


The Digital Divide Exacerbates Disparities in Latinx Recruitment for Alzheimer's Disease and Related Dementias Online Education During COVID-19

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Ángela Gutiérrez, PhD, MPH¹ , Rosalba Cain^{2,3}, Nadine Diaz, DSW, MSW^{2,3}, and María P. Aranda, PhD, MSW, MPA, LCSW^{2,3}

Abstract

Latinx adults experience a high burden of dementia. Given that modifiable factors drive dementia disparities, engaging Latinxs in Alzheimer's disease and related dementias (ADRD) education is critical to address dementia burden among this aging population. Yet, no studies have documented the role of the COVID-19 pandemic on dementia education among Latinxs. This study: (1) elucidates the recruitment and retention processes targeting Latinxs for online educational events during the pandemic; (2) describes facilitators/barriers to participation; and (3) offers lessons learned. We developed online dementia-focused workshops (English and Spanish) and employed a cold-calling approach to invite Latinx participants enrolled in clinical studies ($N = 209$). Bivariate tests assessed demographic and cognitive differences between those who recruiters did ($n = 60$) and did not ($n = 149$) successfully engage. Frequency counts assessed participants' technological access. Only 8/209 attended the online events; all held university degrees, most reported English as their primary language, and none experienced cognitive impairment. Results underscore how educational attainment, cognitive impairment, language preference, and age intersect to shape recruitment in dementia-focused online education. To promote healthy aging and to ameliorate dementia disparities, barriers to online engagement among older Spanish-speaking Latinxs with cognitive impairment and low educational attainment must be addressed.

Keywords

recruitment science, online education, Latinx adults, Alzheimer's disease and related dementias, COVID-19

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Introduction

Latinxs comprise the largest ethnic minority group in the U.S (U.S. Census Bureau, 2017). As older Latinxs will increase to 21% of the over 65 population by 2060 (U.S. Census Bureau, 2018), promoting healthy aging among this population is critical. Moreover, Latinxs have a greater risk of developing Alzheimer's disease and related dementias (ADRD) than non-Hispanic Whites (Mayeda et al., 2016; Wu et al., 2016), experiencing dementia symptoms nearly 7 years earlier than non-Hispanic Whites (Clark et al., 2005), and exhibiting higher levels of dementia-related behavioral symptoms

(Salazar et al., 2017). Despite their high burden of ADRD, Latinxs are underrepresented in ADRD research (Gilmore-Bykovskiy et al., 2019). Given that modifiable

¹Ohio University, Athens, OH, USA

²University of Southern California, Los Angeles, CA, USA

³USC Alzheimer's Disease Research Center, Los Angeles, CA, USA

Corresponding Author:

Ángela Gutiérrez, Department of Social Medicine, Heritage College of Osteopathic Medicine, Ohio University, Irvine 128A 57 West Oxbow Trail, 1 Ohio University Drive, Athens, OH 45701-2979, USA.
Email: agutierrez@ohio.edu



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Table 1. Participant Characteristics (N = 209).

Characteristic	n(%) or M ± SD
Gender	
Female	146 (69.9)
Male	63 (30.1)
Age	69 ± 16.3
Education	
Less than high school or GED	74 (35.4)
High school, GED	32 (15.3)
Some college	57 (27.3)
Bachelor's or graduate degree	46 (22.0)
Primary language	
English	81 (38.8)
Spanish	125 (59.8)
Other/Unknown	3 (1.4)
Global clinical dementia rating	
No impairment	104 (49.8)
Questionable impairment	63 (30.1)
Mild impairment	17 (8.1)
Moderate impairment	9 (4.3)
Severe impairment	16 (7.7)

Note. Percents may not add up to one-hundred due to rounding.

factors (e.g., obesity and low educational attainment) drive ADRD disparities (Livingston et al., 2020), engaging Latinxs in ADRD education is critical to address dementia among this aging population.

Recruitment and Retention Science in ADRD Research

The National Institute of Aging (NIA) has called for the development of an applied recruitment science that would result in effective evidence-based ADRD-focused outreach and recruitment strategies (National Institute of Aging, 2018). Recruitment signals processes related to the retention of current study participants as part of the continuum of research engagement. The quantity and quality of research in this nascent field as applied to the recruitment and retention of underrepresented populations in ADRD research is low (Gilmore-Bykovskiy et al., 2019). To enhance ADRD recruitment science, researchers must systematically document and report their recruitment practices, results, and context.

The COVID-19 pandemic (herein, pandemic) has shaped health, psychological, social, and economic wellbeing across the globe (World Health Organization, 2020), including the exacerbation of health disparities (Van Dorn et al., 2020). The pandemic has shaped caregiving (Sheth et al., 2020), dementia management (Tousi, 2020), and excess deaths among adults with cognitive impairment or dementia (Alzheimer's Association, 2021). However, no studies have documented the role of the pandemic in ADRD education or among Latinxs who have experienced the triple impact of high dementia prevalence, high COVID cases, and COVID-related

mortality (Centers for Disease Control and Prevention, 2021). Although research documents both dementia education (Valle et al., 2006) and challenges to research participation (Aranda, 2001; Gelman, 2010b) among Latinxs, no studies have documented the role of the pandemic on ADRD outreach and education, and specifically among Latinxs. This gap obscures the impact of COVID-19 and online education on ADRD-focused education programs among aging Latinxs. Consequently, this study (1) elucidates the recruitment and retention process targeting Latinxs in a federally funded, specialized ADRD research center for online education events during the pandemic; (2) describes facilitators and barriers to participation of USC Alzheimer's Disease Research Center Latinx participants in online events during COVID-19; and (3) offers lessons learned from the front lines about barriers and facilitators to participation.

Methods

Setting, Strategy, and Participants

Setting: This study is based on three community events sponsored by the USC Alzheimer's Disease Research Center (herein, USC Alzheimer's Disease Research Center). Located in the greater Los Angeles area, and funded by the NIA, the specialty research center serves the greater Los Angeles area, which is primarily comprised of Latinx residents who are underrepresented in ADRD research (Olin et al., 2002).

A central ADRC activity is to maximize retention of research participants through community events aimed at providing state-of-the-science educational events on dementia, aging, clinical trials, and caregiver support. Under the purview of the USC ADRC Outreach, Recruitment, and Education (ORE) Core, online English and Spanish events were sponsored in 2020. Due to the pandemic, all community events transitioned to online.

Strategy: This paper focuses on three of the initial online events, which 1) targeted USC ADRC Latinx study participants and 2) shared knowledge about the latest discoveries in dementia research. Although the overall goal of the online education events was to enhance retention of current ADRC participants, this paper focuses on the recruitment of these participants for online education.

We employed a *cold-calling* approach, which is typically used in marketing strategy and social research (Hammerback et al., 2018; Lavrakas, 2008). *Cold-calling* refers to contacting a person by phone without prior contact or without a lead. Two intensively trained bilingual (English/Spanish) ADRC staff members (herein, recruiters) conducted all cold-calling and data entry activities. Because participants engaged in research activities with staff from distinct ADRC cores, the recruiters had no prior connection with participants. Moreover, there was no warm hand-off of participants to recruiters. Consequently, recruiters contacted participants via cold-calling.

Table 2. Social Characteristics and Cognitive Impairment by Engagement Status.

Characteristic	Participants who engaged with recruiters (n = 60)	Participants who did not engage with recruiters (n = 149)
	n(%) or M ± SD	(%) or M ± SD
Gender		
Female	42 (70.0)	104 (69.8)
Male	18 (30.0)	45 (30.2)
Age	66.3 ± 17.51	70.1 ± 15.72
Education*		
Less than high school or GED	16 (26.7)	58 (38.9)
High school, GED	4 (6.7)	28 (18.8)
Some college	21 (35.0)	36 (24.2)
Bachelor's or graduate degree	19 (31.7)	27 (18.1)
Primary language		
English	31 (51.7)	50 (33.6)
Spanish	29 (48.3)	96 (64.4)
Other/Unknown	0.0 (0)	3 (2.0)
Global clinical dementia rating*		
No impairment	41 (68.3)	63 (42.3)
Questionable impairment	10 (16.7)	53 (35.6)
Mild impairment	3 (5.0)	14 (9.4)
Moderate impairment	3 (5.0)	6 (4.0)
Severe impairment	3 (5.0)	13 (8.7)

Note. *Indicates significance <.05. Significance tested using chi-square and t-tests.

Participants: Participants were involved in brain health and ADRD observational and clinical parent studies. For this study, the ADRC biostatistician identified participants from the central database who self-identified as Latinx/Hispanic ($N = 209$).

Procedures

Participants were called via telephone; follow-up communication was conducted by email or phone. The calls lasted 20 minutes on average (R: 10–40 minutes) and included gauging participants' interests about event participation, access to technology, and interest in future events. The three virtual events were titled: (1) *Participant Appreciation Event*; (2) *First Latinx Appreciation Event*; and (3) *The Growing Epidemic of Dementia among Latinxs in the U.S. and Beyond* and were conducted online through Zoom Video Communications, Inc. Demographic and clinical data were obtained from participant case records from prior research visits. The study procedures were approved by the university's institutional review board. Participants provided written informed consent.

Measures

Clinical Dementia Rating. Per the parent study research protocols, experienced ADRC clinicians administered the Global

Table 3. Access to and Navigation of Technology (n = 60).

Characteristic	n(%)
Access to technology	
Yes	42 (70.0)
No	16 (26.7)
Missing	2 (3.3)
Able to navigate technology	
Yes	30 (50.0)
Yes, with assistance	5 (8.3)
No, cannot navigate zoom or computer	3 (5.0)
No, cannot navigate technology	15 (25.0)
Missing	5 (8.3)
Access to which type of technology	
Computer	5 (8.3)
Cellular phone	19 (31.7)
Computer and cellular phone	25 (41.7)
None	3 (5.0)
Missing	7 (11.7)

Note. Percents may not add up to one-hundred due to rounding.

Clinical Dementia Rating (CDR) scale (Morris, 1993) during participants' initial and follow-up visits. The CDR is a 5-point scale used to stage the severity of Alzheimer's disease (AD) in six domains: memory, orientation, judgment and problem-solving, community affairs, home and hobbies, and personal care. Scoring was calculated based on established guidelines:

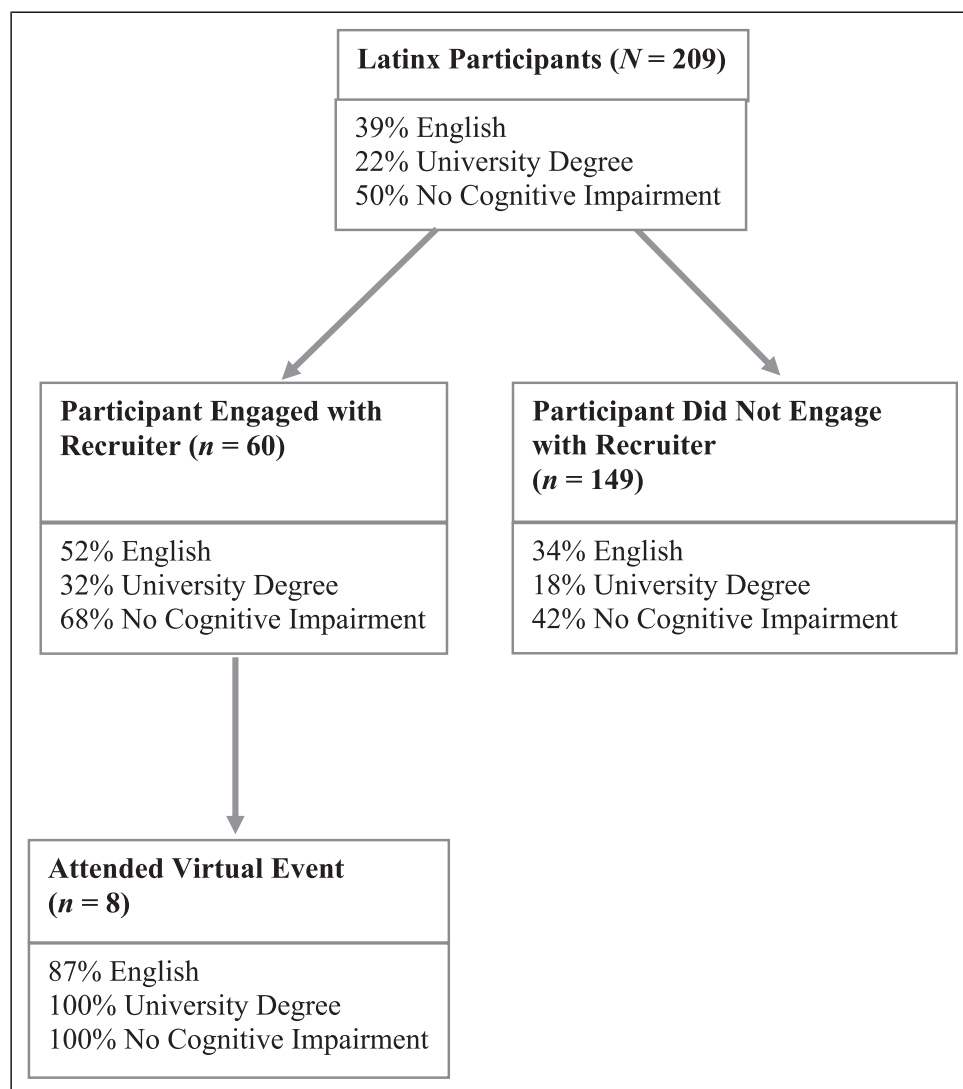


Figure 1. Flowchart of Participant Recruitment. Note. English refers to primary language; University Degree refers to bachelor's or graduate degree.

0 = none; 0.5 = questionable impairment; 1 = mild impairment; 2 = moderate impairment; and 3 = severe impairment (Morris, 1993).

Demographic Characteristics. Participant's sex was assessed as (0) male or (1) female. Age was measured continuously (R: 23–100). Education was assessed as: (0) Less than a high school degree or General Education Development (GED) degree; (1) High school degree or GED degree; (2) Some college; (3) Bachelor's or Graduate Degree. Primary Language was assessed as (0) English; (1) Spanish; (2) Missing (Other/Unknown).

Open-Ended Questions. Participants were asked: whether they had access to technology; whether they could navigate technology; the kind of technology accessible to them; and interest in attending future online or in-person educational events.

Data Analysis

Descriptive statistics were used to describe participant characteristics (see Table 1). Chi-square and t-tests assessed demographic and cognitive impairment differences between those who did ($n = 60$) and did not ($n = 149$) speak with recruiters (see Table 2). Frequency counts assessed participants' access to technology (see Table 3). Open-ended responses were analyzed by developing categories to thematically organize responses and calculating frequency counts. Quantitative analyses were conducted using Stata 16.

Results

Participant characteristics are presented in Table 1. Most participants were older adults ages 60 years and older (80%), followed by an equal distribution (10%) of young adults ages 23–44 and middle-aged adults ages 45–59. Most participants

were women (70%) and most reported Spanish as their primary language (60%). Over one-third of participants had earned less than a high school degree (35.4%), followed by those with some college (27%), a bachelor's or graduate degree (22%), and a high school or GED degree (15%). One-half had no cognitive impairment, 30% had questionable impairment, 8% had mild cognitive impairment, 4% had moderate cognitive impairment, and 8% had severe cognitive impairment.

Participant Recruitment

A flowchart depicting participant recruitment is presented in [Figure 1](#). Of the 209 participants that recruiters contacted, recruiters spoke with 60 participants and invited them to the virtual events. Recruiters were not able to make contact and/or recruit 149 participants, primarily due to participants not answering recruiters' phone calls ($n = 77$), followed by no phone number provided in the cold call list ($n = 43$), phone number no longer in service ($n = 11$), wrong number ($n = 3$), participant passed away ($n = 2$), participant is under doctors care such as hospice ($n = 3$), participant requested to no longer be contacted or be in the study ($n = 7$), participant requested a call back ($n = 1$), and missing ($n = 2$).

Demographic Characteristics and Cognitive Impairment between Those Who Did and Did Not Engage with Recruiters

Demographic and cognitive impairment characteristics of those who did and did not engage with recruiters are presented in [Table 2](#). There were significant educational differences between the two groups, $p = 0.010$. Participants who spoke with recruiters had higher educational attainment, such that 67% of participants that recruiters spoke with had a college degree or some college education compared to 42% of those who recruiters were not able to engage. There were also significant cognitive differences between the two groups, as those who recruiters did engage with tended to have no cognitive impairment, $p = 0.012$. Specifically, 68% of those who recruiters engaged had no cognitive impairment, relative to 42% of those who recruiters were not able to engage. There were no differences between the two groups on gender, age, or language preference.

Virtual Event Attendees

Of the 60 participants invited, eight attended the online events. All but one were 60 years or older. Half were men, half were women. All held bachelor's or graduate degrees. All but one reported English as their primary language. None experienced cognitive impairment. No participant attended the Spanish-language events.

Access to Technology

Participants' access to technology is presented in [Table 3](#). Seventy percent of participants had access to technology. One quarter of participants could not navigate technology well enough to join virtual events while another 13% of participants could navigate technology with assistance.

To assess the number of participants who could join a virtual event with no issues, participants' responses across four technology-related questions were tracked. Results show 30% of participants who spoke with recruiters could join a virtual event with no issues. Most participants who could join a virtual event with no problem were female (56%), had some college (44%) or university degree (56%), reported English as their primary language (83%), and had no cognitive impairment (94%). All other participants expressed barriers to participating in online ADRD education. Specifically, 72% of adults 60 and older reported barriers to joining virtual events. Technological issues impeded event attendance, as some participants tried but were unable to join due to computer or internet issues ($n = 2$). Participants also cited work conflicts ($n = 3$), parent emergencies ($n = 1$), health conditions ($n = 2$), and forgetting about the event ($n = 3$) as reasons why they registered but did not attend the event.

Discussion

The purpose of this study was to (1) document the recruitment and retention process targeting Latinxs for online ADRD education workshops during the pandemic and (2) describe facilitators and barriers to participation in online ADRD education workshops. We offer lessons learned from the front lines in the discussion. Results provide insights on recruitment for ADRD education among Latinxs during COVID-19.

Applying a Cold-Calling Approach

Using a cold-calling approach, seasoned bilingual recruiters contacted 209 Latinx clinical and observational study participants. Recruiters reached and invited 60 participants to the online events. Eight participants attended. In other words, fewer than 4% of participants attended the online events. Recruitment yield in this study (4%) was lower than in another study (32%) using a cold call approach ([Hammerback et al., 2018](#)). However, the recruitment context for this study was unique: cold calls were conducted in the initial months of the pandemic. The low engagement yield may be a result of the challenges inherent in using a cold-calling approach ([Egelhoff et al., 2015](#); [Hammerback et al., 2018](#)), coupled with the well-documented challenges in ADRD research recruitment ([Dilworth-Anderson et al., 2020](#); [Gilmore-Bykovskiy et al., 2019](#)) and in engaging Latinxs, especially older Latinxs, in online research ([Ashford et al., 2020](#); [Yoon et al., 2021](#)). Nevertheless, findings extend recruitment science in ADRD as this study is the first to employ a

cold-calling approach and to document the recruitment process and recruitment yield of Latinxs in ADRD virtual educational events during the pandemic.

Recruitment Barriers for Online ADRD Education: The Digital Divide

Results underscore the role of the digital divide in exacerbating ADRD recruitment and education challenges among Latinxs (Gelman, 2010b). With the COVID-19 shelter in place orders, in-person activities came to a halt, catapulting researchers to turn to virtual platforms to engage research participants. Results suggest that limited access to technology and technological literacy are major barriers to engaging this population via online platforms, especially as less than one-third of participants who spoke with recruiters had access to technology and could navigate technology enough to join online events. In other words, lack of technology-related resources diminished engagement of this population in online education. The technological divide was starker for older adults, as most participants 60 years and older reported difficulties accessing and navigating technological devices well enough to join virtual events. Among those who could join virtual events, all had at least some college education or a university degree, underscoring a marginalization of non-college-educated groups. Seventy percent of participants who recruiters spoke with experienced technological barriers that diminished their ability to join virtual ADRD education events. These findings suggest that technological barriers deter participants from engaging in online ADRD events.

In the wake of the pandemic, advocates have called for a digital revolution, where telemedicine and digital devices address the needs of patients with dementia (Cuffaro et al., 2020). However, this study underscores the need to continuously monitor who is unlikely to join these digital programs due to technological barriers. Findings suggest the digital divide is widening ADRD-focused education disparities between younger and older adults. Although not statistically significant, data trends suggest older adults experience more technological barriers to virtual engagement than their younger counterparts. Although the present study had a small sample size, prior research with larger samples documents lower digital literacy and internet use among older Latinxs (Yoon et al., 2021). Furthermore, research documents disparities in internet access and technological devices between Latinxs and non-Hispanic Whites (De Jesus & Xiao, 2012; Gonzalez et al., 2016; Yoon et al., 2021). Latinxs are less likely to use virtual health-focused platforms than non-Hispanic Whites (Gonzalez et al., 2019). Collectively, results demonstrate the role of digital inequality in exacerbating existing disparities in ADRD research participation among Latinx subgroups (e.g., older adults, those with low educational attainment), ultimately widening ADRD disparities.

These findings are especially salient as digital technology will likely remain a feature of research activities in the long term.

Recruitment Barriers for Online ADRD Education: Cognitive Impairment, Educational Attainment, and Language Preference

Cognitive impairment, educational attainment, and language preference shape online ADRD recruitment among Latinxs. These factors shaped all phases of recruitment, especially event attendance. All attendees held bachelor's or graduate degrees. No attendee experienced cognitive impairment or dementia. Although there was an equal distribution of English and Spanish-speakers, all but one attendee reported English as their primary language. Although events were held in English and Spanish, nobody attended the Spanish-language events.

Collectively, findings suggest that the intersecting factors of educational attainment, primary language, and cognitive impairment shape participants' abilities to access and engage in virtual ADRD education. Research shows individuals with low educational attainment are less likely to participate in online research (Ashford et al., 2020). Our results support prior research documenting low educational attainment as a barrier for online ADRD research participation.

Prior research documents low English language proficiency as a challenge in dementia care among Latinxs (Alzheimer's Association, 2021; Gelman, 2010a). Our results show primary language is associated with online ADRD engagement. Although Spanish-language information is important for recruiting and retaining Latinx research participants, results underscore that more than Spanish-language research staff and programming are needed. Spanish-speaking recruiters invited participants to workshops and developed Spanish-language workshops. Yet, other characteristics (i.e., educational attainment and technological literacy) were barriers in engaging Spanish-speaking participants, thus supporting earlier work indicating a pattern of exclusion of Latinx subgroups in ADRD recruitment and retention research (Gilmore-Bykovskiy et al., 2019).

Results document challenges to accessing ADRD virtual education participation among Latinxs with cognitive impairment or probable dementia. Despite the goal of engaging current ADRD research participants in education events, only participants with no cognitive impairment attended these events, highlighting the barriers to inclusion of people living with dementia in events that have been inadvertently normed towards technologically savvy participants during a pandemic. Collectively, our results extend prior research documenting the role of the "digital divide" and the "language divide" in predicting virtual health information seeking behavior by also documenting an "education divide" and "cognitive impairment divide" that are intersecting to exacerbate ADRD disparities. Collectively, these barriers

diminish access to online ADRD education among populations who are over-burdened by ADRD, yet typically excluded within ADRD research. Results underscore the need for researchers, public health practitioners, and community advocates to increase the accessibility of these programs. To address these barriers, research and program recruitment, design, and implementation must be improved.

Limitations

Several limitations should be considered. First, this study employed cold-calling. Although cold-calling is not a best-practice for recruitment and retention, cold-calling was the only feasible option as research staff transitioned to virtual platforms due to the pandemic. Recruiters were unable to reach over half of the sample, highlighting challenges associated with cold-calling (Egelhoff et al., 2015; Hammerback et al., 2018). We also caution others against disclosing information when receiving calls from unknown parties. Online fraud and scams increased during the COVID-19 pandemic. Researchers and the public should practice caution around cold calls. To reduce concerns, recruiters clearly identified themselves, did not ask any sensitive information from participants, and all follow-up communication came from university channels (university email). Nevertheless, findings report on recruitment and retention processes that occurred during the pandemic and extend recruitment science in ADRD among a population underrepresented in this area of research. This study is the first to document the recruitment process of Latinx participants in ADRD online education during COVID-19. Second, we did not distinguish those who explicitly stated they did not want to be contacted from those who were not able to be reached (e.g., never answered phone). Although these two groups are conceptually distinct, recruiters called participants eight to eleven times and left voicemail messages each time, making it unlikely that participants who did not answer the phone were unaware of the purpose of the calls. Thus, the distinction between not-being-reached and not-wanting-to-be-reached diminished, which served as the rationale for aggregating these two groups. Third, this study did not assess why 52 of the 60 participants who recruiters invited did not attend the virtual events. Some participants contacted the recruiters following the virtual events to report that unexpected (e.g., technological, work, family, and health) issues prevented them from attending. To identify additional barriers to virtual ADRD participation, future research should systematically explore these reasons. Fourth, data come from participants involved in ADRC studies, which limits generalizability of findings to the broader U.S. population. Future studies using a nationally representative sample of Latinxs can assess patterns across Latinx subgroups. Nevertheless, ADRD-focused recruitment and retention has been underexplored, especially among older Latinxs. This study extends

research among a population disproportionately burdened by ADRD.

Lessons Learned

We learned several lessons in the field regarding facilitators and barriers to ADRD online engagement among Latinxs. First, recruiters developed a rigorous tracking system in which they documented all communication efforts (phone calls, follow-up emails). Recruiters provided participants with clear instructions and signaled to participants next steps to look out for (e-mail with instructions to join virtual event). These efforts worked to make it as easy as possible for participants to engage in the education events. Second, to build strong rapport with participants, recruiters committed ample time to each participant. Recruiters began the cold calls by checking in with participants and reminding them that they were enrolled in ADRC research studies. By priming their memory, participants were more likely to engage in the call, respond to recruiters' questions, and disclose concerns or hesitations regarding virtual educational events. Recruiters learned they needed to wear multiple hats, such as recruiter and liaison connecting participants with requested resources (e.g., caregiver resources). Third, it was critical to form research teams who were culturally proficient with the population of interest. Having bilingual recruiters enhanced fostering rapport.

We also identified several challenges associated with online ADRD education events, such as limited technological access and literacy and anxiety related to navigating digital devices well enough to access virtual events. Participants also hesitated to disclose technological challenges. To reduce these challenges, recruiters provided individualized technological support to participants via phone calls and email. Research teams should develop strong rapport to mitigate participants' barriers (e.g., disclosing technical limitations) in accessing online health information. Second, competing priorities and concerns tempered participants' interests in engaging in virtual events. Participants reported concerns over COVID-19, such as the social isolation they experienced; concern about family members with AD becoming COVID-19 positive; difficulty juggling health concerns with joblessness and adult children moving back home; losing family members to COVID-19; and fear of going outside or participating in events. Beyond affecting their ability to engage in ADRD-focused events, these concerns highlight the need to link research participants with resources to ameliorate these concerns. Collectively, we recognized the incessant amount of work and time that recruitment and retention research require, especially in online contexts.

Conclusion

Educational attainment, cognitive impairment, language preference, and age intersect to shape recruitment in

dementia-focused online education. This study identifies older Spanish-speaking Latinx adults with cognitive impairment and low educational attainment as Latinx subgroups who may be overlooked in online ADRD education. Results are especially salient as online activities remain high and are projected to remain common. To promote healthy aging and to ameliorate ADRD disparities among Latinxs, barriers to online engagement must be addressed. To increase accessibility to online health promotion and disease prevention programs, researchers, public health practitioners, and community advocates must consider the ways recruitment, program design, and program implementation function to include or exclude populations that are over-burdened by ADRD yet underrepresented in ADRD research.

Declaration of Conflicting Interests

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ORCID iD

Ángela Gutiérrez  <https://orcid.org/0000-0003-4450-7439>

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