 ± 2.0, range 3–9), green = clinical research (mean = 8.1 ± 2.0, range = 4–10). AD, Alzheimer's disease.

about “illnesses worse than AD,” only “cancer” (*cancer*) and “mental illness” (*enfermedades mentales*) were cited more frequently (20% and 11%). Across responses to all but two prompts, the theme “don't know” (*no sé*) emerged at a frequency of 2-7%, reflecting limited familiarity among a minority of respondents. The theme “don't know” (*no sé*) comprised none of the responses to the prompts about “genes” and “illnesses worse than AD,” reflecting awareness of these concepts. Prompts about “reasons to have an AD genetic test” and “more use-

TABLE 3 Results of word cluster prompts.

Theme	English translation	Proportion of unique responses k, %
Words for AD, k = 177		
Olvido/pérdida de memoria	Forgetfulness /memory loss	32.8
Envejecer/adulto mayor	Aging/elderly	8.5
Tu mente borra/todo	Broken/erased mind	6.2
Confusion/se le va la onda	Confusion/out of it	5.6
Locura/demente/psicópata	Craziness/loony /psychopath	5.6
Tristeza	Sadness	3.5
No sé	Do not know	4.5
Tonto	Dumb	0.6
Debilitado	Weak	0.6
Words for dementia, k = 201		
Locura/demente/psicópata	Craziness/loony /deranged	13.9
Olvido/pérdida de memoria	Forgetfulness /memory loss	12.4
Envejecer	Aging	9.5
Tu mente borra	Erased mind	9.5
Confusion/se le va la onda	Confusion/out of it	5.6
No sé	Don't know	4.0
Cerebro se hace pequeño	Brain gets small	1.5
Malvado/perverso	Evil/wicked	1.5
Agresividad	Aggressive	0.5
Depresivo	Depressive	0.5
Words for inherited, k = 145		
De familia	Family	22.8
En tus genes	In your genes	12.4
Transmisión de características físicas/viene de familia	Transmission of physical characteristics/comes from family	11.7
En la sangre	In the blood	4.8
Nace con eso	Born with it	3.4
No sé	Do not know	2.1
Tierras/dinero/propiedad	Land/money/property	2.1
No se hurta	Not stolen	2.1
No es contagiar	Not contagious	1.4
Words for genes, k = 191		
Herencia/se transmiten	Hereditary/are transmitted	21.5
La familia/los ancestros	Family/ancestor	19.4
En la sangre	In the blood	14.1
Características/rasgos	Characteristics/traits	7.8
ADN	DNA	6.3

(Continues)

TABLE 3 (Continued)

Theme	English translation	Proportion of unique responses k, %
Desde el nacimiento	Since birth	3.7
Células	Cells	0.5
Illnesses worse than AD, k = 132		
Cáncer	Cancer	19.7
Enfermedades mentales	Mental illness	11.4
Enfermedad de Alzheimer	Alzheimer's disease	7.6
Diabetes	Diabetes	6.8
Enfermedades de los pulmones	Lung disease	4.5
COVID	COVID	4.5
Ataque al corazón	Heart attack/disease	4.5
Síndromes genéticos	Genetic condition	3.8
Derrame cerebral	Stroke	0.7
Vitíligo	Vitiligo	0.7
Causes of AD, k = 179		
Envejecer	Aging	14.0
Genes	Genes	10.6
La dieta/ nutrición/estilo de vida	Diet/nutrition /lifestyle	10.6
No sé	Do not know	6.1
Deteriorando	Deterioration/decay	3.3
No es una persona activa/ falta de ejercicio	Physical inactivity	3.3
No estimulado mentalmente/interactuó con menos gente	No mental stimulation/social isolation	3.3
Contusión/golpe en la cabeza	Brain injury	2.2
Mucho estrés físico/ nuestro cuerpo ya no es	Stress on/failure of body	1.7
Reasons to have AD genetic test, k = 214		
Si un padre o familiar lo tiene	If parent or family member has it	15.9
Olviden las cosas	Forgetting	13.1
No sé	Do not know	6.5
Prepararse/dejar asuntos en orden/planear nuestro cuidado	To prepare or plan	4.2
Si veo alguien de mi edad que lo tenga	When someone you know (not a family member) has Alzheimer's	4.2
Prevención/medidas preventivas	Prevention	3.7
Nuestra propensión/saber lo que te espera en el futuro	To determine predisposition	3.7
Nuestros hijos	For children	2.3
Curiosidad	Curiosity	0.9

(Continues)

TABLE 3 (Continued)

Theme	English translation	Proportion of unique responses k, %
Reasons not to have AD genetic test, k = 142		
No se te olvida/ no tienes ninguna pérdida de memoria/tu mente está bien	Memory is fine	13.4
Miedo saber	Afraid	9.9
No quiero saber/ no quisiera cambiar mi estilo de vida	Do not want to know/do not care/would not change lifestyle	6.3
Ha de ser un proceso caro/no tiene los recursos	Cost/expense	5.6
Ningún familiar ah ha tenido	No relatives with disease	5.6
Causa angustia/empezar a mortificar	Causes anguish/shame/embarra	3.5
No hay alguien que los guíe/ignorancia	No guidance/ignorance	2.1
No sé	Do not know	2.1
No hay tratamiento/no hay nada que hacer	No treatment/nothing to do	2.1
More useful tests than AD genetic test, k = 207		
Prueba de memoria	Memory test	10.1
Chequeo médico	Medical evaluation	6.8
No sé	Do not know	6.3
Scan del cerebro	Brain scan	4.8
Evaluaciones psicológicas	Psychological evaluation	3.9
Prueba de sangre	Blood test	2.9
Una observación de parte de los familiares	Others' observations	1.9

Abbreviations: AD Alzheimer's disease; COVID, coronavirus disease.

ful tests than an AD genetic test" yielded the greatest proportions of "don't know" (*no sé*) (7% and 6%).

3.3 | Participants know AD as a memory disorder

When asked about AD, participants referenced "forgetfulness/memory loss" (*olvido/pérdida de memoria*) most frequently (33%), nearly four times more frequent than the next theme. The concept of AD as a memory disorder appeared to be common knowledge. Additionally, a minority of responses (6%) highlighted "craziness/loony/psychopath" (*locura/demente/psicópata*), consistent with beliefs that AD is a behavioral or psychiatric condition.

3.4 | "Inherited" and "genes" have cultural salience

Themes from the "inherited" and "genes" prompts reflected familiarity with discrete hereditary units passed from generation to generation. These prompts' most frequent themes—"family" (*de familia*) (23%) and "hereditary/are transmitted" (*herencia/se transmiten*) (22%)—represented the second and third most frequent themes overall. This suggested these concepts hold broad cultural salience, with minimal variation in discussion. A minority of responses (2%) associated the non-medical use of "inherited" with bequeathing material items, reflected by the theme "land/money/property" (*tierras/dinero/propiedad*).

3.5 | AD genetic testing explains the past/present rather than prepares for the future

When asked about "causes of AD," the top themes identified were "aging" (*envejecer*) (14%), "genes" (*genes*) (11%), and "diet/nutrition/lifestyle" (*la dieta/ nutrición/estilo de vida*) (11%). Although participants perceived diet/lifestyle and genes as contributing equally—suggesting awareness that AD could occur without family history—they also implied an isolated occurrence of AD did not warrant genetic testing. When prompted for "reasons to have an AD gene test," top themes were "if parent or family member has it" (*si un padre o familiar lo tiene*) (16%) and "forgetting" (*olviden las cosas*) (13%). These suggested participants view genetic testing as a tool for understanding past or present health, not forecasting future risk. If understood as solely diagnostic, testing may be perceived as offering limited value for long-term planning. Future-oriented motivations appeared in a minority of responses: "prevention" (*prevención/medidas preventivas*) and "to determine predisposition" (*nuestra propensión/saber lo que te espera en el futuro*) (4% each).

By contrast, the theme "memory is fine" (*No se te olvida/ no tienes ninguna pérdida de memoria/tu mente está bien*) (14%) most frequently characterized "reasons not to have an AD gene test," followed by "afraid" (*miedo saber*) (10%), highlighting how emotion might also influence decision-making. Other themes, such as "do not want to know/do not care/would not change lifestyle" (*no quiero saber/ no quisiera cambiar mi estilo de vida*) (6%), suggested a test with a direct, tangible impact is more meaningful than one with no actionable information. The theme "no relatives with disease" (*ningún familiar ah ha tenido*) (6%) implied salience of the idea that genetic testing could not be uncoupled from family history, despite the recognition from other themes that AD could occur without affected relatives. While genetic testing for AD seemed pertinent to many, participants also recognized the role of other medical procedures. Themes of "memory test" (*prueba de memoria*) (10%) and "medical evaluation" (*chequeo médico*) (7%) emerged from the question about "more useful tests than an AD gene test."

TABLE 4 Results of narrative vignette prompts.

Theme (regarding H/L man's reaction to a genetic result...)	English translation	Proportion of unique responses k, %
Confirming a diagnosis of autosomal dominant AD, "Rodriguez", k = 190		
Que sabe lo que está pasando/Ellos ni saben que están enfermos	Not aware of what is going on	9.5
Ellos están ahí para ayudarlo/ Al pendiente de él	There is help/[someone is] looking out for him	8.4
Estaría triste/Se va a poner depresivo	Sad/depressed	7.4
Enojar	Anger	7.4
Más alerta	More alert	3.7
Un choque fuerte	Shock	2.1
Vergüenza	Shame	0.5
Incertidumbre	Uncertainty	0.5
Indicating moderate risk to develop AD in the future, "Enriquez", k = 261		
Preocupado/miedo	Concerned/afraid/worried	11.9
Inevitable de la edad/ya mayor	Inevitable of age/already older	5.7
Indiferencia/ no tomarlo muy en serio	Indifference/not take it seriously	5.0
Pensar a future/para planear el diagnóstico	Think ahead/plan for the diagnosis	5.0
Buscar información	Seek information	4.2
La familia me cuidará	Family will take care of me	3.8
Enojar	Anger	1.9
Sorprendido	Surprised	1.9
Excluding monogenic AD, but identifying a hereditary cancer gene variant, "Mendoza", k = 220		
Miedo/preocupación	Fear/concern	16.8
Triste/deprimido	Sad/depressed	8.6
Necesita ayuda	Need help	6.8
Prepararse para el futuro	Prepare for the future	5.0
Sentirse responsable	Feeling responsible	4.5
Ya tiene Alzheimer	Already has Alzheimer's	3.6
Malentendido	Misunderstanding	3.2
Excluding monogenic AD, but identifying a medication response result, "Ochoa", k = 200		
Enojo	Anger	16.0
Triste/deprimido	Sad/depressed	12.5
Hacer las cosas que antes él hacía solo	Loss of independence	8.5
Frustrado/irritado	Frustrated/irritated	7.0
El medicamento no está funcionando	Medication is not working	3.5
Porque de ser hombres que podían hacer todo	Because of being men who could do everything	3.0
Preocupado	Worried	3.0

Abbreviations: Alzheimer's disease; H/L, Hispanic/Latino.

3.6 | Return of genetic results to individuals with AD invokes sadness and fear

Besides the word/phrase prompts, participants were presented with vignettes in which an individual receives AD genetic results (Table 4). When asked about reactions of the fictional H/L man, participants frequently described emotional responses. Feelings of "sadness/depression" (*estaría triste/se va a poner depresivo* and

triste/deprimido) were noted for all vignettes about the man with AD: (1) "Rodriguez," receiving a result confirming autosomal dominant AD (7%); (2) "Mendoza," receiving a result excluding monogenic AD cause but identifying a hereditary cancer variant (9%); and (3) "Ochoa," receiving a result excluding monogenic AD but identifying altered medication metabolism (13%). Only the vignette about the man without memory problems ("Enriquez") did not yield "sad/depressed." Themes of fear emerged from all vignettes without a high penetrance AD

variant: (1) “Enriquez,” “concerned/afraid/worried” (*preocupado/miedo*) (12%); (2) “Mendoza,” “fear/concern” (*miedo/preocupación*) (17%); and (3) “Ochoa,” “worried” (3%). Only the “Rodríguez” vignette did not yield a theme of fear.

3.7 | Weakly predictive genetic results engender either a passive or active stance

The “Enriquez” vignette—describing a man without memory problems learning his (qualitative) AD risk was moderate—elicited “inevitable of age/already older” (*inevitable de la edad/ya mayor*) (6%) and “indifference/not take it seriously” (*indiferencia/ no tomarlo muy en serio*) (5%). These suggest a passive stance toward genetic information: risk is acknowledged but not seen as actionable in the absence of certainty. However, an active stance—interpreting risk as a prompt to plan, prepare, and change behavior—was also salient, as highlighted by “think ahead/plan for the diagnosis” (*pensar a futuro/para planear el diagnóstico*) (5%), “seek information” (*buscar información*) (4%), and “family will take care of me” (*la familia me cuidará*) (4%).

3.8 | Return of non-AD risk results generated unanticipated responses

The “Mendoza” vignette—describing a man with AD learning that he lacked a high penetrance AD gene variant but was predisposed for cancer—elicited “misunderstanding” (*malentendido*) (3%). No other vignette generated similar themes, suggesting a minority of participants did not anticipate genetic results relevant to other health conditions.

The “Ochoa” vignette—describing a man with AD receiving a medication response result—elicited the theme “because of being men who could do everything” (*porque de ser hombres que podían hacer todo*) (3%). The scenario described the man’s irritability and suboptimal anti-depressant treatment because he was an ultra-rapid metabolizer, as well as his distress at losing independence. Description of the man in distress prompted respondents to identify prideful masculinity as salient, though whether this stemmed from return of genetic results or from functional decline could not be determined.

4 | DISCUSSION

This study reveals the words that Spanish-preferring Mexican/Mexican American adults in Houston use to talk about AD and genetics as well as perceptions about genetic testing in the context of AD. Participants were generally familiar with both “AD” and “dementia,” but the latter term was more likely to be associated with mental illness. Although few studies have focused on perceptions among H/L individuals, this result is consistent with other published work suggesting more limited awareness of the behavioral and neuropsychiatric

manifestations of AD.^{20,32,33} Our results also add to prior studies highlighting awareness among H/L adults that AD is a multifactorial disorder with important contribution from genes along with aging and other lifestyle choices/behaviors that may impact brain health.^{20,33,34} We documented a high level of overall interest in AD genetic testing, and greater proximity to the disease influenced the desire to have such testing (e.g., if either the participant or their friends/family were displaying symptoms). While most respondents were familiar with the idea that biological traits can be transmitted across generations, the word “inherited” was associated with “property” or “something bequeathed” in a small though notable proportion of responses, suggesting the need for clearer explanation or alternative wording, as well as information about non-amnestic features, in AD education models to achieve universal understanding. Results from our freelist interviews are consistent with other studies indicating that many H/L adults are already aware that genetic testing can reveal disease risk, including for themselves and their families, and may also inform disease treatment.^{35,36}

Participants were likely to participate in research involving AD genetic testing, though some were uncertain of its personal relevance or utility. This may reflect a perceived technological imperative surrounding genetic testing.³⁷ Such technology can create pressure to use it, and declining it may provoke feelings of guilt, irresponsibility, or self-blame.^{38,39} Exploring whether advances in AD genetics foster responsibility to pursue testing despite limited awareness may inform strategies for H/L education and outreach. For example, explanatory materials might explain what AD genetic testing is, how results could be used, and their limitations.

Importantly, our results identify several potential barriers to acceptance of AD genetic testing among Spanish-preferring Mexican/Mexican American adults. Many participants cited intact memory as a reason not to pursue genetic testing, reflecting a view that testing is useful primarily for clarifying a diagnosis rather than anticipating future AD risk. Although some responses referenced planning for the future, such comments were less frequent. Overall, participants tended to view genetic testing as appropriate only once cognitive symptoms were present. This pattern reflects a predominantly present-oriented health disposition, in which action is taken in response to symptoms rather than in anticipation of future decline. This perspective mirrors clinical practice: Outside of asymptomatic individuals from autosomal dominant AD families, there is no established role for genetic testing to predict future AD risk. *APOE* genotyping is used among individuals with mild cognitive impairment or mild AD to guide treatment decisions, reinforcing an existing present-focused model of care. As the field progresses, educational materials may need to address how genetic information could eventually support risk estimation and motivate health-promoting behaviors among cognitively normal adults, while emphasizing the limitations of genetic testing when interpreted alone. Predictive genetic testing for non-autosomal dominant AD, if validated, may help estimate AD risk, motivate lifestyle change, and enhance multimodal assessment when combined with plasma, cerebrospinal fluid (CSF), and neuroimaging biomarkers,^{40–43} including among understudied H/L adults. Growing interest in primary-prevention trials may

therefore signal the emergence of a more future-oriented health perspective.

In addition, our study revealed that many individuals lack understanding of the potential for secondary findings during genetic testing, making information about both primary and secondary findings important to include in educational materials. Current guidelines recommend returning secondary, medically-actionable findings from clinical genetic testing.⁴⁴ However, few studies have examined pertinent beliefs among patients and caregivers in the context of clinical care and counseling for AD genetic testing. In addition to its potential impact on future clinical care, the disclosure of individualized actionable findings is recognized as a key motivator for participation in genomic research—contributing to both recruitment and retention,^{45–48} including among individuals from underrepresented groups such as H/L adults.

Our results, combined with findings from similar studies, can powerfully inform initiatives to improve communication with Spanish-preferring H/L adults about AD and genetic testing in the future, ensuring better-informed decisions for patients and their family members. Community-tailored communication strategies should also be developed in partnership with H/L community members and advisors. Evidence suggests expert-only genetic testing materials underperform among H/L communities because content is not linguistically or culturally aligned, or does not bridge health literacy or trust gaps between experts and the community.^{18,49} Our thematic findings hew closely to the words used by a community of Mexican/Mexican American adults which, if leveraged to co-create educational materials with experts, could contribute to messaging that is trusted by community members because of its shared authorship. In addition to guiding the development of print and digital materials, these findings highlight the need to enhance training of physicians, genetic counselors, and other members of clinical care and research teams to deliver culturally relevant information and to engage the H/L community in meaningful and effective ways. Although genetic counseling is well established in genetics clinics and neurology practices at many academic centers caring for patients with familial AD and other neurodegenerative diseases with strong genetic contributions,⁵⁰ many clinicians who care for older adults at risk for AD may be ill-equipped to discuss genetics results and their implications, particularly with Spanish-preferring H/L individuals.

Our participants regarded *familismo*, a H/L cultural value characterized by a high degree of social interaction, obligation, and support among nuclear and extended family members (see [Supplemental references S20–S21](#)) as highly important. Accordingly, AD genetic testing outreach may be strengthened by emphasizing that test results can inform and potentially benefit relatives, aligning with familial priorities and support systems. Prior studies have documented that deep spiritual and religious beliefs can be integrated into the daily lives of individuals from many H/L cultures (see [Supplemental references S22–S24](#)) potentially influencing perceptions of health and aging. Interestingly, we did not identify themes of spirituality in responses from this study, possibly because participants were primed to think about biological factors, based on the order of presentation and nature of the interview prompts and vignettes.

A potential limitation of our study is that findings may be restricted to participants who identified as Mexican or Mexican American and whose ages spanned adulthood. Although several themes emerged robustly, many appeared in fewer than 10% of unique responses, underscoring heterogeneous perspectives about AD genetic testing. Establishing generalizability will require studies across diverse H/L heritage groups that account for substantial heterogeneity (see [Supplemental Discussion](#)).

Another limitation is that, although freelisting is designed to be efficient and low burden, many participants provided narrative rather than list-based responses, limiting the method's typical advantages. Freelisting can complicate interpretation of low-frequency responses, which may reflect idiosyncratic or subtle but meaningful perspectives. Because of the narrative nature of many responses, we applied inductive thematic analysis to capture richer contextual detail and strengthen analytic rigor. Other qualitative approaches may have elicited additional or different themes (see [Supplemental Discussion](#)).

Overall, our findings from this study offer a foundation for developing culturally informed communication strategies, shaped by contributions of both H/L community members and researchers. Effective AD education and outreach, incorporating content that community members identify as salient about genetic testing and its varied results, can help ensure all individuals have an opportunity to engage in and benefit from ongoing advances in AD research.

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CONFLICT OF INTEREST STATEMENT

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. Author disclosures are available in the [Supporting Information](#).

CONSENT STATEMENT

The authors obtained study approval from the Institutional Review Board at Baylor College of Medicine (H-49633). All participants provided informed consent.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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