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Authors

Perales-Puchalt, Jaime
Shaw, Ashley
McGee, Jerrihlyn
et al.

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Preliminary efficacy of a recruitment educational strategy on Alzheimer's disease knowledge, research participation attitudes and enrollment among Hispanics

Jaime Perales, PhD, MPH,
University of Kansas Alzheimer's Disease Center, MS6002, Fairway, KS 66205

Ashley Shaw, PhD, MPH,
University of Kansas Alzheimer's Disease Center, MS6002, Fairway, KS 66205

Jerrihlyn L McGee, DNP, RN, CNE,
University of Kansas School of Nursing, MS4043, Kansas City, KS 66160

W. Todd Moore, MPS,
Community Partnership for Health, University of Kansas Medical Center, 3901 Rainbow Blvd. MS 3064, Kansas City, KS 66160

Ladson Hinton, MD,
Department of Psychiatry and Behavioral Sciences, University of California, Davis, Sacramento, CA 95817

Jason Resendez, BA,
LatinosAgainstAlzheimer's Coalition; UsAgainstAlzheimer's; 2 Wisconsin Circle, Suite 700, Chevy Chase, MD, 20815

Stephanie Monroe, BA,
AfricanAmericansAgainstAlzheimer's Coalition; UsAgainstAlzheimer's; 2 Wisconsin Circle, Suite 700, Chevy Chase, MD, 20815

John Dwyer, BA,
Global Alzheimer's Platform Foundation, Washington, D.C., 20005

Eric D Vidoni, PhD
University of Kansas Alzheimer's Disease Center, MS6002, Fairway, KS 66205

Abstract

Introduction: Hispanics remain underrepresented in dementia clinical research. This one arm trial aimed to assess the preliminary efficacy of a culturally-tailored recruitment educational strategy among Hispanic older adults on dementia knowledge, research participation attitudes and enrollment.

Corresponding author: Eric Vidoni, University of Kansas Alzheimer's Disease Center, MS6002, Fairway, KS 66205, USA. 913-588-5312, evidoni@kumc.edu.

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Methods: The recruitment strategy included six one-session culturally-tailored dementia education events at trusted community senior centers. Participants received a pre-post-survey including a 5-point Likert scale and the epidemiology/etiology disease scale (EEDS) to assess dementia knowledge, and a 4-point Likert scale assessing research participation attitudes. We gave participants contact information slips to complete if interested in dementia research. We also tracked participants' enrollment into the National Alzheimer's Coordinating Center (NACC) Cohort.

Results: Dementia knowledge increased 0.9 points (5-point Likert scale) and 2.2 points (EEDS, $p<0.001$). Interest in participating in dementia research increased from 61.7% to 80.9% ($p=0.039$), 64.0% returned their contact information slips and 41.1% successfully enrolled into the NACC Cohort.

Conclusion: A recruitment strategy including culturally-tailored dementia education improves dementia knowledge, research participation attitudes and enrollment among Hispanic older adults.

Keywords

Alzheimer's disease; Hispanic Americans; health education; minority health; recruitment; engagement

Purpose

Increasing research participation of Hispanics into Alzheimer's disease and related dementias (ADRD) research is a federal public health priority (National Institute on Aging, 2018b; U.S. Department of Health & Human Services, 2015). ADRD is growing exponentially and is a major cause of death, disability, family suffering and social costs (Alzheimer's Association, 2016). Hispanics are the largest US ethnoracial minority (18%) and are the fastest growing elder group, projected to increase more than sevenfold by 2060 (Administration on Aging et al., 2016; Wu et al., 2016). ADRD in the Hispanic community is projected to grow up to 2.6 million by 2050 (Wu et al., 2016). However, Hispanics are largely underrepresented in ADRD clinical research. They comprise only 8% of those 50+ in the National Alzheimer's Coordinating Center (NACC) Cohort, 4% of National Institute on Aging-funded ADRD trials and 0.4% of industry-funded ADRD trials (Faison et al., 2007; National Alzheimer's Coordinating Center, 2018).

An appropriate representation of Hispanics in ADRD research is paramount to uncover answers related to ADRD natural history and intervention efficacy among other aspects (Chin et al., 2011). The need to better represent Hispanics in ADRD clinical research is supported by differences with non-Hispanic whites regarding ApoE-e4 gene distributions, literacy levels and cardiovascular risk factors (Black et al., 1999; Haan et al., 2003; U.S. Department of Health and Human Services, 2017). Research suggests that Hispanics' low participation in ADRD clinical research is due to low literacy and ADRD knowledge, lack of trust in research, language barriers, the belief that life events are beyond one's control (fatalismo) and strict eligibility criteria that exclude chronic conditions that are common among Hispanics such as diabetes (Gallagher-Thompson et al., 2003). The aim of this study was to assess the preliminary efficacy of a culturally-tailored recruitment educational

strategy among older Hispanics on three outcomes: 1) ADRD knowledge, 2) research participation attitudes and 3) enrollment. We hypothesized that participating in an ADRD educational presentation would increase participants' desire to participate in research. As a secondary aim, we assessed whether baseline ADRD knowledge or its change after an ADRD educational session were associated with research participation attitudes.

Methods

Study design and participants.

This was a one arm pre-post trial including 50 Hispanic older adults attending three community senior centers between October 2017 and March 2018. The senior centers were selected given their predominant Hispanic population, convenient location and bilingual staff. We had previously partnered with these centers by holding an ADRD lunch and learn session with their leaders along with Hispanic caregiver advocates and national Hispanic leaders. We also maintained engagement through a community advisory board and through a series of networking activities supported by a national ADRD coalition focused on the Hispanic community (LatinosAgainstAlzheimer's). Senior centers advertised the educational sessions via word of mouth and posters two weeks in advance. All individuals attending the senior center on the scheduled date were invited to the ADRD educational session, including non-Hispanic individuals. Inclusion criteria for the final analytic sample included identifying as Hispanic, speaking Spanish or English and being 60 or older. ADRD educational session participants were invited to enroll in the local NACC Cohort (Beekly et al., 2007). The NACC Cohort's eligibility criteria includes being 60 and over if non-demented or any age if demented, speaking English or Spanish and having no history of cognitive impairment due to conditions other than ADRD. Our team included one person who partnered with the senior centers, presented Envejecimiento Digno, enrolled Hispanic participants in the NACC Cohort and assessed them annually. For this reason, we decided that our workforce availability allowed the enrollment of 30 Hispanics in the NACC Cohort, which was achieved in August 2018. All procedures were approved by the University of Kansas Medical Center's Institutional Review Board. For recruitment, we provided each participant with a letter summarizing the project and emphasizing their right to withhold participation in any part of the activities. Written, informed consent was obtained from all participants or their legal representative as appropriate before enrollment into the evaluation portion of the study.

Recruitment educational strategy.

The recruitment strategy included Envejecimiento Digno (Honorable Aging), a 45-minute ADRD educational presentation that delivers culturally-tailored evidence-based content. Envejecimiento Digno was developed with the Hispanic community and includes evidence-based information about 'What is ADRD', 'ADRD Diagnosis', 'ADRD Treatment', 'Promoting Brain Health' and 'ADRD Resources'. In a previous study we showed that Envejecimiento Digno was feasible, acceptable and increased ADRD knowledge among Hispanics (Perales et al., 2018). Envejecimiento Digno was designed and implemented to address common barriers to research participation (Gallagher-Thompson et al., 2003). Low ADRD knowledge was addressed by educating on ADRD. Language barriers were

addressed by conducting bilingual presentations. Low literacy levels were addressed by including colloquial and pictorial slides and asking for feedback regularly. Transportation issues were minimized by presenting at conveniently-located senior centers. “Fatalismo” was addressed by balancing fear vs hope messages on modifiable vs non-modifiable risk factors for ADRD. The NACC Cohort provided free memory assessments, which addressed barriers related to socioeconomic status. The NACC Cohort had broad eligibility criteria, aimed at reducing participation barriers. The Envejecimiento Digno presenter conducted all NACC Cohort assessments to assure continuity between recruitment and the research. This evaluator was a Hispanic bilingual researcher with a psychology background trained in cultural proficiency. The presenter/evaluator’s continuity as well as his educational, cultural and linguistic background helped address language barriers and research mistrust. NACC Cohort assessments could be conducted at flexible hours at senior centers to reduce availability, transportation and trust barriers.

Procedure.

The presenter explained the purpose of Envejecimento Digno in English and Spanish and gave participants time to read a letter summarizing the purpose of the project and their rights as participants. Following the letter, participants completed the pre-survey. The presenter introduced Envejecimiento Digno and administered a post-survey immediately after the presentation. Near the end of the presentation, the presenter made a call to action to complete contact information slips if interested in participating in our local NACC Cohort. The presenter contacted individuals who provided their contact information via phone call within two weeks of the presentation to capitalize on its momentum. The presenter attempted a maximum of one call every two days per individual at the time they specified in the contact slip or at different times of the day if their preferred time was not indicated or they did not answer the phone at their preferred time after two calls.

Data collection and measures.

Pre-survey socio-demographic information included age, gender, ethnicity, education, insurance status, country of birth and preferred language. ADRD risk factor questions asked about self-reported weight and height and diagnosis of diabetes, hypertension and high cholesterol (Purnell et al., 2009). Preliminary efficacy outcomes included ADRD knowledge, research participation attitudes and enrollment. 1) ADRD knowledge: A pre-post-survey five-point Likert scale item developed by our team assessed subjective ADRD knowledge (1 ‘very low’ to 5 ‘very high self-rated knowledge’) and the 14-item true/false Epidemiology/Etiology Disease Scale previously validated among Hispanics assessed objective ADRD knowledge (Connell and Holmes, 1996; Roberts and Connell, 2000). The subjective ADRD knowledge item asked “How would you rate your knowledge of Alzheimer’s disease”. Sample objective ADRD knowledge items included: “There is no cure for ADRD (true),” and “Drugs are available to treat the symptoms of ADRD (true)”. 2) Research participation attitudes: Pre-post-surveys asked how interested participants were in participating in ADRD research (four points: not at all - very interested). 3) Enrollment: We counted the number of contact information slips returned by Hispanic participants to participate in the NACC Cohort. We also tracked participant subsequent enrollment by following up with those who completed their contact information slips plus additional

Hispanics referred by participants who attended the educational sessions by asking them about their reference source (snowball effect). Since pre-post-surveys were anonymous, enrollment data tracked via contact slips could not be combined with survey information including ADRD knowledge or research participation attitudes.

Analysis.

Descriptive statistics were calculated for baseline characteristics. Preliminary efficacy analysis: Since the distribution of objective and subjective ADRD knowledge was normal, we used paired-samples t-tests to assess their pre-post-survey change. The distribution of interest in participating in ADRD research was not normal. Therefore, we grouped the lowest two values into “low” and the highest two values into “high” interest. We analyzed the change in interest in participating in ADRD research using a McNemar test. We used descriptive statistics to calculate the contact information slips returned by Hispanic participants and subsequent enrollment. Mechanistic analysis: We used four unadjusted logistic regressions and four logistic regressions adjusting for potential confounders including age, gender and level of education to assess 1) the association between baseline objective ADRD knowledge and gain in interest in participating in ADRD research and 2) the association between objective ADRD knowledge change from pre to post-survey and gain in interest in participating in ADRD research, 3) the association between baseline subjective ADRD knowledge and gain in interest in participating in ADRD research and 4) the association between subjective ADRD knowledge change from pre to post-survey and gain in interest in participating in ADRD research. We used a significance of $p<.05$.

Results

We conducted six bilingual Envejecimiento Digno sessions, reaching 61 older adults, 50 of which were included in the final analytic sample, as they identified as Hispanic. Two Hispanic older adults (4.0%) left the session before completing the post-survey due to time constraints. Most participants were women (n=37; 77.1%). The mean age was 75 (SD 11.0), 44.7% (n=21) had less than high school education and 98.0% (n=48) had health coverage. Half of the participants were US born (n=24) and proficient in English (n=25). Participants’ prevalence of self-reported diabetes was 52.4% (n=22), 75.6% for hypertension (n=34), and 54.5% for high cholesterol (n=24). Participants’ average BMI was (29.4, SD 5.2).

Table 1 shows the preliminary efficacy of the recruitment educational strategy on ADRD knowledge and research participation attitudes. Subjective ADRD knowledge (scores ranging from 1 to 5) increased from 2.1 at pre-survey to 2.9 at post-survey ($p<0.001$). Objective ADRD knowledge (scores ranging from 0 to 14) increased from 7.7 at pre-survey to 9.9 at post-survey ($p<0.001$). At pre-survey, 61.7% (n=29) of participants had a high interest in participating in ADRD research, which increased up to 80.9% (n=38) at post-survey ($p=0.039$). Neither objective nor subjective baseline ADRD knowledge scores nor their change from pre to post-survey were associated with gains in interest in participating in ADRD research in unadjusted or adjusted logistic regressions (all p values >0.05).

Figure 1 shows the flow of Hispanics enrolled into the NACC Cohort. Out of the 50 Hispanics reached via our recruitment educational strategy, 64.0% (n=32) completed and

returned their contact information slip to participate in our research and 34.0% (n=17) were successfully enrolled in the NACC Cohort. Six additional Hispanics called us directly asking to participate in the NACC Cohort as referred by individuals who participated in Envejecimiento Digno (snowball effect). These additional six participants were successfully enrolled in the NACC Cohort. In total, 23/56 (41.1%) Hispanics exposed to Envejecimiento Digno or its snowball effect enrolled in the NACC Cohort, which is 77.0% of the Hispanic participants recruited into the NACC Cohort. Other recruitment strategies in the NACC Cohort included direct recruitment by the research team or clinical partners (n=3), appearances on the media (n=1) and other outreach presentations (n=3). Enrollment ceased once we reached 30 participants in the NACC Cohort due to our workforce availability. By the time enrollment ceased, two individuals had not been screened and nine not consented. Also, four individuals had screened negative due to lack of interest in the NACC Cohort.

Discussion

The objective of the present study was to assess the preliminary efficacy of a recruitment educational strategy among older Hispanics on ADRD knowledge, research participation attitudes and enrollment. We used different outcomes to assess the strategy's preliminary efficacy including self-reports and metrics. In line with our hypothesis, we found that participating in an ADRD educational presentation increased participants' desire to participate in research. In addition, ADRD knowledge increased upon exposure to Envejecimiento Digno, 64.0% of Hispanics returned their contact information slip to participate in research and 41.1% successfully enrolled into the NACC Cohort. Results from this study provide support for the preliminary efficacy of our recruitment educational strategy using Envejecimiento Digno at senior centers. These results are important as Hispanics remain underrepresented in ADRD clinical research (Faison et al., 2007; National Alzheimer's Coordinating Center, 2018). Further, the results underscore the importance of bilingual education tools to serve the segment of the community that prefers Alzheimer's health information in Spanish. According to the Alzheimer's Disease Center Latino Special Group, 70% of Hispanic participants enrolled in Alzheimer's Disease Center studies report Spanish as their first language (Rascovsky and Quiroz, 2019). Ensuring Hispanic representation in research may increase external validity of findings and uncover answers related to their ADRD natural history and intervention efficacy.

This study shows consistent evidence of preliminary efficacy of our recruitment educational strategy using Envejecimiento Digno sessions at senior centers among Hispanic older adults. Other Alzheimer's research centers have used a similar approach as part of their multifaceted recruitment strategies. For example, researchers in California increased their ethnic minority representation in their longitudinal aging cohort from 71 in 1996-2001 to 291 in 2002-2007 by shifting to a pro-active community-based approach (Hinton et al., 2010). Their strategy included hiring bilingual/bicultural recruiters who were also evaluators. These recruiters would present educational sessions at community venues and circulate educational and research information. The cohort study they recruited for had broad eligibility criteria and assessments could be conducted offsite. Our findings also support the California study's emphasis on the importance of snowball effects in enhancing recruitment efficacy. In our study, we achieved six new potential participants through

snowball effect after reaching 50 individuals through Envejecimiento Digno. These six new potential participants recruited through snowball effect are the equivalent to one additional session of Envejecimiento Digno at no cost. Another comparable experience included two ADRD edutainment theater plays tailored to African Americans in Ohio (Fritsch et al., 2006). These plays increased ADRD knowledge scores, improved research attitudes and achieved 9.8% research enrollment among large African American groups. We have had a similar experience with a culturally-tailored ADRD educational play among 299 African Americans (Forget Me Not). While these theater plays are an excellent platform for providing ADRD education to large groups of minorities in one session, other strategies might be needed to translate outreach into research enrollment. Smaller groups such as Envejecimiento Digno sessions allow bidirectional interactions between the presenter and the public, which might be key for building trust.

Gain in reported research participation interest was not associated with ADRD knowledge. However, Envejecimiento Digno increased levels of objective and subjective ADRD knowledge similar to our previous research (Perales et al., 2018). The lack of association between ADRD knowledge and participation interest is inconsistent with the notion that health literacy increases research participation (Evans et al., 2012), but is in line with findings from a cancer study (Echeverri et al., 2018). In this cancer study, researchers administered a survey on cancer health literacy and research participation attitudes to a large and ethnically diverse sample. Results showed no association between cancer health literacy and willingness to participate in cancer research in the total sample and among Hispanics, Whites and African Americans independently. Other non-measured components of our recruitment strategy might account for the increase in reported research participation interest. For example, characteristics of the presentation (interaction, language, cultural tailoring), presenter (rapport ability and cultural closeness and proficiency) and context (participants' senior centers) may have increased research trust. The free memory assessment offered in the minimally-invasive NACC Cohort may have increased interest in participating too as Hispanics remain largely undiagnosed (Lines and Wiener, 2014). The number of participants who completed the contact information slips was smaller than those who reported having high interest in participating in ADRD research in their post-surveys. According to the theory of planned behavior, interest to participate in ADRD research would lead to participation only when the perceived ease to attend the study or to perform in assessments is strong (Ajzen, 1985). Therefore, participants may have required a "very high" rather than "high" interest or perceived fewer barriers to participation in order to complete the contact information slips. Some participants may have reported higher interest as an act of cordiality after the presentation.

The present study has several limitations. We used a small non-probabilistic sample and most participants were women, limiting external validity. The study sample only included individuals who decided to attend, potentially introducing selection bias leading to a sample with high baseline ADRD research interest. Even though we were able to track NACC Cohort enrollment subsequent to the contact slips completed during Envejecimiento Digno, we could not match that data with Envejecimiento Digno surveys as these were anonymous. This limitation prevented us from assessing the association between ADRD knowledge or interest in participating and actual enrollment into the NACC Cohort. The trial lacked a

control group and randomization, thus preventing causality inference. It remains unknown whether our recruitment educational strategy would perform as well when recruiting for more invasive and time-consuming studies. Future studies should explore which components of the strategy are most effective. For example, if an educational presentation about research in general had similar success, different centers within the same university might prefer to invest in a centralized recruitment strategy to save costs. Would showing a video version of Envejecimiento Digno lead to similar outcomes? Recruiters should develop recruitment strategies to increase snowball effect rates. To capitalize on snowball effect, studies might want to carefully select whether and how to incentivize word-of-mouth (Haenlein and Libai, 2017). We might have been able to accrue additional participants had we had the workforce capacity to do so. The field needs to make substantial, sustainable investment in building the capacity to increase the representation of minority populations, especially those whose first language is not English.

Conclusion.

A recruitment strategy using a brief in-person culturally-tailored session of ADRD education in senior centers increases ADRD knowledge, interest in participating in ADRD research and leads to important Hispanic enrollment rates into ADRD clinical research. Findings from this study provide useful information to address the historical lack of diversity in ADRD research, an increasing requirement by the NIA to increase generatability of results and reduce health disparities (National Institute on Aging, 2018b). ADRD knowledge does not explain gains in research reported participation willingness. Approaches such as the NIA's grant to examine diversity, recruitment and retention in aging research may help identify mediators to improve the impact of recruitment strategies for this underserved population (National Institute on Aging, 2018a).

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Abbreviations:

ADRD	Alzheimer's disease and related dementias
NACC	National Alzheimer's Coordinating Center
NIA	National Institute on Aging
ADC	Alzheimer's Disease Center

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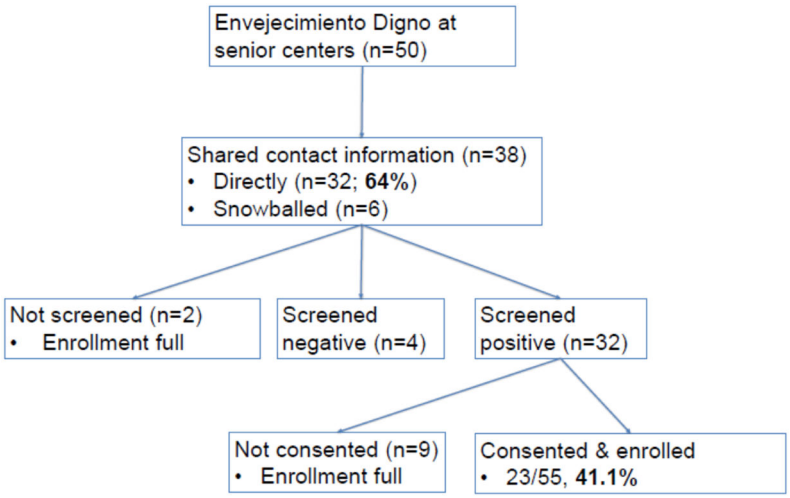

Figure 1.

Preliminary efficacy of the recruitment educational strategy on enrollment into NACC Cohort from November 2017 to August 2018.

Table 1.

Preliminary efficacy of the recruitment educational strategy on ADRD knowledge and research participation attitudes, n=50

	Pre-survey	Post-survey	P value
Subjective ADRD knowledge (1-5), mean (SD)	2.1 (1.0)	2.9 (1.1)	<0.001
Objective ADRD knowledge (0-14), mean (SD)	7.7 (2.7)	9.9 (2.6)	<0.001
Interest to participate in ADRD research (high), n (%)	29 (61.7)	38 (80.9)	0.039