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## Increasing Community Awareness About Alzheimer's Disease in Puerto Rico Through Coffee Shop Education and Social Media

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### Abstract

Alzheimer's disease (AD) is the fourth leading cause of death in Puerto Rico. Using multi-media resources and in-person education may be an effective approach to improve knowledge and awareness of AD. The Un Café por el Alzheimer program in Puerto Rico incorporates an education component at coffee shops and a social media campaign using Facebook. The current study evaluates this initiative through an analysis of pre/post education survey results and social media content and use. Surveys contained close-ended and open-ended questions to understand participants' perceptions and knowledge about AD. Post-education surveys also included questions related to program satisfaction. Social media analysis of the Facebook community page examined posts from March 1 to September 30, 2015. Descriptive statistics were used to analyze survey and Facebook data. Four education sessions were conducted with a total of 212 participants. Fifty-one of the participants completed both pre- and post-surveys. Following the education program participants reported improved knowledge of risk and protective factors. All participants reported learning new information from the program. There were a total of 250 posts on the Un Café por el Alzheimer community Facebook page; 168 posts related to AD. The Facebook page reached 294,109 people, with 9963 page likes, 610 comments, 17,780 post clicks, and 3632 shares. There was an average increase of 64.8 % in number of people reached by the Facebook page following the education sessions. The approach of combining social media resources and in-person education is beneficial to increase public awareness of AD and disseminate health information.

### Keywords

Alzheimer's disease; Community-engaged research; Facebook; Content analysis; Survey

## Introduction

Alzheimer's disease (AD), the most common dementia, is a debilitating neurodegenerative condition that affects millions of individuals in the United States (US) and abroad. The disease interrupts the transmission of information from neuron to neuron, eventually leading to the death of synaptic connections, and, over time, significant shrinkage of the brain [1]. Currently, AD is the sixth leading cause of death in the US [2]. According to a 2015 report from the Alzheimer's Association [3], an estimated 5.3 million Americans have AD, and by 2025, that number is projected to double. Reducing the risk of cognitive impairment, AD, and dementia is considered a public health priority [4, 5].

In Puerto Rico, a territory of the United States, AD is the fourth leading underlying cause of death; however, the occurrence of AD mortality was higher in Puerto Rico than in the contiguous United States from 1999 to 2004 [6]. Research has shown that Hispanics are 1.5 times more likely to suffer from AD compared to older whites [7]. Since Puerto Ricans are the second largest group among Hispanics living in the United States, awareness and education about AD is particularly important for this population [8].

Research indicates that people are very concerned about the status of their cognitive health and of developing AD [9–11]. This is especially true for those who know someone within their family and social circle who has been diagnosed with AD.

Prior research demonstrated that individuals and families are in need of education and information about AD [12, 13]. An analysis of the Porter Novelli Health Styles survey data indicated that close to 30 % of consumers have searched specifically for cognition and AD-related information online [14]. Findings from the Health Information National Trends Survey (HINTS) for Puerto Rico showed that nearly 60 % of respondents used the Internet as their primary source of health information [15]. Statistics from the Pew Research Center also show that 65 % of adult Internet users reported using a social network site such as MySpace or Facebook in 2015 [16]. The use of social media websites for older adults (defined as age 65 and older) has increased significantly from 11 % in 2010 to 35 % in 2015. In 2013, 55 % of adult Internet users gained information about a disease or medical problem through the use of the Internet [17]. Among adult users, 26 % have followed someone else's personal health experiences [17], and 18 % have used the Internet to find other people with similar health concerns [18].

The benefits of using social media for the widespread dissemination of health-related messages include increased interaction among individuals, finding peer support, and raising awareness of health issues [19]. As social networking websites have become increasingly popular, health researchers have studied the influence of platforms such as Facebook and Twitter as a means of communicating health-related information and fostering support groups. Mamun et al. [20] investigated Facebook groups focused on diabetes in order to determine the accuracy and relevance of posted information. Of the posts they reviewed, they found that the main communication involved requesting for diabetes help/guidance, sharing personal stories and management techniques, and providing emotional support for patients. Importantly, the researchers found few posts that contained inaccurate or

unverifiable recommendations, most of which were in reference to natural remedies that had not been approved by the Food and Drug Administration. Bender et al. [21] analyzed Facebook groups related to hypertension and found that a majority of the groups (59.9 %) were focused on raising awareness for the disease. Donelle and Booth [22] found that 44.7 % of the breast cancer Facebook groups analyzed for their study were focused on raising funds. Additionally, Twitter has also become a major online social media platform for users to share information [23–25]. A study performed by Robillard et al. [25] analyzed tweets related to dementia over a 24-h period and found that 77 % of those tweets contained links to health information websites and recent studies involving reducing the risk of dementia.

Multimedia approaches are being used and recommended for health programs and interventions [8, 11, 26, 27]. A systematic review study evaluated the effectiveness of networked information and communications technology interventions (ComputerLink, ALzOnline, Caring for Others and two REACH projects) in supporting caretakers of people with dementia and found these interventions had moderate effects on improving caretaker's mental health and perceived social support [28]. Additionally, the effectiveness of using a combined technological and in-person approach in the communication of health information has been recommended [29–31]. The current study examines an initiative created to raise awareness of AD in Puerto Rico. Entitled *Un Café por el Alzheimer*, this program incorporates both an in-person education component at coffee shops and other venues and a social media campaign using Facebook.

## Methods

### Setting and Population

Un café por el Alzheimer is an initiative established during September, 2014. The project is a collaboration between the Puerto Rico Department of Health, the University of Puerto Rico (School of Medicine and School of Public Health,) as well as volunteers and other persons representing organizations providing services for individuals living with AD. It consists of a dialogue between the participants and an expert panel in coffee shops or in other public places (universities, community colleges, community centers, theaters and public squares, among others). The complete panel includes staff from the Puerto Rico Alzheimer's Registry, a geriatrician, a clinical psychologist, a neurological pharmacologist, a lawyer, and a representative of a nonprofit organization providing cognitive stimulation and adapted physical activity for persons living with AD.

The program comprises the following topics: AD definition, signs and symptoms, risk factors, diagnosis, medications and other therapies. Participants can raise questions at any time during the conversation and encouraged to share testimonials and comments. At the end of the program, the moderator invites people to follow the Facebook page. After the conversation, the experts are available for participants who want to speak with them privately.

During the period of August through September 2015, the Cafés were conducted in 15 scenarios. However, the pre/post surveys were implemented during only four of these

sessions. The first one was in a community college in the western region of Puerto Rico where undergraduate students and instructors participated. The second Café involved participation of 8 Nutrition and Dietetics interns. The third Café was done in a municipal theater in a northern coast town for the general public. The fourth Café was sponsored by the nursing program of a community college in San Juan in which students, instructors, and administrative personnel participated.

## Survey

Two surveys were developed with the pre-test being administered prior to all of the cafés. The post-test was administered following the delivery of the education program. Surveys were initially developed in English and translated into Spanish. Surveys contained both close-ended and open-ended questions. The pre-test consisted of 12 statements requiring true/false responses, 7 qualitative questions (findings not reported in this paper), and 4 demographic questions (age, gender, education, and employment). Sample statements with true or false responses were: AD is a type of dementia, memory loss is a symptom of AD, and being able to easily plan things is a symptom of AD. The post-test consisted of the same 12 statements requiring true/false responses, 9 open-ended questions (findings not reported in this paper), 6 Likert-scale program satisfaction questions, and 5 questions requiring yes, no, or don't know responses regarding understanding of the program content. The true/false knowledge responses were coded as 0 for incorrect and 1 for correct to analyze changes between pre- and post-tests.

## Social Media Analysis

A comprehensive codebook was developed for the analysis of *Un Café por el Alzheimer* Facebook fan page. Codebook development was guided by previously published content analysis work that has focused on both online health and medical information [32]. Social media analysis began with posts starting on March 1, 2015 and concluded with posts on September 30, 2015. Variables coded included: the Facebook post title or the first five words, the date content was posted, for number of likes, comments, shares, clicks and the total number of people reached, type of post (e.g., link, shared video, photo, status), target audience (e.g., Alzheimer's patients, caregivers, family members related to Alzheimer's patients, friends of Alzheimer's patients), target age, target gender, authorship (e.g., representative of nonprofit organization, medical doctor or researcher, layperson, government official or employee, for profit representative), content (e.g., awareness, prevention, diagnosis, treatment, quality of life, testimonial, resources), main purpose of post (e.g., expresses an opinion issues concerning Alzheimer's, provides health risk information, provides general information about Alzheimer's, shares general personal information or situation, identifies symptoms of Alzheimer's, seeks or asks for advice in relation to Alzheimer's, announces upcoming event, meeting or forum on Alzheimer's, provides social support), imagery (e.g., photos, illustrations, images of people similar to the target population, Hispanic population depicted, age of population depicted), and mobilizing information (e.g., information leading people to additional information or resources, time and place of an activity or an event, contact information for people or groups, explicit or implicit instructions provided on certain health behaviors, link that takes you away from the page to get additional information).

To measure whether the education program participants were mobilized to seek additional information about AD from the Facebook community page, online engagement data was collected after each educational session. This included total number of page likes, total number of people the post served, total number of likes and comments, and total number of post clicks. Engagement was also measured based on demographics of the pages' users. This included the percentage of participants who liked the page by gender and age, the percentage of participants the post reached by gender and age, and the percentage of participants who liked, commented or shared anything from the page by gender and age. Nonparametric (frequencies, percentages, and chi-squares) and parametric ( $t$  tests) statistics were used to analyze data.  $p < .05$  was considered significant.

## Results

### In-person Education Program Participants

*Un Cafépor Alzheimer* held four official education sessions with a total of 212 participants in August 2015 during which survey data was collected. A total of 51 participants (24.1 %) completed both the pre- and post-surveys. Most participants were female (80 %), under 40 years of age (82 %), and with high school or less than high school education (52 %). Only 12 % reported being a caregiver for somebody with AD.

### Pre/post Survey Results

Overall, participants demonstrated improved knowledge of AD following the in-person education sessions (see Table 1). The most noted improvements were in identifying social interaction as a protective factor against AD ( $t_{(df = 50)} = -4.35, p < .001$ ), identifying hypertension as a risk factor for AD ( $t_{(df = 49)} = -2.54, p = .010$ ), and identifying higher educational level as a protective factor for AD ( $t_{(df = 49)} = -3.01, p < .001$ ). Knowledge about signs and symptoms increased slightly; however, participants had good knowledge about signs and symptoms prior to the education program as indicated by pre-survey results.

Most participants were “very satisfied” with all components of the in-person program: format (84 %), educational materials (84 %), and speakers (82 %). Most (96 %) reported that they understood the information presented and that they would recommend the program to others and 98 % learned about the Alzheimer's disease. All participants said they learned something new from the program and 80 % said most of the information presented was new to them.

### Facebook Engagement

User statistics were gathered prior to and following each of the scheduled cafes to track online engagement and whether education program participants were mobilized to seek additional information about AD from the Facebook community page. Table 2 reflects average engagement of the Facebook page following the in-person education sessions.

### Facebook Content Analysis

From March 1st to September 30th, 2015 (the time period for the social media content analysis), there were a total of 250 posts on the *Un Cafépor el Alzheimer* community

Facebook page, with 168 posts related to AD. Table 3 presents the total number of posts that were made each month and the total number of posts that contained information on AD by each month. Overall, the Facebook page reached 294,109 people, with 9963 page likes, 17,780 post clicks, and 3632 shares. Individuals made 610 comments related to the posts.

Most of the posts were links (59.5 %) or photos (31.6 %). Few posts (26.8 %) explicitly targeted a specific audience: 10.7 % targeted caregivers, 10.1 % targeted family members, and 7.1 % targeted patients. Educational content focused mainly on awareness (36.3 %). Fewer posts had information on prevention or risk reduction (11.3 %), quality of life (10.7 %), treatment (8.3 %), or diagnosis (3.0 %). About 25 % of posts included content with resources and 5.4 % contained testimonials/personal stories.

Most of the posts (60.7 %) did not provide information about authorship. Among the other 39.3 % posts, government official and employees authored more of them (17.9 %) compared with representatives of nonprofit organizations (4.8 %), medical doctors/researchers (3.6 %), and laypeople (1.2 %). Twenty of the posts were initiated by journalists/news sources.

Chi-square results showed a significant association between the authorship of posts and the main purpose of the post ( $\chi^2_{(df=49)}=86.24, p=.0008$ ). Posts by government officials or employees mainly provided health risk information (50 %). Six posts by medical doctors or researchers focused on health risks, general information or opinions about AD.

Almost 50 % of posts focused on providing health risk information (18.5 %) or general information about AD (22.6 %). Other purposes of the posts included announcing upcoming events, meetings, or forums about AD (28.6 %) and providing social support (17.9 %). Posts announcing upcoming event, meeting or forum on AD had the most number of likes (n = 2736, 27.5 %), followed by general information about AD (n = 2156, 21.6 %), offering social support (n = 2133, 21.4 %), and health risk information (n = 1149, 11.5 %).

One hundred and forty-four posts (85.7 %) contained inviting visuals. About 26.2 % of the images were of individuals similar to the target population. The age groups depicted most often in the images were middle-age adults (30.4 %) and older adults (27.4 %).

There were 157 posts with mobilizing information (MI; 93.5 % of the sample), of which 114 posts included interactive MI, i.e., links to additional educational information about AD.

Results (Table 4) show associations of the post's purpose with locational MI

( $\chi^2_{(df=14)}=149.18, p<.0001$ ), identificational MI ( $\chi^2_{(df=14)}=51.37, p<.0001$ ), tactical MI ( $\chi^2_{(df=14)}=51.07, p<.0001$ ), and interactive MI ( $\chi^2_{(df=14)}=99.14, p<.0001$ ).

Specifically, posts aimed at announcing upcoming events, meetings, or forums about AD typically had locational MI related to time and place of the activities/events (60.6 %).

Eighteen of those posts also included identificational MI or information with names and other contact information of various people and/or groups. Of those posts providing health risk information, 17 (37.0 %) had explicit or implicit instructions about certain health behaviors (i.e., tactical MI).

## Discussion

To our knowledge, this is the first study examining an initiative involving an in-person and social media education program about AD in Puerto Rico. Following the education program AD knowledge improved regarding items such as disease risk factors. All participants reported learning new information in the program. There were a total of 250 posts on the *Un Café por el Alzheimer* community Facebook page; 168 posts related to AD. There was an average increase of nearly 65 % in number of people reached by the Facebook page following the education sessions. Women were more engaged on the *Un Café por el Alzheimer* community Facebook page than men. While one would expect that the majority of Facebook users would be younger adults, those 35–54 were more engaged in social media. Participants received most of their MI in the posts that encouraged them to attend other events where they could learn more about AD. Fewer posts provided health risk information with explicit or implicit instructions about certain health behaviors. Mobilizing people to seek both health information and support can be an important feature of social media posts and is recommended for future posts on the Facebook page [33, 34].

This study has limitations. First, a small sample size of 51 individuals completed the pre/post education surveys. Despite the limited number of program participants, this pilot initiative provides important information on a sample of Puerto Ricans knowledge about AD and their perceptions about the program and strategies for improving the program. Given the small sample size results should not be generalized to other populations. Findings may not represent the views of Puerto Rican adults in other communities. Second, while a post-survey was administered immediately following the education program, we did not follow up with participants to find out how they engaged with the Facebook page. An analysis of user statistics was conducted and presented in this paper, however, a more qualitative exploration of participants' perceptions of the social media content is recommended. Third, while a comprehensive analysis of the Facebook content was conducted, future research should include an analysis of the content readability and cultural sensitivity.

Understanding how social media can be used in combination with an in-person education program to increase awareness will prove beneficial in disseminating health information about AD in Puerto Rico. Using an approach that effectively works in providing salient messages to the population of Puerto Rico is important being that there tends to be differences in how Puerto Ricans talk about AD compared with non-Latino whites [35]. The social media component allows for education program participants to remain actively engaged with AD information and resources while fostering social support and reducing stigmas and myths surrounding the disease.

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**Table 1**

Participant knowledge about AD (n = 51)

Knowledge statement	Mean value		Mean differences	p value
	Pre-test	Post-test		
1. AD is a type of dementia	.88	.92	.04	.53
2. Memory loss is a normal part of aging	.35	.51	.16	<b>.09</b>
3. Being able to easily plan things is a symptom of AD	.84	.78	-.06	.41
4. Trouble with speaking or writing is a symptom of AD	.53	.69	.16	<b>.06</b>
5. Confusion with time and place is a symptom of AD	.88	.94	.06	.18
6. Change in mood is a symptom of AD.	.72	.84	.12	<b>.03</b>
7. If my parents had AD, I will develop the disease	.74	.36	-.38	<b>.00</b>
8. People with high educational level are at less risk for AD	.14	.38	.24	<b>.00</b>
9. Smoking helps prevent AD	.94	.86	-.08	.16
10. People who have diabetes cannot develop AD	.90	.82	-.08	.16
11. Social interaction may help to delay AD	.51	.78	.27	<b>.00</b>
12. Hypertension is not associated with AD	.46	.72	.26	<b>.01</b>

**Table 2**

Participant engagement with Facebook post education session

	<b>Median (%)</b>
Gender	
Women	77
Men	21
Age	
13–17	0.34
18–34	19
35–54	35
55?	14
<i>Participants the post reached</i>	
Gender	
Women	73
Men	25
Age	
13–17	0.33
18–34	25
35–54	33
55+	14
<i>Participants who liked, shared, or commented</i>	
Gender	
Women	82
Men	16
Age	
13–17	0.25
18–34	24
35–54	36
55+	21

**Table 3**

## Facebook Posts by Month

	<b>Facebook posts</b>	<b>Facebook posts with Alzheimer's disease content</b>
March	44	31
April	20	18
May	27	24
June	15	15
July	25	25
August	18	14
September	101	41
Total	250	168

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**Table 4**

Primary purpose of Facebook posts by type of mobilizing information

	Primary purpose of the post							Total
	Express an opinion n = 14	Health risk information n = 46	General information n = 38	Share personal information n = 10	Announcement of event n = 71	Social support n = 32	Not related to AD n = 1	
Mobilizing information (MI)								
Locational MI	1 (7.1 %)	0 (0 %)	0 (.0 %)	0 (0 %)	43 (60.6 %)	1 (3.1 %)	0 (0 %)	45
Identificational MI	1 (7.1 %)	0 (0 %)	1 (2.6 %)	0 (0 %)	18 (25.4 %)	0 (.0 %)	0 (0 %)	20
Tactical MI	1 (7.1 %)	17 (37.0 %)	6 (15.8 %)	2 (20.0 %)	1 (1.4 %)	5 (15.6 %)	0 (0 %)	32
Interactive MI	11 (78.6 %)	29 (63.0 %)	31 (81.6 %)	8 (80.0 %)	9 (12.7 %)	26 (81.3 %)	1 (100.0 %)	115
								212 <sup>a</sup>

<sup>a</sup>This total number of posts with MI (n = 212) is greater than the number of posts that contained MI (n = 157) because some posts contained more than one type of MI