

RESEARCH ARTICLE

A boot camp translation of Alzheimer's disease in Hispanic/Latino communities

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Abstract

Introduction: Hispanics/Latinos (H/Ls) are significantly underrepresented in Alzheimer's disease (AD) research participant samples. This exclusion limits our interpretation of research findings and understanding of the causes of brain health disparities. The Engaging Communities of Hispanics/Latinos for Aging Research (ECHAR) Network was created to engage, educate, and motivate H/Ls for participation in brain aging research by addressing several barriers to inclusion, including health literacy and AD-related communication.

Methods: We used a novel community-engaged method—Boot Camp Translation (BCT)—to translate medical jargon into action-based, community-relevant messages. H/L community members ($n = 39$) were recruited from three cities to work with local research teams and co-develop culturally responsive AD-related messaging. BCT meetings leveraged various techniques to identify key messages, the target audience for the messages, and methods to disseminate these messages. Themes were constructed collaboratively between BCT facilitators and community members as the group iteratively refined the conceptual framework and language for the main messages, with the goal to make AD messaging accessible for H/L community members.

Results: H/L community members showed significant improvements in subjective understanding (Cohen's $d = 0.75$; $P < 0.001$) and objective knowledge of Alzheimer's disease (Cohen's $d = 0.79$; $P < 0.001$) at BCT completion. H/L community members identified key messages that converged for all three cities. These were related to reducing stigma, emphasizing brain health and risk mitigation, and acknowledging the impact of AD on multi-generational families/households. Participants also recommended sharing these messages with H/Ls across the lifespan using multi-media avenues.

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Discussion: The collaborative efforts identified culturally responsive and community-relevant messaging that may help address health literacy barriers contributing to AD-related disparities in H/L communities.

KEYWORDS

community-based participatory research, health disparity, minority health, research subject recruitment

HIGHLIGHTS

- Hispanics/Latinos are underrepresented in Alzheimer's disease and related dementias (ADRD) research despite increased risk.
- Limited ADRD health literacy may act as a recruitment barrier.
- Boot Camp Translation (BCT) is a process that targets health communication.
- We carried out BCT in three cities to co-develop ADRD messaging.
- Results highlight regional similarities and differences in ADRD communication.

1 | BACKGROUND

At 18% of the population (about 50.5 million people), Hispanics/Latinos (H/Ls) are the largest and one of the fastest-growing ethnic groups in the United States.¹ Their life expectancy is greater than non-Hispanic Whites¹ and is projected to increase to age 87 by 2050.² Although the underlying reasons remain unclear,^{3,4} H/Ls are at increased risk (50% higher than non-Hispanic White individuals) for Alzheimer's disease and related dementias (ADRD). The higher life expectancy and growing population trends have important implications (e.g., clinical, financial, and caregiver burden) for H/L populations. By 2050, H/L older adult populations are expected to double or triple.¹ It is projected that by 2060, H/Ls living with ADRD will increase by > 800%, costing the US economy \$2.35 trillion in cumulative costs.⁵

Despite the implications of their increased risk, H/Ls continue to be significantly under-represented in National Institutes of Health (NIH)-funded clinical trials and across the approximately 30 NIH-funded Alzheimer's Disease Research Centers (ADRCs).⁵ Limited representation clearly impacts our ability to characterize the Alzheimer's disease (AD) clinical phenotype in these individuals as well as our ability to develop culturally appropriate treatments. Consequently, these limitations continue to contribute to health disparities in this community, showing there is a critical need to address the recruitment and retention of H/Ls in aging and ADRD research.

Unwillingness to participate is often cited as a source for limited representation of H/Ls in research, but findings show no significant difference in willingness between H/Ls and non-Hispanic Whites.⁶ Numerous systemic and institutional barriers have been identified as factors that have resulted in the historic exclusion of culturally and linguistically diverse groups from participating in research; these include geographic distance and/or access to the large academic medical centers that tend to carry out research, sampling and recruitment methods

that can miss people from diverse communities, and inclusion/exclusion criteria (e.g., requiring English language proficiency) that can unintentionally restrict participation by certain groups.⁷ Mistrust of scientific personnel, a main barrier in Black individuals' participation,⁸ has also been observed in H/Ls, but other factors—mainly poor health literacy—appear to be greater barriers in H/Ls compared to Black individuals.⁹ Indeed, many ethno-racially diverse older adults are willing to participate in research studies but report limited awareness and knowledge about the disorder (e.g., viewing memory loss as a part of normal aging) as a reason for not participating.¹⁰ These findings suggest that addressing ADRD health literacy and clarifying the distinction between typical aging and ADRD may enhance willingness to participate in research. Moreover, evidence suggests that culturally modified recruitment approaches aid in improving the recruitment of H/Ls.¹¹ Therefore, leveraging existing community resources is a crucial step in engaging historically neglected and underrepresented communities.^{12,13} Along these lines, effective recruitment of H/Ls must include culturally responsive strategies to address barriers, improve communication, and increase community engagement.

The Engaging Communities of Hispanics/Latinos for Aging Research (ECHAR) Network was established to address the limited representation of H/Ls in research related to cognitive aging and ADRD. The ECHAR Network is a transdisciplinary, multi-site collaboration between researchers and community partners from metropolitan areas in Houston, Texas; Denver, Colorado; and Las Vegas, Nevada in the United States. Combined, these three metropolitan areas boast a H/L population of approximately 1.443 million.

In recognition of the disparities seen in cognitive aging for H/Ls and underrepresentation in ADRD research, the ECHAR Network has several aims related to the involvement of H/L community members in the research enterprise. One of these aims is to work closely with community members to co-develop community-relevant

awareness and education materials. As such, the main objective of the work we report here is to describe our application and results of a community-engaged process—Boot Camp Translation (BCT)¹⁴—with local H/L individuals residing in our three metropolitan areas to identify community-relevant ADRD messaging. BCT is a manualized community-based participatory research model in which culturally appropriate awareness and education materials are co-created by translating medical jargon into meaningful, actionable messages. BCT has been shown effective in improving health care for numerous medical conditions, including colon cancer, asthma, and hypertension in rural communities.^{15–17} Performing the same BCT in separate cities with similar populations (H/Ls) provides an innovative opportunity to examine similar approaches across communities and highlight unique regional differences.

2 | METHODS

2.1 | Sample

Each site within the ECHAR Network (Houston, Texas; Denver, Colorado; Las Vegas, Nevada) was tasked with recruiting 10 to 15 community members to participate in region-specific BCTs related to ADRD. Community participants were recruited to partner with the local research teams for each site in several ways, including with the help of local health agencies and community-based organizations (e.g., local chapters of the Alzheimer's Association and other non-profit organizations that work with older adults), community health workers, social media, and word of mouth. For inclusion in BCT, participants had to either identify as a member of the local H/L community or as an individual that worked very closely with H/L communities, but otherwise represented diverse linguistic, immigration, education, occupational, socioeconomic, residential, and age backgrounds (although middle to older age groups were the main focus of recruitment). Notably, knowledge of ADRD was not required for participation. All community participants were informed of the purpose, expectations, and procedures of the BCT partnership and provided written consent.

2.2 | Approach

Details and typical schedule of the BCT process are described elsewhere.¹⁴ Briefly, research teams meet with community members using an iterative and flexible schedule that includes longer, face-to-face meetings as well as shorter teleconferences that are more focused on their agenda. Additional correspondence via e-mail and/or postal service is carried out between meetings. Participants spend ≈20 to 25 hours over multiple months working closely with the research team to change the local conversation about the health issue at hand. For our purposes, we carried out AD-focused BCTs for local H/L communities.

Over the course of 6 to 8 months, two co-facilitators trained in the BCT process coordinated meetings, which were a combination of longer face-to-face meetings (half-day or full-day) as well as

RESEARCH IN CONTEXT

1. **Systematic Review:** The authors reviewed the literature using traditional (e.g., PubMed) sources. Relevant sources are appropriately cited.
2. **Interpretation:** Our findings identify culturally responsive and community-engaged messaging related to Alzheimer's disease relevant for Hispanic/Latino communities residing in the United States. Such messaging holds promise in improving brain health communication with Hispanic/Latino communities.
3. **Future Directions:** The article identifies characteristics of brain health messaging relevant to Hispanic/Latino communities that can be used to develop culturally responsive products. Additional research can help examine the reach and effectiveness of these tools to better understand (1) the applicability of these tools for younger Hispanic/Latino individuals and (2) the effect of these tools on improving recruitment into research studies.

brief (30-minute) conference calls and correspondence between the longer meetings. As needed, communication at each site was provided in both English and Spanish by bilingual research staff and/or interpreter services. Due to the pandemic, all face-to-face meetings were carried out via videoconferencing software (Zoom). At the initial BCT meeting, members in all three cities received the same comprehensive AD education—provided by a content expert—on the disease itself and care context of the disease process, including disease background, risk factors, genetics, diagnostics, caregiver burden, ethno-racial differences and disparities, and local resource information. While the educational content was not tailored for the local community members or for the H/L community more broadly, BCT members were encouraged and supported by the co-facilitators to ask as many questions necessary to fully understand the content provided. In subsequent meetings, BCT members sought to identify (1) key messages for their community (*What*), (2) target audience(s) to receive their messages (*Who*), and (3) dissemination strategies unique to their communities (*How*). See Figure 1 for a sample BCT timeline. Following standard practices of BCT,¹⁴ meetings leveraged various techniques to help answer these questions, including brainstorming, small and large group discussions, member polling, and copious notes readily shared with the group. At the end of each meeting, co-facilitators provided a recap, reflecting on key themes constructed by the group. Meeting notes were then synthesized by the co-facilitators after each meeting and shared with BCT participants for their revisions and approval between meetings. Notes, including constructed themes, were discussed as a group in subsequent meetings as the group iteratively refined the conceptual framework and language for the main messages. Visuals and mock-ups of materials were shared and voted upon by the group. Conversations allowed each individual to share their intellectual

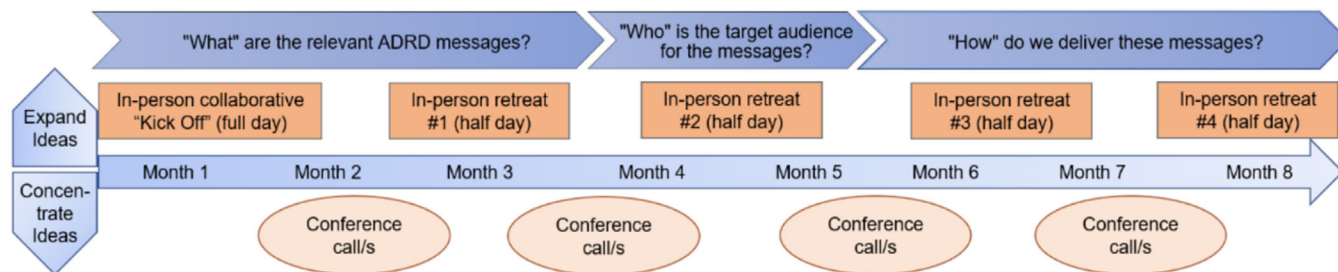


FIGURE 1 Sample timeline for Boot Camp Translation process. ADRD, Alzheimer's disease and related dementias.

and visceral reactions, making for lively discussions at each step of the process toward making the ADRD messaging accessible for all group members.

2.3 | Measures

To help describe the group of BCT participants, pre- and post-data collection included BCT members' subjective ratings of AD knowledge and completion of the Alzheimer's Disease Knowledge Scale (ADKS)¹⁸ to detect change in perceived and actual knowledge of AD. Specifically, BCT members were asked to rate themselves on a scale of 0 to 100 for "How well do you understand Alzheimer's disease?" The ADKS is a 30-item, true/false measure of AD-related factual knowledge. It was chosen as a measure for evaluating change in AD health literacy and for its lay-friendly language, validity, and reliability in research contexts. Pre-/post-data were compared using paired samples *t* tests and analyzed using SPSS version 28.¹⁹

3 | RESULTS

3.1 | Overall summary

A total of 39 individuals were recruited to participate in BCTs across the three sites. As shown by Table 1, recruitment sources resulted in variable success as calculated by the recruitment success factor (RSF = [number of participants yielded + 1]/[number of efforts made + 1]).²⁰ Highest recruitment success came from a combination of community health work groups and agencies as well as social media. Reported reasons for wanting to participate included a desire to learn more about ADRD out of personal interest or because of a personal connection (e.g., family member with ADRD), occupational interest (e.g., a health-care worker), or an altruistic desire to help the H/L community. Participant demographics are summarized in Table 2. Nearly 59% of BCT participants were in the 45 to 64 age range and 75% were female. Sites did not significantly differ in their distributions (age: $\chi^2[2, N = 39] = 1.61, P = 0.45$; sex/gender: $\chi^2[2, N = 39] = 0.63, P = 0.73$). Information about education, household income, and heritage groups was not uniformly collected at all three sites. Education level was collected by one site, household income by two sites, and heritage group by two sites. Available data at these sites suggest nearly half of the sample had more than a high school education. Nearly 21% reported annual

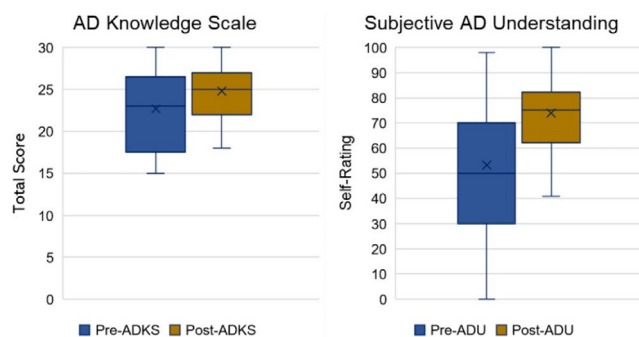


FIGURE 2 Pre- and post-comparison of objective AD knowledge (ADKS) and subjective AD understanding (ADU) in BCT participants. AD, Alzheimer's disease; ADKS, Alzheimer's Disease Knowledge Scale; BCT, Boot Camp Training.

household incomes < \$50,000 and 26% reported incomes > \$50,000 but < \$75,000. About 76% of the overall group identified as being of Mexican heritage.

Pre-/post-comparisons showed significant improvement in subjective understanding (pre: 53.2 ± 25.7 , range 0–98; post: 73.9 ± 14.2 , range 41–100; Cohen's *d* = 0.75; $P < 0.001$). On average, participants showed low confidence in their understanding of ADRD at the beginning of BCT. Compared to baseline scores, average confidence increased, and the range was notably narrower at the end of BCT. A similar pattern was observed on the ADKS, a measure of objective ADRD knowledge (pre: 22.7 ± 4.6 , range 15–30; post: 24.8 ± 3.4 , range 18–30; Cohen's *d* = 0.79; $P < 0.001$; Figure 2). While participants generally showed high ADRD literacy both at BCT kickoff and at the end of the process, post-BCT scores showed a higher average as well as a narrower range. Notably, despite the presentation and discussion of the evidence base for ADRD being the focus of the BCT kickoff (i.e., the first day), participants continued to engage with the content across the months-long process and discussions, likely contributing to the observed increase in subjective and objective ADRD health literacy. We provide these pre/post comparisons mainly for descriptive purposes to highlight the range of comfort with ADRD observed across our participants, as knowledge of ADRD was not required for participation. Moreover, the range in pre-BCT ADRD health literacy observed in our BCT members has implications on the final messaging produced by the process as it can potentially reach a similar range in health literacy.

After completing BCT, we found evidence of convergent themes across the three locations. Notably, we found similarities in the need

TABLE 1 Recruitment success factor (RSF) by recruitment source per site.

Denver, Colorado					
Source	Participants	% of total	Efforts	% of efforts	RSF
Community health worker group	11	68.75	2	14.29	4.00
Personal contacts & connections	5	31.25	12	85.71	0.46
Houston, Texas					
Source	Participants	% of total	Efforts	% of efforts	RSF
Community health care worker group	3	33.33	9	64.29	0.40
Social media (Facebook) group	4	44.44	2	14.29	1.67
Community agency/ies	2	22.22	3	21.43	0.75
Las Vegas, Nevada					
Source	Participants	% of total	Efforts	% of efforts	RSF
Personal contacts & connections	6	42.86	141	37.70	0.05
E-mail blasts (direct, list service)	3	21.43	152	40.64	0.03
Social media (Facebook)	2	14.29	45	12.03	0.07
Community agency/ies	2	14.29	5	1.34	0.50
Flyers	1	7.14	20	5.35	0.10
Local organization meetings & events	0	0.00	11	2.94	0.08

TABLE 2 Summary of demographics.

	Denver, Colorado n = 16	Houston, Texas n = 9	Las Vegas, Nevada n = 14	P
Age (range)				0.45
20–24	0	0	2	
25–29	0	0	1	
30–34	0	1	1	
35–44	5	1	2	
45–54	5	2	2	
55–64	6	4	4	
		(1 Unknown)	(2 Unknown)	
Sex/gender (% Female)	81%	89%	55%	0.73

for bilingual messages that promoted brain health and ADRD risk mitigation as opposed to approaches that solely focused on deficits. Community members stressed the importance of the family unit in messaging, and how highlighting inter-generational relationships would leverage the hope of older generations to promote a healthy legacy for younger generations (*What*; Table 3). Along these lines, our community members recommended these messages be shared in a targeted fashion with H/L community members across the lifespan (*Who*). For instance, messaging promoting brain health can be shared with younger and older adult individuals; similarly, messages related to early detection could be tailored for younger adults (e.g., to detect symptoms in their parents/grandparents) as well as for older adults (e.g., to detect symptoms in themselves). Our community members also provided information about myriad avenues to share these messages, such as social media (e.g., Facebook, WhatsApp, TikTok), billboards,

radio/television, health fairs, and local clinics (*How*). Divergence in BCT outcomes was largely affected by regional variability in available resources for Spanish-speaking and/or undocumented individuals. The lack of resources was identified as a barrier to care and participation in research, which discouraged community messaging related to seeking care or research. Convergence and divergence of themes are further discussed below in a site-specific summary.

3.2 | Site-specific summary

3.2.1 | Denver, Colorado

In Denver, 16 community members completed BCT. Participants were recruited with the help of community health worker groups as well as

TABLE 3 Summary of key themes and sample messages.

Cross-cutting themes		
	<ul style="list-style-type: none"> Risk mitigation and brain health Role of/impact on H/L families 	<ul style="list-style-type: none"> Resilience in the H/L community Destigmatizing AD
Site-specific themes		
Site	Key themes	Sample messages
Denver, Colorado	<ul style="list-style-type: none"> AD awareness and stigma Prevention Risk factors Strength and solidarity of H/L communities 	<ul style="list-style-type: none"> Forgetfulness does NOT have to be a normal part of getting old Don't be ashamed of talking about your memory changes Exercise your body AND your brain Alzheimer's is between us. Look for help now.
Houston, Texas	<ul style="list-style-type: none"> Risk mitigation and brain health Responding to fear and stigma Impact of AD/ADRD on families, multi-generationally Understanding how AD/ADRD is different for every person Importance of self-care for caregivers 	<ul style="list-style-type: none"> In taking care of our brains, we take care of others Memory loss can be delayed Patience with the patient Ask your doctor for five more minutes
Las Vegas, Nevada	<ul style="list-style-type: none"> Responding to stigma, normalizing AD/ADRD Responsibility, love, & respect for the family Love as education, protection, planning Strength and solidarity of H/L communities 	<ul style="list-style-type: none"> To love is to know The community cares. Let's talk. Alzheimer's is a health condition we can face together

Abbreviations: AD, Alzheimer's disease; ADRD, Alzheimer's disease and related dementias; H/L, Hispanic/Latino.

via personal contacts and connections. The Denver BCT included public health officials and community health workers among its community members; all self-identified as H/L. The BCT participants met regularly between July and November 2021.

As a result of BCT, the group focused messaging on reducing stigma about ADRD, including four main messages about ADRD awareness and symptoms, brain health, and ADRD risk reduction. In the early stages, the group identified the exclusion of the H/L community in ADRD resources, health care, and research as a key message. However, after extensive discussion, the group did not move forward with the messaging on H/L community exclusion due to concerns of potential community harm. More specifically, the group wanted all messages to be relevant for undocumented and monolingual H/L individuals. In light of this, there were valid concerns from the group that local health care and research entities were not equipped to accommodate this group as evidenced by barriers related to participant payment for undocumented individuals and exclusion of non-English speaking participants due to a lack of Spanish-speaking personnel on care or research teams. Additionally, multiple group members had personal stories of difficulty accessing local neurological care and/or Spanish-speaking providers and resources. The group moved forward with three main themes (ADRD awareness, brain health, and ADRD risk). The group worked with a local graphic designer to co-create materials displaying their messages and a group-created logo "United Against Alzheimer's." Materials included flyers, handouts, t-shirts, and branded stress balls shaped like brains. After completion of the Denver BCT, the group formed a community action board (CAB) to continue working in this area together. In response to the stated need, the Denver research team has been working with the CAB to develop a list of local resources available on their website, including phone numbers, addresses, links,

and contacts that provide resources and clinics that support low income and undocumented individuals. The CAB has already helped plan a community health event with further event planning underway. Moreover, the research team has incorporated CAB feedback into recent hiring practices to add Spanish-language providers to existing clinical services at the research team's institution.

3.2.2 | Houston, Texas

A total of nine community members completed the BCT process in Houston. Participants were recruited through local organizations, social media, and word of mouth. All members identified as H/L. Participants met in three, 4-hour virtual sessions and several phone conferences from February to June 2021.

Overall, messaging centered around brain health to reduce AD stigma, importance of geriatric education for care providers, and self-care in caregiving. Messaging was in English and Spanish and included phrases such as: "What is good for your heart, is good for your brain!"; "Heart health and brain health are connected"; and "Memory loss can be delayed." Targeted audiences for these messages were (1) the general Houston Latino population, (2) care providers (i.e., doctors, nurses, psychologists, hospitals), and (3) caregivers (informal/formal). As a result, dissemination strategies emphasized family and intergenerational relationships, with imagery and colors reflecting the diversity and vibrancy of the Houston H/L community. The final products suggested included graphics/printed materials, such as billboards and visual imagery, and a "telenovela-style" educational video series. The 5-part telenovela, "Recuerdos de mi Abuelo," was developed with University of Houston students and faculty, local H/L actors, and local

H/L community members. It depicts the story of a H/L family struggling with the early signs of AD and is available in both English and Spanish. Currently, the telenovela series is being distributed to local ADRD organizations, medical offices, and various social media platforms. Finally, a CAB was established and meets on a quarterly basis to continue discussing dissemination-based strategies, increasing H/L recruitment in research studies, and potential future events for the community (e.g., health fairs).

3.2.3 | Las Vegas, Nevada

The Las Vegas BCT group comprised 14 community members. Recruitment of members in Las Vegas, relative to the other two cities, required substantially more effort (see Table 1), due in part to a lack of ADRD clinical care infrastructure in the city. The majority of members were identified through community connections, targeted e-mail blasts, social media, and community agencies. Notably, not all BCT members personally identified as H/L ($N = 3$); these members expressed interest in the cause as related to their clientele and/or local residents in H/L neighborhoods. The BCT participants met regularly between August 2021 and January 2022.

As reflected by the key messages identified (Table 3), BCT members highlighted opportunities for community members to engage and support message dissemination, and for decisions and actions to be decided within the context of the family or with loved ones. In addition to the messages identified, meetings discussed and identified local challenges specific to the culture and infrastructure of Las Vegas and Nevada. Members highlighted that a lack of care services and accessible information in the city could prevent calls to action in response to the recognition of AD symptoms. Many BCT members joined our CAB; they emphasize the need for ongoing advocacy in the state, Spanish-language resources, and an online presence that simplifies and supports navigation of services and information.

4 | DISCUSSION

With a goal of addressing disparities in cognitive aging and ADRD, the ECHAR Network has been working closely with local H/L communities in three metropolitan areas in the United States: Houston, Texas; Denver, Colorado; and Las Vegas, Nevada. We sought to describe how the ECHAR Network has been collaborating with local H/L community members to co-develop culturally responsive messaging for ADRD. Using the established process of BCT to translate scientific and medical jargon, we examined regional themes identified across our three sites. While slight differences in wording and messaging were noted, results suggest key similarities between each of the three BCT groups. Participants identified English/Spanish bilingual messaging related to AD-related stigma among H/L communities, the impact of ADRD on families and multi-generational households, and a desire for positive and uplifting messaging that emphasizes prevention/risk mitigation. In

terms of the target audience for these messages, all three groups similarly noted a need for H/Ls across the lifespan (i.e., from children to older adults) to hear these messages, especially as it relates to risk mitigation and brain health. Last, in relation to how best to communicate these messages, all three groups put forth varied options (e.g., social media, radio/television, and health fairs), emphasizing the need for multi-media approaches for delivery.

Results from carrying out BCTs in these three cities also highlight some important regional differences worth mentioning. Messaging co-created with our H/L community members reflected variability in available infrastructure for clinical services. For instance, group members in Denver reported being discouraged from recommending other community members talk to health-care providers or researchers about memory concerns due to the lack of available Spanish-language professionals/services. In contrast, group members in Houston, which may relatively have more infrastructure for Spanish speakers, decided on messaging specifically related to or targeting care providers (e.g., "Ask your doctor for five more minutes"). Limited infrastructure was noted as affecting access to care and recruitment for research at our Las Vegas site while other institutional barriers (e.g., policies surrounding participant payments) were discussed by Denver community members as contributing to the systematic exclusion of H/Ls from ADRD care and research. Overall, community members indicated interest in accessing more ADRD information, care, and research, but cited multiple institutional and systemic barriers that limit their ability to do so.

The present work is not without limitations. While BCT groups showed some diversity in terms of H/L heritage groups, participants mostly represented Mexican heritage groups (76%) with some representation of Caribbean and Central American heritage groups. As such, there was a limited representation of other H/L heritage groups (e.g., South American), which may limit the reach of the ADRD messaging identified. Similarly, the three metropolitan areas in which we carried out the BCT process may not be representative of H/L communities in other regions. BCT participants identified a need to target messaging for H/L individuals across the lifespan given the impact of ADRD on families across generations and the potential for risk mitigation (via brain health promotion). However, given that the age ranges represented by the participants were relatively restricted, the BCT messaging described may not be appropriate for younger or older adults (age 65+) individuals. This is an area of current exploration by members of the ECHAR Network.

Despite notable limitations, the present work has several strengths worth mentioning. Our BCT groups comprised individuals from diverse backgrounds both in terms of demographic characteristics and ADRD knowledge. Three quarters of our BCT members were female; notably, the prevalence of ADRD is higher in women²¹ and women are more likely to serve as caregivers for ADRD.²² The process of BCT reflects a deeper level of community engagement that leverages the expertise and knowledge of community members as they navigate health information and spaces in their own way. BCT introduces these community members as partners in the research infrastructure, empowering local

communities toward a common goal of addressing health disparities. Upon completion of BCT, the majority (>70%) of participants agreed to continue working with the ECHAR Network research teams as members of local CABs; CAB members will help identify other ways to improve communication about ADRD while also recommending culturally responsive strategies for outreach to H/L communities. As products are developed and become available, they will be shared on our network's website (www.echarnetwork.com). Improving brain health communication with communities at increased risk for ADRD in a culturally responsive manner is a logical first step to reduce risk and possibly close gaps in brain health disparities.

In summary, we present here a model for engaging communities in recruitment infrastructure with the goal of co-developing community-relevant and culturally responsive brain health messaging related to AD. We summarize cross-regional similarities in ADRD communication for H/Ls that emphasize positive messages related to reducing stigma, mitigating risk, and empowering families. Moreover, H/L communities acknowledge a need for these messages to reach members of all ages and across media types. Ongoing and future work will examine the reach and effectiveness of these community-engaged messages in increasing ADRD health literacy toward reducing ADRD disparities in H/L communities.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. Author disclosures are available in the supporting information.

CONSENT STATEMENT

The described work did not involve human subject research. Therefore, consent was not necessary. Nevertheless, community members were informed of the process and consented to partner with the research team to carry out the described program.

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REFERENCES

1. US Census Bureau. 2010 Census Data. 2010. Accessed June 3, 2012. <http://2010.census.gov/2010census/>
2. Valle R, Lee B. Research priorities in the evolving demographic landscape of Alzheimer disease and associated dementias. *Alzheimer Dis Assoc Disord*. 2002;16(Suppl 2):S64-76.
3. Gurland BJ, Wilder DE, Lantigua R, et al. Rates of dementia in three ethnorracial groups. *Int J Geriatr Psychiatry*. 1999;14:481-493.
4. Alzheimer's Association. 2013 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2013;9:208-245. doi:10.1016/j.jalz.2013.02.003
5. USC Edward R. Roybal Institute on Aging, Latinos Against Alzheimer's Network. Latinos and Alzheimer's Disease: New Numbers Behind the Crisis; 2016. https://roybal.usc.edu/wp-content/uploads/2016/10/Latinos-and-AD_USC_UsA2-Impact-Report.pdf
6. Wendler D, Kington R, Madans J, et al. Are racial and ethnic minorities less willing to participate in health research? *PLoS Med*. 2005;3:e19. doi:10.1371/journal.pmed.0030019
7. National Academies of Sciences, Engineering, and Medicine. *Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups*. Washington, DC: The National Academies Press; 2022. doi:<https://doi.org/10.17226/26479>
8. George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health*. 2014;104:e16-31. doi:10.2105/AJPH.2013.301706
9. Calderón JL, Baker RS, Fabrega H, et al. An ethno-medical perspective on research participation: a qualitative pilot study. *MedGenMed*. 2006;8:23.
10. Areán PA, Gallagher-Thompson D. Issues and recommendations for the recruitment and retention of older ethnic minority adults into clinical research. *J Consult Clin Psychol*. 1996;64:875-880. doi:10.1037/0022-006X.64.5.875
11. Haack LM, Gerdes AC, Lawton KE. Conducting research with Latino families: examination of strategies to improve recruitment, retention, and satisfaction with an at-risk and underserved population. *J Child Fam Stud*. 2014;23:410-421. doi:10.1007/s10826-012-9689-7
12. Baucom KJW, Chen XS, Perry NS, Revolorio KY, Reina A, Christensen A. Recruitment and retention of low-SES ethnic minority couples in intervention research at the transition to parenthood. *Fam Process*. 2018;57:308-323. doi:10.1111/famp.12287
13. Bishop JB. The counseling center: an undervalued resource in recruitment, retention, and risk management. *J College Stud Psychother*. 2010;24:248-260. doi:10.1080/87568225.2010.509219
14. Norman N, Bennett C, Cowart S, et al. Boot camp translation: a method for building a community of solution. *J Am Board Fam Med*. 2013;26:254-263. doi:10.3122/jabfm.2013.03.120253
15. Westfall JM, Zittleman L, Sutter C, et al. Testing to prevent colon cancer: results from a rural community intervention. *Ann Fam Med*. 2013;11:500-507. doi:10.1370/afm.158
16. Bender BG, Dickinson P, Rankin A, Wamboldt FS, Zittleman L, Westfall JM. The Colorado Asthma Toolkit Program: a practice coaching intervention from the high plains research network. *J Am Board Fam Med*. 2011;24:240-248. doi:10.3122/jabfm.2011.03.100171
17. DeAllemaume L, Parnes B, Zittleman L, et al. Success in the Achieving CARDiovascular Excellence in Colorado (A CARE) home blood pressure monitoring program: a report from the shared networks of Colorado ambulatory practices and partners (SNOCAP). *J Am Board Fam Med*. 2015;28:548-555. doi:10.3122/jabfm.2015.05.150024
18. Carpenter BD, Balsis S, Otilingam PG, Hanson PK, Gatz M. The Alzheimer's disease knowledge scale: development and psychometric properties. *Gerontologist*. 2009;49:236-247. doi:10.1093/geront/gnp023
19. IBM Corp. SPSS Statistics, Version 28.0. 2021.

20. Alvarez RA, Vasquez E, Mayorga CC, Feaster DJ, Mitrani VB. Increasing minority research participation through community organization outreach. *West J Nurs Res*. 2006;28:541-560. doi:[10.1177/0193945906287215](https://doi.org/10.1177/0193945906287215)
21. Rajan KB, Weuve J, Barnes LL, McAninch EA, Wilson RS, Evans DA. Population estimate of people with clinical Alzheimer's disease and mild cognitive impairment in the United States (2020-2060). *Alzheimers Dement*. 2021;17:1966-1975. doi:[10.1002/alz.12362](https://doi.org/10.1002/alz.12362)
22. Kasper JD, Freedman VA, Spillman BC, Wolff JL. The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Aff*. 2015;34:1642-1649. doi:[10.1377/hlthaff.2015.0536](https://doi.org/10.1377/hlthaff.2015.0536)

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