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Elderly Latino Community Members Make an Educational Video: An Academic-Community Collaboration to Promote Memory Evaluations

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Abstract

Objectives: To develop an educational video to reach elderly Latinos in order to improve understanding and encourage evaluation of cognitive changes by 1) using focus groups to identify dementia knowledge gaps, health communication preferences and trusted advisors for health concerns 2) collaborating with elderly Latino community members to create a video. 3) collecting survey data regarding community response to the video.

Design: Grounded theory qualitative approach using focus groups; collaborative community based model to create the video and anonymous survey at community screenings.

Setting: Community senior centers in East Harlem, New York

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Description of authors' roles:

M. Umpierre and J. Neugroschl designed the study.

M. Umpierre participated in, supervised and executed the data collection and analysis of focus groups, developed the video script and assisted in writing the article.

M. Sewell and J. Neugroschl did data analysis and wrote the article.

R. Rodriguez assisted in writing the article and assisted in developing the video script.

L. Meyers assisted in writing the article and assisted in developing the video script.

S. Kranes assisted with writing the article.

C. Aldrete was a co-facilitator of the groups and transcribed the focus group data.

A. Collazo was a group facilitator.

L. Valois was a group facilitator.

M. Sano assisted in writing the article.

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Participants: A team of low-income mono and bilingual Elderly Latino community residents, researchers, clinicians and a film professional.

Measurements: Thematic analysis of focus group transcripts; three item survey. Results: A collaboratively produced video and initial assessment in 49 Latino elders which indicated the video had a positive effect on interest in obtaining a brief memory screening at outreach events (71%) Conclusions: The project demonstrates the feasibility of this interdisciplinary partnership to create a culturally and linguistically sensitive video to promote service use concerning memory loss and cognitive evaluations among elderly Latinos. Initial survey results suggested a positive response and an increase in interest in memory screening.

Keywords

Cross cultural; Education; Interdisciplinary; Stigma; Screening

Introduction and Background

Latinos are the fastest growing group among the aged in the United States, and will be disproportionately represented among those at risk for Alzheimer's Disease (AD) (Valle and Lee, 2002) (Tang et al., 1998) (Valle, 2005). Delays in diagnosing AD among Latinos stems from gaps in knowledge and misconceptions about the differences between normal aging and AD (Gallagher-Thompson et al., 2003) (Ayalon and Arean, 2004) (Valle, 2005). Beliefs about what constitutes normal aging preclude some Latinos from considering that memory loss is a problem requiring medical assessment and treatment (Gelman, 2010). One study (Ayalon and Arean, 2004) demonstrated that Latino and Asian elders have larger gaps in knowledge about AD compared to age matched African Americans and Caucasians.

Gelman (Gelman, 2010) proposed that knowledge gaps among Latinos should be addressed using culturally attuned health communication materials developed in collaboration with consumers. Research in cancer care suggests that for health education to be most effective, affected individuals should be involved in the conceptualization and development of materials and methods (Davis et al., 2002).

According to the National Adult Literacy Survey, one in five Americans may lack the necessary literacy skills to obtain and understand health information needed to make healthcare decisions (Davis et al., 2002). Low health literacy correlates with both low socioeconomic status and older age, and for Latinos, is compounded by low English proficiency (Davis et al., 2002). The addition of alternative materials (such as pictures or videos) may enhance understanding and recall of health information, since stories and pictures are more memorable and more important motivators than statistics and instructions among low literacy individuals (Davis et al., 2002), including Latinos (Borrayo, 2004).

A study by Karlawish et al. (Karlawish et al., 2011) identified notable differences in language and concepts used by Puerto Ricans and non-Latino Whites when talking about AD, and these differences need to be considered in developing outreach and educational materials, or interacting with patients and caregivers. Borrayo (Borrayo, 2004) proposed that culturally sensitive health communications are more likely to motivate Latinos to engage

in care. Although Latinos are a socioeconomically and culturally diverse group, they share some common behaviors and values, and may prefer informal communication styles to receive health information (Mendez and Westerberg, 2012); (Cabassa et al., 2012) (Borrayo, 2004).

Health education materials (Gagliano, 1988), including those that use consumers as collaborators, (Chavez et al., 2004) and videos using entertainment education strategies (Borrayo, 2004) (Sood, 2002) (Storey and Sood, 2013) have been successfully employed to promote participation in health services among low literacy Latinos in the United States (Cabassa et al., 2012) (Borrayo, 2004). Entertainment education has roots in Latin America (Singhal and Rogers, 2002). Educational health messages were introduced into a Mexican “telenovela” (soap opera), and changes in behavior and health practices were documented (Sabido, 2002). Videos and telenovelas may help promote change through affective identification with the characters, their situations and health promoting behaviors. (Bhana et al., 2014) (Sood, 2002) (Storey and Sood, 2013) Using a directed interview with patients, caregivers and staff, Baruch et al created an educational video to describe the process of memory evaluation and allay fears in a clinic in Britain (Baruch et al., 2017).

There are two interventional studies using fotonovelas for urban Latino elderly with low English proficiency, literacy levels and education, and one using a video. Two interventions (one fotonovela (Valle et al., 2006) and one video (Grigsby et al., 2017)) provided education about Alzheimer’s disease and both studies demonstrated improved knowledge over the course of the intervention period. The second study using a fotonovela compared standard informational brochures to a fotonovela to address caregiver distress and depression (Gallagher-Thompson et al., 2015). Results suggested reduced distress with the fotonovela, and that subjects used the fotonovela more frequently and found it more helpful. However, to our knowledge there have been no interventions directed at engaging this population in memory screenings and evaluations, nor any that include community members as creative partners. Therefore we developed an educational video, using entertainment education strategies, to improve understanding and encourage evaluation of cognitive changes by 1) using focus groups to identify dementia knowledge gaps and health literacy needs 2) identifying health communication preferences; 3) determining trusted advisors for health concerns, aging issues and memory loss, and 4) collaborating with members from senior centers in East Harlem, New York City.

Phase 1: Focus Groups

Recruitment:

The project team contacted senior center directors from community-based senior centers located in an urban low-income community, who then invited members and/or their caregivers to join. The participants were primarily bilingual or Spanish-speaking. The project team included three bilingual social workers (community-based and academically-based), several bilingual social-work trainees, a bilingual college student, a psychologist and a geriatric psychiatrist. Thirty-three consented to participate. All participants signed consent to participate and be videotaped. Each member received a gift card for their participation and travel expenses.

Moderators:

The principal investigator/project director trained a bilingual Master's level mental health professional to conduct focus groups with older Latinos. Training included reviewing issues relevant to working with older adults such as noting potential vision and hearing loss, and to be mindful of variations in dialect between bilingual and monolingual older Spanish-speakers. To ensure the group members understood each other's comments, the moderator was instructed to paraphrase, summarize, and translate as needed and then to confirm with the participants that they were able to understand each other.

Structure:

A moderator's guide was developed by the project team to facilitate the focus group conversations. Open-ended questions, including probes in English and in Spanish, explored attitudes, perceptions and understanding of normal aging and memory, memory impairment, and knowledge about symptoms, causes, and treatments of dementia. Participants were asked in what format they preferred to obtain health information, (e.g. books, newspapers, television, or the internet). Secondly, participants' preference for a formal or informal style of information delivery was assessed by showing two brief health-related Spanish videos with markedly contrasting styles. Finally, participants were asked to identify trusted advisors for health concerns (e.g. who would you turn to if you were worried about your memory?).

Six groups of 3–8 participants met with the moderator for one 90-minute videotaped session at a senior center or community agency (total n=33). All sessions were conducted in a combination of English and Spanish, integrating “Spanglish” terms as necessary. See Table 1 for demographic characteristics of the participants.

Content Evaluation:

Information was captured through digital video recordings and extensive notes. The videos were transcribed by a research assistant. Content analysis was conducted using a grounded theory approach (Glaser and Strauss, 1994) to identify salient themes and concerns. A list of themes and concepts from all groups was compiled.

Findings:

1) Knowledge gaps regarding cognitive health.—Two significant gaps in knowledge were identified in all six focus groups. The first was related to the association of the word “demencia” with being “crazy”. The words “crazy”, “craziness” or “loco” and “locura” were mentioned in all of the focus groups. Participants noted that these terms are pejorative, demeaning and devaluing, despite their use to describe individuals with cognitive decline. In Spanish “demencia” is primarily defined as “locura, trastorno de la razón un demente” (“madness, insanity, demented, mad person, lunatic”); a second definition is synonymous with the English definition of cognitive decline that affects function¹⁹. The second misapprehension was the association of memory evaluations with electroconvulsive therapy, in which focus group participants feared having their “heads wired” or having “cables en la cabeza” (cables in the head) as part of the evaluation.

2) The need for linguistically, culturally and literacy-level-sensitive health communication materials about memory and aging in diverse formats.—

Participants in all groups noted that education materials should be available in a variety of formats and in both Spanish and English. Some felt most comfortable obtaining health information from the library or written pamphlets, whereas many others relied on the Internet e.g. Google or YouTube, physicians' offices, social workers, family members or television programs to learn about health issues. Because of their varied linguistic and educational backgrounds, all of the groups concluded that a video format for health communication would be most likely to reach the broadest spectrum of their peers.

3) Preference for informal video: Participants were asked to select their preference for one of two brief health communication videos in Spanish. The two videos were on similar topics with markedly contrasting styles. The first was a professionally produced health news segment from Mount Sinai and Univision, and the other was a community collaboration produced as part of a research study by Latino parents and researchers (Umpierre et al., 2015). The professionally produced video, narrated by a doctor, provided health information directly, while the other provided health information indirectly through an informal conversation between two friends. In all of the focus groups, the preference was for the collaboratively produced video because it reflected how people "actually talk" among themselves. Whereas the informal video sparked a great deal of discussion in all of the groups, the didactic one did not.

4) Trusted Advisors: When asked who they would turn to if they were concerned about their memory, all agreed they would turn to their peers for advice. Others identified their children, the directors of the senior centers, and some health care providers. For example, one participant noted, "I say no, no, for me a doctor, no. It would be the last thing I would do. If I have a problem I speak with my daughter, a granddaughter, a friend, my sister." Another participant said, "For me the most important thing is to talk to my family and seek guidance, from sisters and...there are trusted friends, a trusted friend is also there."

Phase 2: Creation of Video

Establishment of Community Advisory Board (CAB):

Focus group participants were invited to join a Community Advisory Board (CAB) to act as a working group to develop a video intervention for community education and outreach. Forty six percent (15 participants) joined. This group was charged with the collaborative production of a video using the information gleaned from the focus groups. The CAB was self divided into two groups, an advisory group of eight members who provided input into construction and content, and a production group of seven members who acted in the video and worked on improvisational skits to develop content. The purpose of the video was to provide culturally and linguistically sensitive information to other seniors about memory and aging with the aim of increasing seniors' interest and engagement in memory evaluations. The CAB met with the project team eleven times over five months to generate ideas as to how to best provide relevant and useful information about memory and aging to their community.

Video Production:

The focus group's key findings, as well as the CAB members' further experiences with memory loss and memory evaluations, informed the video production process. Three skits were developed by the advisory group for the full CAB and professional videographer to review, refine and ultimately select for the final video. Rather than formal structured scripts written by the project team, the CAB improvised the three narratives.

1. Skit 1 portrayed the interaction between a bilingual daughter, her monolingual Spanish-speaking father with memory loss and an English-speaking primary care doctor. The doctor suggested a memory screening. The daughter, acting as translator, presented this option to her father who emphatically refused. The skit highlighted the value of respect for parents and for authority figures by presenting the daughter as conflicted, caught in between her father's wishes and the doctor's recommendations. The skit ended with the doctor sending the daughter to seek advice from a social worker who provided information that empowered the daughter to continue the conversation with her father.
2. Skit 2 showed an informal interaction between a Spanish-speaking woman and her Spanish-speaking physician. The patient was worried about memory loss. The physician reassured her that her blood-work physical exam was normal and there is nothing to worry about. The patient insisted and the doctor gave her a referral to see a memory expert. A voiceover describes the benefits of memory evaluations as part of medical care in older adults. The voiceover introduced depression as a reversible cause for cognitive changes and highlighted the importance of expert advice concerning memory health and aging.
3. Skit 3 shows two friends chatting informally about memory issues and aging. One of them said she had heard of someone who had misplaced a bag of groceries in her apartment, including a frozen chicken that she later found under the bed. The friend shows disbelief and acknowledges that she herself has misplaced keys. She explained that memory changes are normal as we get older but putting a chicken under the bed is worrisome. They describe being afraid of developing AD and how much better they would feel if there were a test that would tell them if they were okay. A voiceover describes the cognitive testing and where to get it.

All three skits were videotaped and shown to the entire group for feedback and final selection. The project team, with the videographer's input, selected the third skit for production, as this scenario offered a visually appealing narrative and the opportunity to use humor to address a difficult topic.

In the final production, the two friends are played by CAB members, highlighting a peer relationship where one peer acts as a trusted advisor. The friends' informal conversation normalizes common misconceptions about memory evaluations, and highlights the difference between normal forgetfulness and potentially abnormal memory loss. Because all focus groups expressed the fear that evaluations include "cables in the head", the CAB and videographer decided to directly address this concern in the video. Humorous visual

elements, including a video shot of a frozen chicken under the bed, were integrated to engage the audience.

Phase 3- Initial Community Responses:

For the initial evaluation of this project, we created a three item survey to be administered at outreach events to assess whether watching the video had a subjective effect on attendees interests in obtaining a memory screening. The video was shown to 49 seniors (mean age 75) at 4 community outreach events at senior centers in East Harlem NY that primarily serve Latino elders. Attendees filled in an anonymous questionnaire that asked 3 questions: did you learn something new about memory and aging, would you like to obtain a brief memory screen here today, would you say the video influenced your decision to get the brief memory screen. Ninety-eight percent (48/49) reported learning something new. Of those who responded, 80% (35/44) said that they would like a MMSE, and 71% (30/42) said the video affected their decision.

Discussion and Application to Practice

Here we report on a novel collaboration among an interdisciplinary group of bilingual academic researchers, providers, and low-income, low-English proficiency older adults from an urban Latino community. The year long project demonstrates the feasibility of this dynamic interactive partnership to create a culturally and linguistically acceptable video in Spanish to disseminate information about memory loss and evaluations and to promote engagement and service use. To our knowledge, this is the only video produced by a community academic partnership in which Latino older adults are engaged as advisors, writers and actors, using words and themes that emerged from their focus groups. While other researchers have documented the use of videos to educate and engage Latinos in care, they report using professional actors (Borrayo, 2004) (Morales, 2003).

The project's framework is anchored in the field of Entertainment Education (EE) (Sabido, 2002) and informed by research demonstrating the effectiveness of using videos and graphic novels to promote proactive health behaviors such as breast cancer screenings, depression screenings and treatment as well as dementia evaluations with Latinos (Valle et al., 2006, Cabassa et al., 2012, Borrayo, 2004). Videos convey strong visual messages that words alone cannot. Using videos as health communication tools to complement printed material is therefore valuable. Videos with familiar/relatable faces can provide powerful messages that may promote service use.

A pervasive theme identified in all focus groups included the fear that memory evaluations involve physically invasive procedures, and the misconception that memory loss signifies "craziness," which is consistent with several decades of research. These knowledge gaps are likely related to a number of factors including low education, low-literacy, normalization of serious memory loss and lack of ability to access available Spanish-language materials. (Ayalon and Arean, 2004, Gelman, 2010)

The structure of the video, namely an informal conversation between same-aged peers with one serving as an active healthcare role model, was determined by the results of the

focus groups. This informal interaction style, chosen by the CAB to be easily relatable to the target audience, is consistent with the model described by Sood(Sood, 2002) where relatable characters model positive social interactions that promote affective identification and encourages viewers to make proactive health decisions (Storey and Sood, 2013).

The video's peer discussion format served to present peers as both role models and educators. Research(Gagliano, 1988) suggests that those who have a supportive and pro-medical social network may have better health outcomes and quality of life than those who do not (Perry and Pescosolido, 2015), and that trained Lay Health Educators may be an effective resource for community engagement (Souder and Terry, 2009, Lam et al., 2003). Moreover, our peer-to-peer approach is consistent with literature concerning Latino cultural values such as *personalismo* (preferring interactions on a personal basis) and *confianza* (a careful and significant placement of trust), which have been shown to be crucial elements in engaging Latinos(Gallagher-Thompson et al., 2004).

A challenging aspect of this project was sustaining CAB participation as the filming date approached; some members anticipated that they would feel uncomfortable in front of the camera. The project team and videographer took everyone's concerns into account, and thus were able to include participants in a variety of ways. In this way, the challenge also proved to have unexpected benefits. By staying involved and allowing themselves to participate, the CAB members discovered new interests, tapped into their creativity and an improved sense of self-efficacy. One of the strengths of this project was the engagement of the remarkably motivated and committed community members who compose our CAB. The members remain dedicated to addressing issues of diversity as well as health concerns via new projects in ongoing collaboration with our center. While our center focuses on issues related to cognitive health and clinical research, this peer-to-peer video technique could readily be applied to other issues such as the recognition of and stigma around anxiety, depression and other mental illnesses. Because the videos are freely available on line, they have the potential to impact a large group of individuals. The 2.5 minute video “¿Qué le pasa a mi memoria?” is available free of charge on the Icahn School of Medicine at Mount Sinai's YouTube channel at <https://www.youtube.com/watch?v=1irhcTnsvsg>. To date, the video has been viewed over 1000 times at this URL. However, maximizing the exposure and therefore utility of this video remains a challenge in our target population. Despite the fact that health information is widely available on social media and other internet platforms, results from an informal survey at our center indicate that older, low-income Latinos in our community often have no personal internet access. Therefore sharing the video is necessarily labor intensive, conducted by our staff in the context of community talks. To increase exposure of ¿Qué le pasa a mi memoria?, we have shared the URL with numerous organizations in New York City that work with elderly Latinos as well as with the National Institute for Aging's Alzheimer's Disease Center Outreach and Education Core Directors.

Initial community screenings of the video with Spanish speaking elders elicited positive responses and audience members identified with the characters in the video. Comments included: “Inspires one to take action”; “That happens to all of us”; “That is definitely a conversation we have between friends and family.” The majority of the individuals who saw the video were interested in following up with a brief memory screen, and the

majority of those felt that the video influenced that decision. Future directions might include a larger quantitative study to explore the impact of “¿Qué le pasa a mi memoria?” on memory screening activation and stigma in this urban community. As Internet and social media use increases among both providers (e.g. telemedicine) and consumers, gauging the effectiveness of videos and other internet-based outreach and education in diverse communities will become increasingly important.

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Table 1

N=33

Age	Mean 70.67 (+/- 9.51)		
Language	Bilingual	20	61%
	Mostly or only Spanish	11	33%
	English	2	6%
Marital status (n=32)	Married	12	38%
	Single	8	25%
	Widowed	7	22%
	Divorced	4	13%
	Separated	1	3%
Education (n=32)	8th grade	9	28%
	Some HS	3	9%
	HS graduate/GED	11	34%
	Some college	4	13%
	College graduate	3	9%
	Post college	2	6%