

UCSF

UC San Francisco Previously Published Works

Title

Increasing engagement of Hispanics/Latinos in clinical trials on Alzheimer's disease and related dementias.

Permalink

<https://escholarship.org/uc/item/2zp5d809>

Journal

Alzheimer's & dementia (New York, N. Y.), 8(1)

ISSN

2352-8737

Authors

Marquez, David X
Perez, Adriana
Johnson, Julene K
[et al.](#)

Publication Date

2022

DOI

10.1002/trc2.12331

Peer reviewed

RESEARCH ARTICLE

Increasing engagement of Hispanics/Latinos in clinical trials on Alzheimer's disease and related dementias

David X. Marquez¹ | Adriana Perez² | Julene K. Johnson³ | Michelle Jaldin¹ |
Juan Pinto¹ | Sahrü Keiser³ | Thi Tran³ | Paula Martinez³ | Javier Guerrero³ |
Elena Portacolone^{3,4}

¹Department of Kinesiology & Nutrition, University of Illinois at Chicago, Rush Alzheimer's Disease Center, Chicago, Illinois, USA

²Department of Family & Community Health, School of Nursing, University of Pennsylvania, Philadelphia, Pennsylvania, USA

³Institute for Health & Aging, University of California San Francisco, San Francisco, California, USA

⁴Philip Lee Institute for Health Policy Studies, University of California San Francisco, San Francisco, California, USA

Correspondence

David X. Marquez, Department of Kinesiology & Nutrition, Rush Alzheimer's Disease Center, University of Illinois at Chicago, 1919 W. Taylor, Chicago, IL 60612, USA.
E-mail: marquezd@uic.edu

[Correction added on 22 August 2022, after first online publication: The affiliations for Julene K. Johnson and Elena Portacolone were revised.]

Abstract

Introduction: Despite evidence that Hispanic/Latino populations are 1.5 times more likely than non-Latino Whites to develop Alzheimer's disease and related dementias (ADRD), Latinos are underrepresented in clinical trials testing treatments for ADRD. Data are needed on facilitators of ADRD clinical trial participation in Latinos. We leveraged in-depth qualitative methods to elucidate barriers and facilitators to participating in ADRD clinical trials in a large and diverse sample of Latinos; and to provide timely and actionable strategies to accelerate representation of Latinos in clinical trials on ADRD.

Methods: Data were collected in California between January 2019 and June 2020 from 25 focus groups (FGs): eight with Latino adults ages 18 to 49 ($n = 54$), nine with Latino adults ages 50+ ($n = 75$), and eight with caregivers of Latino older adults with ADRD ($n = 52$). Twelve community-based organization administrators were also interviewed. Transcripts of FGs and interviews were entered into Atlas.ti software. Three independent team members analyzed the transcripts with inductive/deductive qualitative content analysis. We triangulated data from stakeholder groups across sites, we used collaborative coding, and used the Consolidated Criteria for Reporting Qualitative Research.

Results: An overarching theme was a tension between wanting to learn more about ADRD and to participate in ADRD research but having limited awareness and opportunity. Five themes were identified: (1) remaining in limbo, (2) wanting information about ADRD, (3) wanting information on research about ADRD, (4) clearing researchers through trusted local organizations, and (5) practicing altruism through engagement in research opportunities.

Discussion: To increase representation of Latino communities in clinical trials on ADRD, bilingual information and education on ADRD and clinical trials needs to be better disseminated. Also, working with trusted local, regional, and national

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Alzheimer's & Dementia: Translational Research & Clinical Interventions* published by Wiley Periodicals LLC on behalf of Alzheimer's Association.

organizations can increase participation. Importantly, Latino participation can increase when research teams demonstrate altruistic actions and inform participants of public health reasons requiring their involvement.

KEYWORDS

aged, Alzheimer's disease and related dementias, clinical trials, focus groups, Hispanic, Latino

HIGHLIGHTS

- Participation in clinical trials on Alzheimer's disease and related dementias (ADRD) is limited among Latinos/Hispanics.
- Knowing the high prevalence of ADRD in Latinos increases willingness to participate.
- Observing altruism from researchers increases willingness to participate.
- Invitations from multiple organizations increases willingness to participate.
- Researchers should include public health reasons requiring Latinos' involvement.

1 | BACKGROUND

Hispanics/Latinos are the fastest growing racial/ethnic groups in the United States,¹ and account for 18% of the US population (representing 62.1 million people).² However, Latinos account for only 2% of participants in clinical trials on Alzheimer's disease and related dementias (ADRD),³ as well as studies on ADRD funded by the National Institutes of Health.⁴ Manly and Glymour⁵ raised concerns about the recently US Food and Drug Administration–approved aducanumab, a drug to treat Alzheimer's disease (AD), as only 3% of participants in its trials identified as Latino. This underrepresentation is a concern considering projections that the number of Latinos with AD will increase 9-fold by 2060, a growth of 832%.⁶ Emerging evidence also suggests that Latinos are at increased risk for developing ADRD. For example, two studies found that Caribbean Latinos in Northern Manhattan were twice as likely as non-Latino Whites to have ADRD.^{7,8} The Alzheimer's Association estimated that Latinos are 1.5 times more likely than non-Latino Whites using from data from the Health & Retirement Study.⁹ However, two other studies do not suggest higher ADRD incidence among Latinos versus non-Latino Whites in Northern California.^{10,11}

The underrepresentation of Latinos in clinical trials on ADRD reduces the generalizability of research findings because race/ethnicity may influence the efficacy of tested treatments. Despite a limited understanding of the biological underpinnings of race/ethnicity and their relation with ADRD, race/ethnicity is a marker for risk factors in the development of ADRD.^{5,8,12,13} For example, Latinos are at risk of having diabetes and have limited or no health insurance.^{14,15} Related, studies done exclusively with Black American populations might not be extrapolated to Latino populations because of race-specific biological risk factors. For example, compared to Latino populations, Black American populations are more at risk for strokes

and hypertension.¹³ Given that there are 200 clinical trials on ADRD with a goal of recruiting >70,000 participants,^{16,17} a public health issue in the United States is to increase representation of Latinos in clinical research about ADRD.

Studies on specific barriers and facilitators to participation of Latinos in clinical trials on ADRD have been limited. For example, a review discussed these barriers and facilitators drawing from research on cancer or research with people of color.¹⁸ Further, a recent systematic review of 19 articles noted that 15 studies on the topic focused exclusively on Black Americans, two on Black Americans and Latinos, and two on Asians.¹⁹ The few studies concerned with barriers to participation in ADRD clinical trials among Latinos focused on brain donation.^{20–22}

To address these research gaps, the purpose of our study was to leverage the depth of qualitative methods²³ to elucidate barriers and facilitators to participating in clinical trials on ADRD in a large and diverse sample of Latinos in California. Specifically, we wanted to learn from rural and urban Latinos, monolingual Spanish speakers, different age groups, plus caregivers and administrators of organizations serving Latino communities.

To facilitate the translation of research results into actionable strategies for researchers and academic institutions, we applied the Ford conceptual framework that identifies barriers and facilitators to enrollment into research.^{24,25} Initially developed to accelerate the recruitment of underrepresented populations in cancer research, this framework identifies three factors (i.e., awareness, opportunity, acceptance) related to increasing representation of diverse individuals in research, as detailed in Figure 1. Building on this framework,^{24,25} the goal of our study was to provide timely and actionable strategies to accelerate representation of Latinos in clinical trials on ADRD, with an emphasis on facilitators of ADRD research from the perspective of diverse Latino communities.

RESEARCH IN CONTEXT

- 1. Systematic Review:** The authors reviewed the literature using traditional (e.g., PubMed) sources. There have been recent publications describing recruitment of Black Americans into Alzheimer's disease and related dementias (ADRD) research, and one of Hispanics/Latinos, which has been appropriately cited.
- 2. Interpretation:** Our findings show that Latinos are more likely to consider participating in clinical trials on ADRD when they observe altruism from researchers, which is consistent with aspects of previous literature but expands participants' views of altruism.
- 3. Future Directions:** To increase representation of Latino communities in clinical trials on ADRD, information and education on ADRD and clinical trials needs to be better disseminated, and the altruistic actions of the research team and pressing public health reasons requiring Latinos' involvement are essential. Actionable recommendations for researchers and academic institutions to facilitate representation of Latinos in ADRD research based on the Ford framework should be considered.

2 | METHODS

2.1 | Study design

We used qualitative methods to identify factors that influence participation in ADRD research among Latino communities. We examined the perspectives of four stakeholder groups: Latino adults, Latino older adults, caregivers of Latinos with ADRD, and administrators of

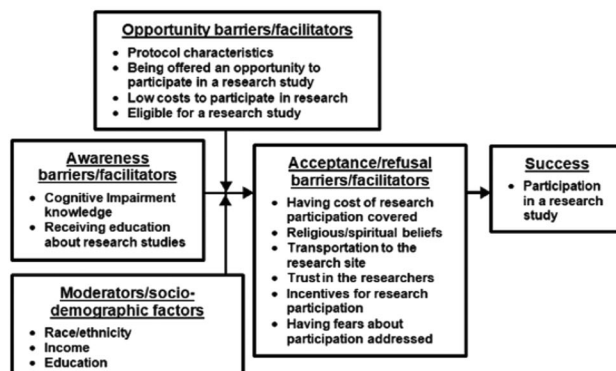
community-based organizations (CBOs). With the first three groups we used focus groups (FGs). To better understand FGs' narratives, drawing from prior research,²⁶ we then conducted one-on-one interviews with CBO administrators.

2.2 | Study participants

Inclusion criteria for adults and older adults was self-identifying as Latino/Hispanic and being aged 18 to 49 and >50, respectively. Inclusion criteria for caregivers included providing or coordinating care without financial compensation⁴³ to at least one Latino individual with diagnosed/undiagnosed cognitive impairment over the last year. Inclusion criterion for CBO administrators was working as an administrator in an organization predominately serving Latino communities and trusted by FG participants. Criteria were assessed by our researchers.

2.3 | Recruitment

We recruited participants in two ways. First, we recruited FG participants via the support of local CBOs (e.g., immigration, social, health-care services, advocacy organizations) serving primarily Latino communities in three sites with a high representation of Latino residents in California: Fresno (41% Latino residents), Los Angeles (49%), and the San Francisco Bay Area (24%). In particular, in each site CBO administrators disseminated our recruitment flyers (in [Appendix](#) in supporting information), and the CBO administrators solicited participation by endorsing our study and sharing recruitment flyers showing university logos and the name and address of their CBO. Some CBO administrators also hosted presentations of our team. For their effort, we initially provided financial compensation (\$450) to each CBO. Second, we recruited CBO administrators from CBOs that FG participants said that they trusted.



Awareness focuses on general knowledge about a study (e.g., knowing about the study, knowing that someone may qualify, having a general understanding about research).

Opportunity focuses on having access to research procedures (e.g., having financial resources and the time to travel to study visits).

Acceptance focuses on the process of decision-making (e.g., deciding to participate after weighing risks and benefits).

FIGURE 1 The Ford et al. conceptual framework

2.4 | Data collection

Data were collected in California from FGs with Latino adults, older adults, and caregivers (January 2019–March 2020) plus interviews with CBO administrators (April–June 2020). The Committee of Human Research of the University of California, San Francisco approved the study (17-23278).

2.4.1 | Methods

The overall goal of the FGs was to understand, in depth, barriers and facilitators to participating in ADRD research. FGs were facilitated by bilingual and bicultural Latino researchers, were designed to last ≈90 minutes, and were audio recorded and professionally transcribed. FGs were held in person in local community centers and CBO facilities. FGs began with facilitators asserting their intention to learn from participants. Next, facilitators defined ADRD and then probed participants' awareness on the fact that Latinos are more likely than Whites to develop ADRD (e.g., "Can I get a show of hands, who thinks that Latinos and White people have the same chance of getting dementia?"). After gauging participants' awareness, researchers used the Alzheimer's Association report to explain that Latinos are 1.5 times more likely to develop ADRD, but most participants of ADRD research are White. Then they explained that the goal of this study was to learn from them about barriers and facilitators for Latino communities in participating in ADRD research. Next, they asked participants about the characteristics of ADRD research (e.g., "What do you think research on dementia looks like?"). After participants offered their perspective, researchers explained different features of ADRD research. Next, they asked about barriers (e.g., "Is there anything that would hold you back?") to participating in ADRD research for themselves (as well as for person they care for in sessions with caregivers). Afterward, participants were asked about barriers for Latino communities in general to engage in ADRD research. Next, participants were asked whether trust was important to participate in research and what makes them trust specific acquaintances or professionals. Researchers then asked if the invitation of trusted professionals of specific investigations on ADRD would encourage participants to consider participating in these investigations. Finally, ending on a positive note, researchers asked about facilitators for Latino communities to participate in ADRD research. To supplement findings from the FGs, administrators of CBOs that were indicated as trusted by older adults and caregivers were interviewed over the phone because of the coronavirus pandemic. Using an interview guide designed to last for 60 minutes, Latino researchers elicited in-depth administrators' perspectives about specific ways to increase representation of Latinos in ADRD research, with emphasis on specific responsibilities of researchers toward CBOs and Latino communities. FGs and interview outlines are in the [Appendix](#). All participants received a \$40 gift card for their time.

2.5 | Analysis

After data collection, transcripts of FGs and interviews were entered into Atlas.ti software. Three independent coders led by the last author analyzed the transcripts with inductive/deductive qualitative content analysis.^{27,28} Transcripts were analyzed line by line²⁹ to understand what factors might influence the decision to participate, or not, in clinical trials on ADRD. The deductive analysis was guided by the Ford framework^{24,25} whereby coders identified barriers/facilitators for each factor of the model. First, we focused on identifying themes and subthemes. Next, we compared narratives from each stakeholder group to assess whether they corroborated, negated, or expanded one another, which adds depth to the analysis. To validate the data, we triangulated data from stakeholder groups across sites, paying particular attention to discrepancies in the data,^{29,30} we used collaborative coding; and used the Consolidated Criteria for Reporting Qualitative Research.³¹

3 | RESULTS

We conducted 25 FGs (14 in English and 11 in Spanish). We also interviewed 12 CBO administrators. Table 1 details participants' characteristics. Table 2 provides representative quotes. Whereas narratives from CBO administrators expanded narratives from participants of FGs, marked differences in narratives among participants' groups did not emerge. An overarching theme was a tension between wanting to learn more about ADRD and to participate in ADRD research but having limited awareness and opportunity.

3.1 | Remaining in limbo

Most participants noted that Latinos, in general, have limited knowledge about ADRD, the specifics of research, as well as the reasons and avenues to engage in ADRD research. One FG participant described it as "remain[ing] in a limbo." Specifically, most participants were concerned about their limited ability to detect ADRD. Most FG participants were unaware that Latinos were 1.5 times more likely than Whites to develop ADRD. Furthermore, a generalized lack of talking about ADRD in Latino communities was noted. Participants agreed that the inclination of Latino households to be private about personal matters has deterred Latino communities from realizing the shared burden brought forth by ADRD, a condition often associated with being "crazy." Because of this stigma attached to ADRD, not knowing was often preferred, and seeking help was considered "embarrassing." Limited education and health-care access also exacerbated this condition.

Superimposed on a limited understanding of ADRD was limited information about ADRD research. The majority of participants pointed to the lack of understanding of Latino communities on how to

TABLE 1 Demographic characteristics of participants

	9 Focus group Latino adults ages 50+	8 Focus group Latino adults ages 18–49	8 Focus group caregivers	CBO administrators	Total
Age (mean, SD, range)	67 years (SD = 12.06) (37–88) ^a	32 years (SD = 10.51) (18–56) ^a	56 years (SD = 16.01) (25–89)	44 years (SD = 9.78) (29–58)	49 years (SD = 12.86) (18–89)
	<i>n</i> (percentage)				
Sex, female	56 (75%)	30 (56%)	39 (75%)	8 (67%)	133 (69%)
Race/ethnicity					
Hispanic or Latino	70 (93%)	52 (96%)	47 (90%)	12 (100%)	171 (89%)
White or Caucasian	32 (43%)	11 (20%)	17 (33%)	4 (33%)	64 (33%)
Black or African American	0	0	1 (2%)	0	1 (1%)
More than one race	1 (1%)	6 (11%)	3 (6%)	0	10 (5%)
American Indian or Alaskan Native	3 (4%)	3 (6%)	0	0	6 (3%)
Not provided/other	38 (51%)	34 (63%)	31 (60%)	5 (42%)	108 (56%)
High school education or above (%)	32 (43%)	45 (83%)	32 (62%)	11 (92%)	120 (62%)
Location					
Rural	15 (20%)	27 (50%)	15 (29%)	9 (75%)	66 (34%)
Urban	60 (80%)	27 (50%)	37 (71%)	3 (25%)	127 (66%)
Monolingual Spanish speakers	36 (48%)	5 (9%)	8 (15%)	0	49 (25%)
Cultural heritage					
Mexico	27 (36%)	37 (69%)	31 (60%)	12 (100%)	100 (52%)
Central America	30 (40%)	11 (20%)	11 (21%)	0	52 (27%)
South America	7 (9%)	3 (6%)	2 (4%)	0	12 (6%)
Puerto Rico	1 (1%)	1 (1%)	0	0	2 (1%)
Not provided	10 (13%)	2 (4%)	8 (15%)	0	27 (14%)
Total	75	54	52	12	193

Abbreviations: CBO, community-based organization; SD, standard deviation.

^aOne participant came to a FG for Latino adults ages 50+ with a 37-year-old friend who was eager to participate, another participant came to a FG for Latino adults ages 18–50 with a 56-year-old friend also eager to participate. On both occasions, the researcher included the outliers to pay respect.

participate in ADRD research. Often FG participants, younger cohorts included, did not know what research on ADRD includes. This lack of information also fomented distrust. Specifically, fear of participating in research emerged, especially fear of receiving a diagnosis of ADRD or other diseases after one's involvement in research studies.

With regard to research, participants said that they rarely saw invitations to participate in research in English, let alone in Spanish. The consequences to participate in specific studies were questioned, as was the purpose of participating in research (e.g., “How could a hair or saliva help Alzheimer's disease?”). Some participants explained that in their native countries participating in research was unheard of.

3.2 | Wanting information about ADRD

The majority of participants were eager to receive information about ADRD: “They should inform us,” one noted. One major draw for this eagerness was hearing from the FG moderators, usually for the first time, that Latinos are more at risk for ADRD than non-Latino Whites.

With regard to wanting information about ADRD, participants wanted to understand the different types of ADRD, its hereditary characteristics, the difference between dementia and senescence, and specific risk factors for Latino communities. “Education” was also sought about symptoms, prevention strategies, and resources. One participant stressed the importance of conveying this information with attention to the “Hispanic culture.” Other participants expanded this point by emphasizing the importance of increasing awareness in Latino communities about the “statistics” of ADRD and the importance of learning and openly talking about ADRD. Most participants explained that this desire to know more about ADRD compelled them to attend the FG.

When asked about avenues to disseminate information about ADRD, especially ways to recognize early stages of dementia, and related research, participants stressed the importance of “informational campaigns” on Spanish-language television, radio (especially to reach farmworkers), social media, and health fairs, perhaps with “prominent” Latinos discussing their experience with ADRD in their families to dispel stigma. Some suggested that researchers learn from

TABLE 2 Participants' quotes by themes identified

Theme	Quote
Remaining in limbo	Because we don't know. We're not informed. It's not really out there, like hey, you know, if you want to do this research or do you know somebody? I didn't even have..., I had no clue. I don't think we're informed of it as much. <i>Participant 1, FG 10, Latino adults ages 18-50</i>
	I don't think the word is out there. I don't think, I mean when they talk about dementia, I've never heard statistics. I've never heard them say anything about the different cultures and who's more prone. I mean, you hear it with everything else, but I've never, everything I've ever heard, that's something I've never heard. So, I don't think they put it out there enough for us to realize it. Hey, where can we go? How can we participate? Maybe more people might be able to go in and participate in forums and research. <i>Participant 6, FG 11, Latino adults ages 50+</i>
	I think the reason there is no participation is because we don't know. The time, when you start it, or we don't really know how to take care of it. Because what we know is because old people have dementia, these have dementia, he died because of dementia. But who knows what happened? How can we help them? Or how can we help ourselves to stop that or to get better? Because I don't know very much about it. I just hear about it, but what is that starts it up? <i>Participant 6, FG 11, Latino adults ages 50+</i>
Wanting information about ADRD	I would say having a cultural awareness of what's a myth and what is not a myth regarding dementia would be a great impact on a community level or even on TV or any type of media, just because they are able to see OK, this is what I thought but in reality this is what it is. So be able to relate. I'm usually visual, so if I can read it, if I have something like that and see the difference, that would help me be aware of dementia. <i>Participant 2, FG 14, Latino adults ages 18-50</i>
	I think it would be more like talking through our story. By providing our story and what we go through they would be more motivated. Saying hey, this really works. They need us out there. Get involved, help find care for us and stuff. So I think telling them our story. Because a lot of them don't know. People don't know like with my dad, what a time I'm going through. They go really? Is that what's going on? So what do you do? So for all them, I think it's word of mouth, telling our story. <i>Participant 2, FG 6, Latino adults ages 50+</i>
	I would agree with that, but also PSAs in local communities. There's a lot of outlets that you can use, and some of them are free resources that you can use to be able to build awareness. <i>Participant 3, FG 14, Latino adults ages 18-50</i>
Wanting information on research about ADRD	If they could explain to me like, "Oh, we've had 200 people in the last 6 months donate their brain, here's what we've been able to find out, here's what's been helpful, here's what we do," and explain the whole process. That would help. <i>Participant 3, FG 22, Latino adults ages 18-50</i>
	So I think the awareness is a big thing. Being aware, like we said at the very beginning, that's we're 1.5 times more likely to have dementia, knowing that alone should be, I would say would be a big catalyst to getting participation. I think people just don't even know what dementia is about or don't even know the likelihood or the risks or anything like that. So I think the awareness would be a big help in getting participation. <i>Participant 5, FG 22, Latino adults ages 18-50</i>
	Make it well known. Magazines, TV, the radio. Make it well known. That way the community will know what's out there for them, not hide it, keep it closed in. So that way they will be coming in. <i>Participant 3, FG 20, Caregivers</i>
Clearing researchers through trusted local organizations	If (Voto Latino) would find the people and the Red Cross would be in charge of the study and everything. I mean, the two organizations together—together, everything is more beneficial for the community. <i>Participant 1, FG 2, Latino adults ages 50+</i>
	It would be really just easier to trust someone that's already like known and recognized. Kind of like #5 said. I mean, we've been to UCSF. But if it was just like some random place, I'd kind of want to think about it. <i>Participant 2, FG 3, Latino adults ages 18-50</i>
	We're meant to save and to help the community, that's what we do. We're servants for the community. But there's also things like military school programs, I would trust in things like that. So, anything that kind of tries to help out the community and kind of uplift everybody else in their success. <i>Participant 1, FG 21, Latino adults ages 18-50</i>
Practicing altruism through engagement in research opportunities	If there's a study and there's benefit for humanity, it's magnificent. <i>Participant 2, FG 2, Latino adults ages 50+</i>
	I would just say, as I mentioned before, our representation, to give a voice to the ethnic group, in this case the Hispanics. So how are they going to be represented in a bigger scale? How many people are represented who don't participate for one reason or another? So I think if someone told me "Oh, we're doing this to provide better services and better representation for Hispanics, it will be more like to get me to participate. <i>Participant 4, FG 3, Latino adults ages 18-50</i>
	Yeah, research is important, you know, if you really stop and think about it. Because it's for the future. Our kids, we don't know they're going to get dementia. Like somebody said right now, it's like for the future, the people of the future, the kids of the future. Maybe by the time they get our age there'll be a cure. If you don't have research, nobody will research it and see if there's something for us. <i>Participant 5, FG 6, Latino adults ages 50+</i>

(Continues)

TABLE 2 (Continued)

Theme	Quote
	<p>Researcher: can you tell me the reason why you would consider it [donating blood for dementia research]?</p> <p>Participant: Because I want to know, if they tell me my results, what they find. <i>Participant 3, FG 12, Latino adults ages 50+</i></p>
	<p>So make it [participating in research] a benefit for the person. \$150 for a survey for somebody to take some blood and saliva tissue, that doesn't help the person at all. Free medical care wherever they're doing the study. Maybe you get somebody with dementia here at [name] hospital and instead of paying them, you give them the treatment for a year or 2 years free of charge. I bet you you'd get a lot of people in on that. <i>Participant 6, FG 13, Caregivers</i></p>

Abbreviations: ADRD, Alzheimer's disease and related disorders; PSA, public service announcement; UCSF, University of California San Francisco.

informational campaigns in Latino communities about cancer. Others suggested ensuring that education about these topics is conveyed to younger Latino generations in school to “develop that train of thought from an early age.” Finally, the role of professionals of trusted organizations was emphasized.

3.3 | Wanting information about ADRD research

Most participants were also eager to better understand the characteristics of research on ADRD as well as opportunities to engage in such research. A major draw was the realization that Latinos are more at risk for ADRD. Another draw was to better understand their own cognitive health.

Most participants wanted to understand the overall purpose of conducting specific studies. Furthermore, they wanted to understand the “purpose” and “effects” of specific procedures and the knowledge gained from these procedures. Knowing the risks associated with participating in research and the procedures to keep the data confidential were also stressed, as well as the contingency plans in case of major adverse events. “Research paperwork” should be “easy to comprehend.” Also, participants wanted to understand “how they are going to use the information that they get from me” and how their data will benefit research, as well as themselves and their communities. Some participants wanted to have access to the data that researchers would learn about them. Others stressed the importance of knowing the research team and other Latinos participating in specific studies, as well as the team periodically sharing the results with study participants.

One participant explained that being able to talk with enrolled participants of ADRD studies would help her better understand whether to participate. In addition, participants wanted to understand the commitment involved, logistics, and accessibility options.

When asked about avenues to learn about research studies, most participants pointed to the role of trusted professionals. Furthermore, they suggested teaching the value of participating in research in schools. Sometimes after our FG ended, participants continued to ask the researchers for information on how to participate in ADRD research.

3.4 | Clearing researchers through trusted local organizations

When asked about best strategies to increase the participation of Latinos in ADRD research, most participants explained that the endorsement of organizations that are trusted by Latino communities would increase their trust in specific studies. These organizations included health centers, immigration centers, organizations supporting farmworkers and voters, and churches. Also, local and national organizations “dedicated” to ADRD and public health (e.g., the Red Cross) were considered with high regard because their mission was to help others, ranging from humanity to local Latino groups. Regarding professionals, physicians and nurses were also mentioned. For example, one participant mentioned the influence of physicians of Spanish-language television programs.³² Other professionals included church leaders and social workers.

Participants unanimously concurred that the simultaneous endorsement of multiple trusted organizations and professionals would encourage the participation of Latino communities in ADRD research, provided that the information about the study would be transparent and clear. Participants explained that the “significance” of an issue was amplified by observing different trusted organizations collaborating toward the same goal, in this case increasing the participation of Latino communities in clinical trials on ADRD.

An added advantage of local organizations supporting research studies is their ability to organize local events where researchers can be introduced to community members by trusted leaders of the community that are known for their commitment to supporting local communities.

3.5 | Practicing altruism

Altruism, defined as “the practice of thinking of the needs and desires of other people instead of your own”³³ emerged as a key facilitator in accelerating the participation of Latinos in ADRD research. At a personal level, participants often mentioned that they felt compelled to learn about ADRD and to participate in related research to support family members, Latino individuals, Latina single mothers, future

TABLE 3 Suggested venues for researchers to engage with Latino communities

Health centers
Community centers
Senior centers
Local organizations
Hospitals
Schools
Workplaces (lunch times)
Barbers, coiffeurs
Health fairs
Harvesting fields
Churches
Town halls
Bingo halls
Private homes
Libraries
Parks
"Big Latin supermarkets" (e.g., Superior, El Super)
Grocery stores
Support groups
Centers to support Latinos
Rehabilitation centers

generations of Latinos, as well as "humanity." Many participants knew someone with ADRD in their social circle and wanted to support them as well as finding a way to halt the trend. Participating in ADRD research was also often referred to as a way to "give a voice" to Latinos. A motivating factor was the hope that there will be a cure through participating in research by the time current children are older adults. Others also noted that participating in research is important because the disease will only end through research.

Participants unanimously pointed to the role of organizations and professionals with altruistic missions to encourage Latino communities to consider participating in research studies. Specifically, the commitment toward supporting others of these organizations gave them the trust and credibility to be considered legitimate.

Participants also suggested that researchers' selfless concern toward supporting Latino communities would be manifest in five ways. First, the clarity and quality of their explanations, materials, and updates in both English and Spanish would be evidence of altruism. Second, the presence of Latino researchers and Spanish-speaking researchers would point to the commitment of researchers toward the health of Latinos. Third, the researchers' physical and invested presence in Latino communities would also signal altruism, especially when this presence creates "a space that makes it safe to ask questions" and when findings are periodically disseminated (see Table 3 for suggested venues from all participants). Farmworkers and other Latinos from rural areas were noted as especially isolated, both geographically and informationally. Fourth, free transportation, available

home visits, accessibility options, and flexible schedules were indicated by participants as strong indicators of the researchers' selfless concern toward the specific needs of Latino participants. Finally, researchers had to offer appropriate incentives. For incentives to attend informational sessions, participants suggested being creative. When reflecting on incentives to engage in research, participants suggested supplementing monetary reward with compensation for lost labor to participate in research, free medical care while engaged in the study, and free doctors' visits. Administrators of organizations also suggested that researchers should financially invest in local organizations that can facilitate introductions with Latino communities and help with recruitment with attention to equity.

4 | DISCUSSION

The results of this study identified an overarching tension between Latinos wanting to better understand ADRD and participate in ADRD research but having limited awareness and opportunities. To increase representation of Latinos in clinical trials of ADRD, findings pointed to the importance of the simultaneous invitation from professionals of local organizations invested in Latino communities. Our findings particularly emphasized altruism as a key lever for Latinos to participate in ADRD research, and the importance of having Latino communities consistently observe researchers' altruistic behaviors.

One contribution of our study is the importance of increasing the awareness of ADRD, clinical trials on ADRD, and its prevalence among Latinos. Almost none of the 181 FG participants were aware that Latinos are particularly at risk to develop ADRD. CBO administrators also often admitted their limited knowledge about the impact of ADRD in Latino communities. We also observed the effects this newfound knowledge had on study participants, which acted as a call to action. Specifically, participants expressed marked interest in considering participation in ADRD research after learning this news, which confirms the importance of altruism as a facilitator. Yet another unique facilitator identified in our study are testimonials from Latinos already participating in clinical trials. Perhaps a related successful approach is to create support groups of Latino participants of specific clinical trials. Findings also point to the importance of explaining the different features of ADRD research. Furthermore, as highlighted in prior research,¹⁸ a facilitator to engage in research was understanding the purpose and protocols of specific studies. Privacy is critical because Latino immigrants—and particularly those who are undocumented—have become increasingly wary of participating in research amidst anti-immigrant rhetoric.³⁴

Our study also resulted in several avenues for disseminating ADRD information. A unique finding of our study was the many venues of dissemination that participants recommended (see Table 3). Other venues stated by the participants include radios, social media, and health fairs, perhaps with "prominent" Latino speakers. Yet another unique finding was the emphasis on teaching the importance of participating in research in schools. On a related note, some participants suggested informing younger generations of Latinos about ADRD to start the conversation with young people.

TABLE 4 Traditional cultural values of Latino communities

Value	Definition
<i>Familismo</i>	Interconnectedness with family is valued often to the point that the needs of the family have priority over individual needs. Family includes networks extending beyond the nuclear family, including aunts, uncles, grandparents, godfathers, and godmothers.
<i>Personalismo</i>	Informal, supportive, and warm interactions are extremely important. Informal and supportive interactions are preferred to formal and professional interactions. As a result, building rapport is essential in formal and professional interactions.
<i>Confianza</i> (trust)	Individuals are invested in establishing relationships that are based on reciprocal trust, with one another's best interest in mind.
<i>Dignidad</i> (dignity)	Individuals are inherently worthy and should be valued and respected.

A unique contribution of our study was to broaden the notion of altruism as a facilitator. As other studies also emphasized,¹⁸ participating in research can be positively interpreted as a personal gratifying act of selfless service toward present and future generations. Altruism evokes *familismo*, *personalismo*, *confianza*, and *dignidad*, all traditional values of "Hispanic culture"³⁵ defined in Table 4. As a result, recruitment materials should emphasize the altruistic features of engaging in research. For example, our flyers noted: "Your opinions will help find better ways to involve Latin Americans in research to improve health."

Findings also pointed to the importance of potential participants observing altruistic behavior in researchers over time. Furthermore, participants characterized the key features of such behavior. A first marker is receiving incentives that express a reflective consideration of the needs and priorities of potential study participants. Specifically, a contribution of this study is to point to the importance of moving beyond the traditional idea of fixed monetary incentives per visit to include reimbursement for lost hourly labor, transportation expenses, and caregiving duties. Additionally, our study pointed to the importance of providing and explaining lab results and other medical services (e.g., eyesight checks) as service to participants. At the Rush Alzheimer's Disease Center, a major drive of Latinos to participate in an ongoing study is to receive free blood tests that they would not receive elsewhere.³⁶ A second marker of researchers' altruistic behavior, as evidenced by prior research,^{6,18} is to support the competing obligations by offering home visits for data collection, accessibility options, and flexible schedules. A third marker is observing researchers partnering with local organizations that have been selflessly serving Latino communities. Related, a unique contribution of our study is that *simultaneous* endorsement of *multiple* trusted organizations is a key facilitator to accelerate participation of Latino individuals in ADRD research. Our group also identified this facilitator within Black American communities.²⁶ A fourth marker was to have researchers regularly update participants and connect them with other Latino participants.

Limitations include having only three sites in one state with a limited sample of participants and CBO administrators, which constrained

the generalizability of our findings. Future studies should focus on specific participants' groups, as well as specific levers for CBO administrators to support recruitment of clinical trial participants. Our sample included predominantly Latinos of Mexican descent, and not all Latinos will hold the same beliefs about ADRD research participation.³⁷ Finally, CBO administrators did not review the recommendations presented below.

4.1 | Recommendations

Guided by the Ford framework,^{24,25} these findings generated preliminary actionable recommendations for researchers and academic institutions to increase representation of Latinos in ADRD research. These include recommendations for raising awareness, providing opportunity, and increasing acceptance, such as considering incentives that include free medical care. See Tables 4 and 5 for details. Building on these findings, our group has spearheaded a new consortium (R24 AG071456) between the National Association of Hispanic Nurses and the Alzheimer's Association to increase awareness about the importance for Latinos to participate in clinical trials on ADRD.

5 | CONCLUSION

Findings indicate that to increase representation of Latino communities in clinical trials on ADRD, bilingual information and education on ADRD and clinical trials needs to be better disseminated, as Latinos have a great interest in participating. In addition, working with trusted organizations can increase participation. Perhaps most importantly, when Latinos perceive the altruistic actions of the research team and pressing public health reasons requiring their involvement, their participation is likely to increase.

ACKNOWLEDGMENTS

This work was supported by the California Department of Public Health (ADRA 18 10612) and the National Institute on Aging (R24 AG071456). No funding source had any role in the study design; collection, analysis, or interpretation of data; writing of the report; or the decision to submit the article for publication. The content is solely the responsibility of the authors and does not necessarily represent the official views of the California Department of Public Health, the National Institute on Aging or the University of California.

CONFLICTS OF INTEREST

All the authors declared that they do not have conflict of interest.

FUNDING INFORMATION

In the past 36 months, D.X.M., A.P., S.K., J.K.J., P.M., and E.P. received funding from the National Institute on Aging (R24 AG071456, paid to E.P. at the University of California San Francisco). Additionally, E.P., S.K., P.M., J.G., T.T., and J.K.J. received funding from the California Department of Public Health (ADRA 18-10612). [Author disclosures](#) are available in the supporting information.

TABLE 5 Actionable recommendations for researchers and academic institutions to facilitate representation of Latino older adults in ADRD research based on the Ford framework

Factors of the Ford framework	Recommendations for researchers and funding institutions	Theme(s) that inspired the recommendation
Awareness	Allocate adequate resources to inform Hispanic/Latino communities of research opportunities and protocols.	<ul style="list-style-type: none"> • Wanting information on research about ADRD
	Inform Hispanic/Latino communities of benefits and risks of participating in research.	<ul style="list-style-type: none"> • Remaining in limbo • Wanting information about ADRD • Wanting information on research about ADRD
	Make arrangements to support the logistics of participating in research studies.	<ul style="list-style-type: none"> • Wanting information on research about ADRD
	Take the time to clearly explain protocols and purpose of their study, the way data are kept private, and how data will be shared in plain and Spanish language.	<ul style="list-style-type: none"> • Wanting information about ADRD • Wanting information on research about ADRD • Practicing altruism through engagement in research opportunities
	Leverage any opportunity to timely disseminate findings through local educational presentations, flyers, and social media.	<ul style="list-style-type: none"> • Wanting information about ADRD • Wanting information on research about ADRD • Clearing researchers through trusted local organizations • Practicing altruism through engagement in research opportunities
	Inform younger generations of Latinos about ADRD and the importance of participating in research from a young age, in schools.	<ul style="list-style-type: none"> • Remaining in limbo • Wanting information about ADRD • Wanting information on research about ADRD
	Have Latino participants of clinical trials talk about their experience in the clinical trial.	<ul style="list-style-type: none"> • Wanting information on research about ADRD
	Partner with media to run “informational campaigns” on Spanish television (e.g., Telemundo, Univision).	<ul style="list-style-type: none"> • Wanting information about ADRD • Wanting information on research about ADRD • Practicing altruism through engagement in research opportunities
	Include radio, social media (e.g., Facebook, Instagram), and health fairs, perhaps with “prominent” Latinos discussing their experience with ADRD in their families.	<ul style="list-style-type: none"> • Wanting information about ADRD • Wanting information on research about ADRD • Practicing altruism through engagement in research opportunities
	Opportunity	Partner with multiple trusted local organizations can increase the interest and trust in specific studies.
Research protocols must be culturally relevant: research staff should speak Spanish and be aware and respectful of Latino/Hispanic cultures.		<ul style="list-style-type: none"> • Practicing altruism through engagement in research opportunities
Acceptance	Consider that incentives to participate in research can include monetary compensations, as well as reimbursement for lost employment income, transportation, and caregiving duties.	<ul style="list-style-type: none"> • Practicing altruism through engagement in research opportunities
	Consider that incentives can include free medical care, blood tests, eye checks, and other health-care services.	<ul style="list-style-type: none"> • Practicing altruism through engagement in research opportunities
	Self-reflect on ways to express altruism and invest in Latino/Hispanic communities over time.	<ul style="list-style-type: none"> • Practicing altruism through engagement in research opportunities
	Promote research that is altruistic and focused on serving Hispanic/Latino communities.	<ul style="list-style-type: none"> • Practicing altruism through engagement in research opportunities
	Create groups of Latino participants that are enrolled in specific trials.	<ul style="list-style-type: none"> • Wanting information on research about ADRD • Practicing altruism through engagement in research opportunities

Abbreviation: ADRD, Alzheimer’s disease and related dementias.

REFERENCES

1. Manly JJ, Gilmore-Bykovskiy A, Deters KD. Inclusion of underrepresented groups in preclinical Alzheimer disease trials-opportunities abound. *JAMA Netw Open*. 2021;4(7):e2114606.
2. US Census. *Hispanic or Latino table*. census.gov: U.S. Census Bureau; 2020 2020.
3. Canevelli M, Bruno G, Grande G, et al. Race reporting and disparities in clinical trials on Alzheimer's disease: a systematic review. *Neurosci Biobehav Rev*. 2019;101:122-128.
4. National Institutes of Health. NIH RCDC Inclusion Statistics Report. National Institutes of Health, 2022.
5. Manly JJ, Glymour MM. What the aducanumab approval reveals about Alzheimer disease research. *JAMA Neurol*. 2021;78(11):1305-1306.
6. Samus QM, Amjad H, Johnston D, Black BS, Bartels SJ, Lyketsos CG. A multipronged, adaptive approach for the recruitment of diverse community-residing elders with memory impairment: the MIND at home experience. *Am J Geriatr Psychiatry*. 2015;23(7):698-708.
7. Tang MX, Cross P, Andrews H, et al. Incidence of AD in African-Americans, Caribbean Hispanics, and Caucasians in northern Manhattan. *Neurology*. 2001;56(1):49-56.
8. Gurland BJ, Wilder DE, Lantigua R, et al. Rates of dementia in three ethnorracial groups. *Int J Geriatr Psychiatry*. 1999;14(6):481-493.
9. Alzheimer's A, 2010 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2010;6(2):158-194.
10. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimers Dement*. 2016;12(3):216-224.
11. Haan MN, Mungas DM, Gonzalez HM, Ortiz TA, Acharya A, Jagust WJ. Prevalence of dementia in older latinos: the influence of type 2 diabetes mellitus, stroke and genetic factors. *J Am Geriatr Soc*. 2003;51(2):169-177.
12. Chin AL, Negash S, Hamilton R. Diversity and disparity in dementia: the impact of ethnorracial differences in Alzheimer disease. *Alzheimer Dis Assoc Disord*. 2011;25(3):187-195.
13. Chen C, Zissimopoulos JM. Racial and ethnic differences in trends in dementia prevalence and risk factors in the United States. *Alzheimers Dement (N Y)*. 2018;4:510-520.
14. Aranda MP, Kremer IN, Hinton L, et al. Impact of dementia: health disparities, population trends, care interventions, and economic costs. *J Am Geriatr Soc*. 2021;69(7):1774-1783.
15. Bailey ZD, Krieger N, Agenor M, Graves J, Linos N, Bassett MT. Structural racism and health inequities in the USA: evidence and interventions. *Lancet*. 2017;389(10077):1453-1463.
16. National Institute on Aging. *Together We Make the Difference: National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research*. Bethesda: National Institute on Aging; 2018.
17. Watson JL, Ryan L, Silverberg N, Cahan V, Bernard MA. Obstacles and opportunities in Alzheimer's clinical trial recruitment. *Health Aff (Millwood)*. 2014;33(4):574-579.
18. Massett HA, Mitchell AK, Alley L, et al. Facilitators, challenges, and messaging strategies for Hispanic/Latino populations participating in Alzheimer's disease and related dementias clinical research: a literature review. *J Alzheimers Dis*. 2021;82(1):107-127.
19. Wong R, Amano T, Lin SY, Zhou Y, Morrow-Howell N. Strategies for the recruitment and retention of racial/ethnic minorities in Alzheimer disease and dementia clinical research. *Curr Alzheimer Res*. 2019;16(5):458-471.
20. Bilbrey AC, Humber MB, Plowey ED, et al. The impact of Latino values and cultural beliefs on brain donation: results of a pilot study to develop culturally appropriate materials and methods to increase rates of brain donation in this under-studied patient group. *Clin Gerontol*. 2018;41(3):237-248.
21. Montoya Y, Balbim GM, Glover CM, Marquez DX. "My Parent's Body Is Sacred": perspectives from adult Latino children about brain donation for Alzheimer disease research. *Alzheimer Dis Assoc Disord*. 2021;35(1):88-90.
22. O'Bryant SE, Johnson LA, Barber RC, et al. The Health & Aging Brain among Latino Elders (HABLE) study methods and participant characteristics. *Alzheimers Dement (Amst)*. 2021;13(1):e12202.
23. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet*. 2001;358(9280):483-488.
24. Napoles A, Cook E, Ginossar T, Knight KD, Ford ME. Applying a conceptual framework to maximize the participation of diverse populations in cancer clinical trials. *Adv Cancer Res*. 2017;133:77-94.
25. Ford JG, Howerton MW, Lai GY, et al. Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. *Cancer*. 2008;112(2):228-242.
26. Portacolone E, Palmer NR, Lichtenberg P, et al. Earning the trust of African American communities to increase representation in dementia research. *Ethnic Dis*. 2020;30:719-734.
27. Forman J, Damschroder J. Qualitative content analysis. In: Jacoby L, Siminoff L, eds. *Empirical Methods for Bioethics: A Primer*. Amsterdam: Jai Press Elsevier; 2008:39-62.
28. Schreier M. *Qualitative Content Analysis in Practice*. Thousand Oaks, CA: Sage; 2012.
29. Miles MB, Huberman MA. *Qualitative Data Analysis: A Methods Sourcebook*. 3rd ed. Thousand Oaks: Sage Publishers; 2014.
30. Farmer T, Robinson K, Elliott SJ, Eyles J. Developing and implementing a triangulation protocol for qualitative health research. *Qual Health Res*. 2006;16(3):377-394.
31. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357.
32. Univision Consulta with Dr Juan Univision. <https://www.univision.com/noticias/salud/doctor-juan-rivera> Published 2021. Accessed September 23, 2021, 2021.
33. Longman. *Advanced American Dictionary*. In: Harlow, UK: Pearson Education Limited; 2013.
34. Doran KM, Castelblanco DG, Mijanovich T. Undocumented Latino immigrants and research: new challenges in changing times. *J Health Care Poor Underserved*. 2018;29(2):645-650.
35. Adames HY, Chavez-Duenas NY, Fuentes MA, Salas SP, Perez-Chavez JG. Integration of Latino/a cultural values into palliative health care: a culture centered model. *Palliat Support Care*. 2014;12(2):149-157.
36. Portacolone E. Personal communication with David Marquez. In: 2021.
37. Boise L, Hinton L, Rosen HJ, Ruhl M. Will my soul go to heaven if they take my brain? Beliefs and worries about brain donation among four ethnic groups. *Gerontologist*. 2017;57(4):719-734.

SUPPORTING INFORMATION

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

How to cite this article: Marquez DX, Perez A, Johnson JK, et al. Increasing engagement of Hispanics/Latinos in clinical trials on Alzheimer's disease and related dementias. *Alzheimer's Dement*. 2022;8:e12331. <https://doi.org/10.1002/trc2.12331>