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Feasibility of an Alzheimer's disease knowledge intervention in the Latino community

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Informed consent: We provided each participant with a letter summarizing the project and emphasizing their right to withhold participation in any part of the project.

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Abstract

Background—Latinos experience disparities in Alzheimer’s disease (AD) knowledge. The aim of this study was to explore the feasibility of a 45 minute culturally-tailored AD knowledge presentation for professionals serving the Latino community and Latinos served by Latino community organizations.

Methods—One-session AD knowledge lunch-and-learn events were conducted with 40 professionals and 37 served Latinos. Participants received a pre-post survey including questions on satisfaction, perceived needs of the Latino community, a subjective AD knowledge question and a 14 item objective AD knowledge questionnaire.

Results—Professionals (54.3%) and served Latinos (94.6%) reported the session as being very enjoyable and increased in objective AD knowledge (2.1 and 2.5 units, $p<.001$) and subjective knowledge (1.1 and 1.7 units; $p<.001$).

Discussion—A brief in-person culturally-tailored session of AD education increases short-term AD knowledge and is perceived as interesting and useful among professionals serving the Latino community and Latinos served by Latino community organizations.

Keywords

Alzheimer disease; Hispanic Americans; knowledge; health disparities

Introduction

Alzheimer’s disease (AD) poses a serious public health threat in the USA and worldwide. Approximately 5.4 million Americans to date have AD, and the prevalence is expected to double by 2050 (Hebert et al. 2013; Alzheimer’s Association 2016). AD is one of the major causes of mortality and disability in later life (Lopez et al. 2006). A total of \$221.3 billion and \$236 billion were spent in 2015 on unpaid informal care and formal healthcare services respectively (Alzheimer’s Association 2016; Hurd et al. 2013).

Latinos experience several disparities in AD linked to their lower access to education, lower income, language barriers, frequent immigrant status and long life-expectancy (Flores 2017; Ryan and Bauman 2016; DeNavas-Walt and Proctor 2015). First, the Administration on Aging projects a 224% increase of the Latino population aged 65 and older compared to 65% increase among non-Latino whites between 2008 and 2030 (Administration on Aging, Administration for Community Living, and US Department of Health & Human Services 2016). This rapid growth of the Latino elder population coupled with their low levels of education, exercise, and cardiovascular health contribute to a higher prevalence of AD than non-Latino whites (Menke et al. 2015; Ryan and Bauman 2016; Centers for Disease Control and Prevention 2017; Alzheimer’s Association 2017). Researchers project an increase of AD among Latinos from 379,000 in 2012 to 3.5 million by 2060—a growth of 832% (Wu et al. 2016). This increase will likely result in the perpetuation of an unjust excess in AD-related

mortality, morbidity and family impact among Latinos (World Health Organization 2012). Second, Latinos are the highest uninsured ethnic group leading to higher out-of-pocket costs and lower healthcare access that may result in the lack of appropriate AD assessment and treatment (Kaiser Commission on Medicare and the Uninsured 2012). The economic impact of Alzheimer's and other dementias on the Latino community is projected to reach a cumulative \$2.35 trillion by 2060 (Wu et al. 2016). Third, Latinos are less likely to participate in clinical trials diminishing the ability to develop and scale interventions that are effective for this population (McGill 2013). Fourth, AD knowledge among Latinos is particularly low and might hinder effective assessment, prevention and treatment seeking behaviors (Roberts, McLaughlin, and Connell 2014).

Increasing AD knowledge at the community level and among the professionals serving them is key to reducing AD disparities (Connell et al. 2009; Ayalon and Areán 2004; Edwards, Cherry, and Peterson 2000; Roberts, McLaughlin, and Connell 2014; Rovner, Casten, and Harris 2013). In fact, the World Health Organization and the U.S. Department of Health and Human Services recently identified AD knowledge as a priority area of public health action (World Health Organization 2012; U.S. Department of Health & Human Services 2016). Further, the first national AD disparities focus research conference identified AD knowledge among Latinos as a key factor to addressing disparate rates of detection, diagnosis and clinical trial participation (UsAgainstAlzheimer's 2016). Promoting AD knowledge in the Latino community and among professionals serving them may empower both groups to reduce misconceptions and stigma while increasing health and treatment seeking behaviors, accurate referrals to healthcare services, accurate identification of AD symptoms and promotion of advocacy to prioritize and address the needs of Latinos with regard to AD (Cahill et al. 2015; Rimmer et al. 2005; Low et al. 2011; Purandare et al. 2007; Werner 2003). Increased AD knowledge might ultimately help address the need for ethnically diverse participants in AD clinical research along with the excess in AD morbidity and mortality among Latinos and the impact on their families.

Research on interventions to promote AD knowledge in the community is scarce. A half-day culturally-tailored workshop conducted by the Alzheimer's Association was followed by increased AD subjective and objective knowledge among African Americans in Los Angeles and Atlanta (Fuller et al. 2012). Two studies on AD knowledge have been conducted among Latinos. A pilot study found that two foto-novela (pictorial story magazines) reading sessions increased AD knowledge in a community sample of Latino older adults (Valle, Yamada, and Matiella 2006). Another study found that a single in-person educational presentation increased AD knowledge among Puerto Ricans including a mixed sample of 51 participants from the general population, students and health professionals (Friedman et al. 2016). Despite the promising outcomes in both Latino studies, attrition rates were high which might have affected the results. These high attrition rates might be related to aspects of the intervention delivery including number of foto-novela sessions and informal nature of the café setting. There is therefore a clear need to rigorously investigate feasible venues to increase AD knowledge in the Latino community. The objective of the present study was to explore the feasibility of a 45-minute AD knowledge presentation conducted at a Latino community center aimed at increasing AD knowledge among professionals serving the Latino community and Latinos served by Latino community organizations.

Methods

Study design and participants

This was a one arm trial of 40 professionals serving the Latino community (professionals) and 37 Latinos served by a Latino community organization (served Latinos) who were interested in participating in an AD knowledge promotion presentation and pre-post assessments. In total, five lunch-and-learn sessions were conducted between June-December 2016. Lunch-and-learn sessions were hosted at El Centro, Inc., a local community organization specialized in assisting the Latino community. This center was recommended by the granting institution to conduct recruitment and provide space for the sessions due to its convenient location within the Latino community. El Centro, Inc. recruited 1) individuals from partner community organizations who serve Latinos and 2) Latino individuals in the community their organization serves. Inclusion criteria for both groups included being 18 years or older. Professionals could be of any ethnicity and had to provide social or health services to the Latino community. Participants in the served Latino group had to identify as Latino and receive services from El Centro.

El Centro invited participants to attend one lunch-and-learn session using a multichannel approach (email, word of mouth and phone call). The presenters were Hispanic and had been trained in cultural proficiency though formal coursework aimed at health providers and exposure to several community health events. The presenters belonged to a Latino health research institution that has gained the trust of the Latino community for years by conducting service and community participatory research and has built strong partnerships with the Mexican consulate, community centers and clinics, Latino associations and churches.

Intervention

The intervention consisted of a 45-minute lunch-and-learn presentation divided into five chapters, namely: 'What is AD', 'AD Diagnosis', 'AD Treatment', 'Brain Health' and 'AD Resources'. Participation in research tends to be low among Latinos (Gallagher-Thompson et al. 2003). Therefore, we chose a lunch-and-learn modality for all participants and increased the pool of potential served Latino participants by scheduling sessions to match specific days El Centro provided holiday give-away gifts. The presentation delivered evidence-based contents from mainly two sources: ADEAR's Alzheimer's disease Fact Sheet and the Alzheimer's Association (Alzheimer's Association 2016; Alzheimer's Disease Education and Referral (ADEAR) Center 2016; Alzheimer's Association 2010). The content and delivery of the presentation and materials were refined following the Cultural Accommodation Model (Burrow-Sanchez et al. 2011). This process included 1) Literature Search: identification of factors related to AD knowledge among minorities and Latinos by conducting a literature review, 2) Research Team Development: ongoing feedback from the research team, including Latino health, AD and community-based research experts, 3) Informed Expert Opinion: feedback obtained after each lunch-and-learn session with the professionals serving the Latino community and 4) Community Stakeholders: consultation with external Latino community liaisons at a presentation with 13 *promotoras de salud* (community health workers) discussing preferences and barriers of the Latino community.

As a result of these four steps, we accommodated the treatment delivery by limiting the presentation to 45 minutes, presenting in English to professionals and in Spanish to served Latinos, adding interactive activities and videos on AD symptoms, assessment and brain health promotion in both groups, and reducing literacy levels, showing more positive, colloquial and pictorial slides and asking for feedback regularly during the sessions in the served Latino group. Accommodation of the intervention content included deemphasizing autosomal-dominant AD to avoid “Fatalismo” or the attitude of resignation in the face of events which are thought to be inevitable in the served Latino group (Gallagher-Thompson et al. 2003). We also added resources in the community for brain health, treatment and caregiving services. The title of the English version was Smart Aging, which was later adapted in Spanish by *promotoras* as ‘*Envejecimiento Digno*’, (Spanish for Honorable Aging).

Procedure

Participants were asked to arrive 30 minutes before the presentation started. All participants were invited to get free lunch at the room where the presentation was held. The presenter explained the purpose of the intervention and gave participants time to read a letter summarizing the project and emphasizing their right to withhold their participation in any part of the project. Following the letter, participants completed the pre-survey. Later, the presenter introduced the presentation content to the audience. Immediately after finishing the presentation, a post-survey was administered. The study explanation, pre and post surveys and activity materials were read aloud to the served Latino groups given the expected high percentage of people with lower literacy levels.

Data collection and measures

Pre-survey socio-demographic information included age, gender, ethnicity, education, working status, occupation, annual income and insurance status. Acculturation was assessed given its previously reported association with health literacy and included country of birth, years living in the USA and primary language (Mantwill and Schulz 2017; Ciampa et al. 2013). Those with either a personal or professional relation to AD might have higher levels of AD knowledge. For this reason, participants were asked whether they knew of several AD resources (i.e. Alzheimer’s Association), anyone with AD/memory loss or had participated in taking care of an older adult. Given that AD knowledge might increase interest in research participation, participants were asked if they were interested in participating in AD prevention studies. AD risk factor questions asked about self-reported tobacco use in the last seven days, physical activity compared to people their age (Gill et al. 2012), weight and height in order to calculate BMI and whether they had been diagnosed by a healthcare professional with diabetes, hypertension, high cholesterol, stroke, heart disease or depression (Purnell et al. 2009). Acceptability (the participant’s acceptance of the intervention) was measured by asking at post-survey how difficult (1 ‘very low’ to 5 ‘very high’), enjoyable and applicable to daily life (1 ‘not at all’ to 4 ‘very much’) the presentation was. Short-term effectiveness (change in AD knowledge immediately following the intervention) was assessed by measuring knowledge both pre and post-survey using two methods. Subjective knowledge was measured by asking a one five-point Likert scale item: ‘How would you rate your knowledge of Alzheimer’s disease?’ (1 ‘very low’ to 5 ‘very

high'). Objective AD knowledge learning was measured using a 14-item true/false instrument that has been used previously to assess knowledge about the disease (Roberts and Connell 2000; Connell and Holmes 1996). The total score ranges from 0 to 14 with higher scores indicating a higher knowledge. Items include common misconceptions and basic facts about AD including 'There is no cure for AD', 'men are more likely to develop AD than women' or 'AD is fatal'. The original authors assessed the scale's reliability by performing item and scale analyses through bi-serial correlations between test items and the total scale score to determine differences among test items in their ability to predict overall AD knowledge. Correlations ranged from 0.16 to 0.46 (all significant at $p < 0.05$), suggesting adequate variation among items.

Analysis

Results are shown separately for professionals and served Latinos. Means, standard deviations, percentages and frequencies were calculated for baseline characteristics and acceptability measures. Paired samples t-tests were conducted to assess the short-term effectiveness. A significance of $p < .05$ was used.

Results

Sample baseline characteristics

Baseline characteristics of both samples are shown in Table 1. A total of 40 professionals and 37 served Latinos participated in the lunch-and-learn sessions. Three professionals (7.5%) and one served Latino (2.7%) left the session before completing the post-survey due to time constraints. The majority of participants were women (73.7% professionals and 83.8% served Latinos). The mean age was slightly higher among served Latinos (48.0; SD 12.8 vs 41.5; SD 18.0) ranging from early 20s up to 70s in both groups. College education was markedly higher among professionals (75.6% vs 13.5%) as was health coverage (86.5% vs 29.7%), being employed (100% vs 25.8%) and having an annual family income higher than \$30k (76.5% vs 6.8%). Professionals' occupations included community customer service (9.7%), social workers and counselors (9.7%), health program managers (22.6%), community center and non-profit managers (22.6%) and community health education and community center academics (22.6%). The percentage of Latinos was 75.7% among professionals. The majority of professionals were from the USA (50.0%) whereas most served Latinos were Mexico-born (80.0%). Professionals were more likely to speak English as the only prime language (43.2% vs 0.0%).

One third of participants in both groups knew someone with memory loss or had been a caregiver for an older adult. Knowledge of AD resources was higher among professionals. Interest in participating in hypothetical research prevention and caregiving support projects was high in both groups although higher among served Latinos. Served Latinos had a high prevalence of diabetes (30.6%), hypertension (32.4%), high cholesterol (33.3%), depression (39.4%) and overweight/obesity (90.3%).

Acceptability of Smart Aging and *Envejecimiento Digno*—Results on acceptability and short-term effectiveness of the interventions are shown in Table 2. Fewer participants in

the professionals group perceived the presentation as having a high level of difficulty (5.7% vs 43.2%). Both interventions were perceived as very enjoyable by most participants (54.3% of professionals and 94.6% of served Latinos); in fact, everyone reported enjoying the intervention. Served Latinos considered the session to be very applicable to daily life more often than professionals did (86.1% vs 34.3%).

Short-term effectiveness of Smart Aging and Envejecimiento Digno on AD knowledge—The mean objective AD knowledge score at baseline was 8.6 (SD 1.9) for professionals and 7.8 (SD 2.4) for served Latinos and increased up to 10.7 (SD 2.2) and 10.3 (SD 2.2) after the session ($p<.001$). Subjective knowledge scores also increased from slightly higher than low to more than moderate among professionals (2.2, SD 0.7 to 3.3, SD 0.7; $p<.001$) and up to almost high among served Latinos (2.1, SD 1.1 to 3.8, SD 1.1; $p<.001$).

Discussion

The objective of the present study was to explore the feasibility of a 45-minute culturally-tailored presentation conducted at a community center aimed at increasing AD knowledge among professionals serving the Latino community and Latinos served by Latino community organizations. Results from this study provide support for the acceptability and short-term effectiveness of Smart Aging among professionals serving Latinos and *Envejecimiento Digno* among Latinos served by Latino community organizations.

A 45-minute presentation was able to show short-term effectiveness both in terms of subjective and objective AD knowledge. In fact, levels of objective AD knowledge among served Latinos increased to a level that is comparable to that of professionals after the presentation. These results strengthen the evidence found in a study conducted in Puerto Rico among Latino undergraduate students, health professionals and the general public (Friedman et al. 2016). The literature suggests that targeting both the community and professionals serving them may be more effective, as it has the potential to address misconceptions, health and treatment seeking behaviors, stigma, accurate referrals to healthcare services and advocacy regarding the needs of Latinos (Cahill et al. 2015; Rimmer et al. 2005; Low et al. 2011; Purandare et al. 2007; Werner 2003). Our finding showing that a brief presentation can increase served Latinos' AD knowledge as much as those of health and social services professionals are promising, as there is a wide educational gap between both groups which suggests that *Envejecimiento Digno* might be key in reducing AD disparities experienced by Latinos.

Overall, acceptability of the intervention was high in both groups. Almost half the sample of served Latinos perceived the presentation as very difficult. This finding contrasts with the adaptations resulting from the Cultural Accommodation Model conducted for this group including the reduction of literacy levels, showing more colloquial and pictorial slides and asking for feedback regularly during the sessions. Qualitative research is needed to further adapt the level of difficulty of the presentation among Latinos with low levels of education, as this is not the specific focus of the Cultural Accommodation Model. However, despite their perception of difficulty, both their objective and subjective knowledge levels increased.

Perception of applicability among the professionals group was not as high as served Latinos. Professionals had higher education levels, were more frequently insured and had a higher baseline knowledge of AD. Therefore, this group might have less interest in learning about the disease itself and how to prevent it but a higher interest in learning specific instructions on how to assist Latinos with AD or their families. Retention rates during the intervention were high which provides rigor to the findings shown in this study. The high retention of these one-session presentations conducted at a conveniently located Latino community center and using a lunch-and-learn format overcomes potential attrition-related problems identified in previous studies including holding sessions in settings that might be too informal or holding more than one session (Valle, Yamada, and Matiella 2006; Friedman et al. 2016).

The present study has several limitations. We used a relatively small non-probabilistic sample potentially limiting external validity of the results. We also did not assess long-term effects of the intervention on AD knowledge, as this was a feasibility study, and its main focus was the short-term effectiveness and acceptability of the intervention. The promising short-term effectiveness of *Envejecimiento Digno* warrants a longer term follow-up to assess if the AD knowledge gain among served Latinos (which reached similar levels as professionals after the presentation) can be maintained in time. Fully powered efficacy trials that compare control groups using foto-novelas or educational materials versus *Smart Aging/Envejecimiento Digno* and assess knowledge months later are needed. Further studies could evaluate the effectiveness of in-person education paired with text messaging or social media to maintain or increase AD knowledge capitalizing on the Latinos' wide use of mobile technologies (Duggan 2013). Future studies should also assess the potential of this intervention in increasing recruitment rates for AD-related studies. The interest in research participation among Latinos in our sample suggest lunch-and-learn sessions might be a promising recruitment strategy for Latinos. Further, the interest of the mostly Latino professionals in AD research suggests targeted outreach to professional groups and employee resource groups in communities with Alzheimer's Disease Centers or ongoing trials could represent an opportunity to improve the lack of diversity in research. While Latinos represent 17% of the U.S. population, they represent just 7.6% of participants in NIH clinical trials (McGill 2013; Colby and Ortman 2015). Finally, AD knowledge building programs and studies should be considered in tandem with providing other services, as knowledge increases expectations that healthcare services will be able to respond in the same way (Ferri et al. 2009).

Conclusion

A brief in-person culturally tailored session of AD education increases short-term AD knowledge and is perceived as interesting and useful by professionals serving the Latino community and Latinos served by community organizations. Raising AD knowledge is the first step to empower the Latino community to reduce misconceptions, stigma, AD risk behaviors and to increase treatment seeking behaviors, accurate referrals to healthcare services and advocacy. Increasing AD knowledge has the potential to improve a wide range of outcomes in an aging Latino community.

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Key messages

- Latinos in the USA have lower levels of knowledge about Alzheimer's disease
- The literature on Alzheimer's disease knowledge promotion among Latinos is scarce and has methodological limitations
- Smart Aging and Envejecimiento Digno, a culturally-tailored short in-person session, increases Alzheimer's disease knowledge and is perceived as interesting and useful by professionals serving the Latino community and Latinos served by community organizations.

Table 1

Socio-demographic characteristics of professionals serving the Latino community and Latinos served by Latino community organizations

	Professionals	Served Latinos
	n=40	n=37
Women, n (%)	28 (73.7)	31 (83.8)
Age, mean (SD) [min-max]	41.5 (13.0) [20-71]	48.0 (12.8) [24-73]
Level of education, n (%)		
No formal education	0 (0.0)	3 (8.1)
Incomplete high school or less	0 (0.0)	21 (56.8)
High School	9 (24.3)	8 (21.6)
College	28 (75.6)	5 (13.5)
Has health insurance, n (%)	32 (86.5)	11 (29.7)
Full time job, n (%)	29 (78.5)	1 (2.9)
Annual family gross income (>30k), n (%)	26 (76.5)	2 (6.8)
Latino	28 (75.7)	–
Born in the USA, n (%)	19 (50.0)	2 (5.7)
Born in Mexico, n (%)	15 (39.5)	28 (80.0)
Born in other Latin American country, n (%)	3 (7.9)	5 (14.3)
Years in the USA (if not born in USA), mean (SD) [min-max]	22.9 (13.9) [10-57]	18.0 (9.14) [2-49]
Primary Language, n (%)		
Spanish	12 (32.4)	35 (94.6)
English	16 (43.2)	0 (0.0)
Both	9 (24.3)	2 (5.4)
Knows someone with significant memory loss, n (%)	13 (35.1)	12 (33.3)
Knows someone with AD, n (%)	13 (35.1)	7 (20.0)
Experience taking care of an adult, n (%)	12 (31.6)	9 (25.0)
Knows the University resources, n (%)	21 (52.5)	2 (5.7)
Knows the Alzheimer's Association, n (%)	23 (62.2)	1 (3.0)
Interested in participating in AD prevention studies, n (%)	18 (54.5)	32 (86.5)
Interested in participating in AD caregiver support groups, n (%)	14 (51.9)	26 (74.3)
Self-reported diagnosis		
Diabetes	–	11 (30.6)
Hypertension	–	11 (32.4)
High cholesterol	–	12 (33.3)
Stroke	–	1 (2.7)
Heart disease	–	3 (8.8)
Depression	–	13 (39.4)
Overweight/obesity	–	28 (90.3)
Smoked in the past 7 days	–	1 (2.9)
Less physically active than others their age	–	8 (22.2)

Table 2
 Acceptability and short-term effectiveness of the Smart Aging and *Envejecimiento Digno* lunch-and-learn sessions among professionals serving the Latino community and Latinos served by Latino community organizations

Outcome	Professionals			Served Latinos		
	Pre-survey (n=40)	Post-survey (n=37)	Post-survey (n=36)	Pre-survey (n=37)	Post-survey (n=36)	Post-survey (n=36)
Acceptability						
Perceived level of difficulty (high), n (%)	-	2 (5.7)	16 (43.2)	-	-	-
Enjoyment of the session (very enjoyable), n (%)	-	19 (54.3)	35 (94.6)	-	-	-
Perceived applicability to daily life (very applicable), n (%)	-	12 (34.3)	31 (86.1)	-	-	-
Effectiveness						
Perceived effectiveness (very effective), n (%)	-	26 (70.3)	33 (91.6)	-	-	-
Objective knowledge, mean (SD)	8.6 (1.9)	10.7 (2.2) *	10.3 (2.2) *	7.8 (2.4)	10.3 (2.2) *	10.3 (2.2) *
Subjective Knowledge, mean (SD)	2.2 (0.7)	3.3 (0.7) *	3.8 (1.1) *	2.1 (1.1)	3.8 (1.1) *	3.8 (1.1) *

* indicates significant difference at the 5% level.