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Vietnamese American Perspectives on Engagement in an Aging-Focused Research Registry

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Abstract

Introduction: We elicited Vietnamese Americans' perspectives on culturally appropriate recruitment into a new research registry: Collaborative Approach for Asian Americans, Native Hawaiians, and Pacific Islanders (AANHPIs) Research and Education (CARE).

Methods: Three focus groups were conducted with 21 Vietnamese Americans. Topics included knowledge about and experiences with research, outreach and recruitment methods for research participation and registry enrollment, and views about research incentives. Focus group transcripts were analyzed thematically.

Results: Mean age of participants was 41 years (range 18–73), 57% were male, 86% were non-US born, and 81% had never participated in a research study. Themes that emerged included (1) motivations to participate in research to gain knowledge: for oneself, for family's benefit, and for the Vietnamese American community as a whole; (2) necessity of trustworthy and credible individuals/spokespersons to promote the research initiative; (3) recruitment strategies that are age-specific and culturally appropriate, and (4) importance of monetary incentives.

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Statement of Ethics: This research was approved by the University of California, San Francisco Institutional Review Board (Protocol # 19-28027) and all participants provided written informed consent.

Conflicts of Interest/Disclosures: The authors have no conflict of interest to declare.

Conclusion: Findings from this study will be used to guide recruitment into and engagement with CARE among Vietnamese Americans, but are also relevant for other registries aiming to diversify their participants.

Keywords

Vietnamese Americans; dementia; ADRD; registry; outreach; qualitative

INTRODUCTION

Alzheimer's disease and related dementias (ADRD) have become a public health priority with an estimated 6 million Americans currently diagnosed with ADRD. ADRD has become especially important in California, where it is the 4th leading cause of death (1). Asian Americans are currently the fastest growing racial group in the U.S., and California is home to 1/3 Asian American and Pacific Islander residents (2). By 2040, the number of Californians living with AD who identify as Asian American, Native Hawaiian, and Pacific Islander (AANHPI) will more than double (3).

Though these figures highlight the necessity of engaging AANHPI communities for ADRD research to be representative and generalizable, AANHPI populations remain among the most underrepresented in research (4). Among AANHPI groups, Vietnamese Americans (VA) specifically are at high risk for ADRD disparities. VAs have a distinct social context in that they suffer disproportionately from early life adversity and trauma, post-traumatic stress, depression, and low socioeconomic status, all of which may increase risk for cognitive impairment and ADRD (5–8). Yet, there have been limited studies to determine culturally responsive practices for engaging VAs in research.

The Collaborative Approach for AANHPI Research and Education (CARE) registry was designed to address disparities in AANHPI representation in ADRD-related research (9). Although registries can be useful, many are limited because most require English language proficiency for their participants, thus limiting their reach. CARE aims to increase AANHPI research participation by building a culturally and linguistically responsive registry of 10,000 AANHPI adults for participation in health research, particularly ADRD, aging, and caregiver-related studies.

Previously, we performed focus groups with several different AANHPI subgroups (10). Those results highlighted recommendations for engaging AANHPI adults more broadly and reported themes that resonated with all of the focus group participants, but did not go in-depth to examine within-group themes. This paper extends those findings by reporting in-depth analyses that emerged from the VA groups specifically. In research with AANHPI communities, it is important to address the heterogeneity in subgroups and the subsequent barriers and facilitators of research participation. Our goal is to understand attitudes and perspectives regarding research registry participation and identify best practices to engage VAs in ADRD research.

METHODS

Sample

Recruitment outreach occurred from January 2020 to April 2020. To be eligible for the overall CARE focus group study, participants had to be at least 18 years old (to capture younger caregivers), identify as AANHPI, and speak English, Cantonese, Korean, Mandarin, or Vietnamese. Trained bilingual staff screened potential participants to determine their eligibility. Community partners in northern and southern California that serve AANHPI populations helped to recruit and enroll participants. Our target number for the Vietnamese focus group participants specifically was initially 20. It was anticipated that 20 people would be sufficient to achieve some saturation around key themes, elicit a broad array of perspectives, and allow for fruitful and in-depth conversations. In collaboration with our community partners and through flyers, word of mouth, and social media, we recruited 21 VAs to participate in 3 focus groups (due to one additional person expressing interest in participating in the initial in-person focus group).

Design

Focus groups were conducted February-April 2020. The first was conducted in-person in Northern California, but due to the COVID-19 pandemic, the remaining two were transitioned to an online format. The in-person Vietnamese-speaking focus group was held in a private room at a community center with 11 participants. Two English-speaking focus groups (n=5 for each group) were hosted on Zoom. During the meetings, experienced bilingual and bicultural facilitators followed a semistructured interview guide (see Table 1). Focus groups lasted 90 minutes on average, and were audio-recorded, transcribed verbatim, and translated to English (for the Vietnamese speaking focus group) for analyses. This research was approved by the University of California, San Francisco Institutional Review Board (Protocol # 19-28027) and all participants provided informed consent.

Data Analysis

Interviews were analyzed iteratively using thematic content analysis (11). Two researchers who were not a part of the focus groups (a bilingual Vietnamese trained undergraduate research assistant and a bilingual Vietnamese CARE co-investigator) independently read the transcripts line by line to get an understanding of the data. The two members met to discuss important phrases/themes and the proposed codes and came to a consensus regarding the final codes and proposed themes that were then operationalized and put into a codebook. Transcripts were then imported into Dedoose qualitative software for coding and analysis (12).

RESULTS

A total of 9 women and 12 men participated in the groups. Mean age was 41 years (SD = 17.89 years) (see Table 2). About 43% said they were not fluent or spoke limited English. Most (81%) said they had never participated in a research study before. Four salient themes emerged from the data. These included (1) motivations to participate in research to gain knowledge: for oneself, for family's benefit, and for the Vietnamese American

community as a whole; (2) necessity of trustworthy and credible individuals/spokespersons to promote the research initiative; (3) recruitment strategies that are age-specific and culturally appropriate, and (4) importance of monetary incentives. These four themes were discussed in both the English and Vietnamese speaking groups.

Motivations to Participate in Research

Participants were motivated to participate in research for their own benefit, that of their family, and the Vietnamese community in general. An overarching theme across these categories was the focus on detection and prevention. Participants wanted to know more about research on the signs and symptoms of ADRD so they could prevent it from happening in their own life or that of their family. One person explained- *“For me I want to see if I have the symptoms of the disease”* (Female, early 70’s, Vietnamese-speaking). Participants described wanting to participate in research so they could be better informed when they spoke to others: *“I’ll participate in research because I feel that I’m valued and I can build my own strength to speak to a group of people”* (Male, mid 50’s, English-speaking).

Participants were also motivated to help their family, *“...my mom was diagnosed with dementia but it wasn’t confirmed... I couldn’t find a lot of information in Vietnamese”* (Female, late 20’s, English-speaking). Wanting to help families better be prepared, another participant stated, *“I have to be able to figure this out if my parents or anyone... would eventually be in these situations”* (Female, early 20’s, English-speaking). Another participant voiced similar concerns about the future, *“[research participation] can be beneficial to me and my family in the future”* (Male, early 70’s, Vietnamese-speaking). In many cases, participants had family members who had memory loss and wanted to gain knowledge about their condition.

The notion of desiring to help one’s community was salient in terms of participants’ motivation to participate in research. One participant described wanting to *“...be able to help the Vietnamese community...and work together and get more information”* (Male, late 20’s, English-speaking). Many participants discussed a need for research in and about the Vietnamese community. *“There are not a lot of research studies done with the Southeast Asian communities, especially Vietnamese. We are not doing a good job of bringing resources to people or letting the Vietnamese community know”* (Female, early 20’s, English-speaking).

Trustworthy and Credible Individuals to Promote the Research Initiative

Another noticeable theme that emerged from the data was the necessity of trustworthy and credible individuals to promote the research initiative. One participant mentioned, *“Well-known organizations or government agencies are more trustworthy. Staff need to be professional and good at speaking”* (Male, early 30’s, Vietnamese-speaking). To alleviate concerns about research, a participant recommended professors or doctors, while another emphasized the importance of *“credibility and authority”* for any representative figure (Male, late 60’s, Vietnamese-speaking). Celebrities or local community champions were also suggested as effective representatives due to older adults’ familiarity with them through

cultural or entertainment productions. To promote the registry, participants suggested that research representatives like community leaders could enroll themselves as a model, allowing them to share their experiences with future participants to demystify the process.

Recruitment Strategies that are Age-Specific and Culturally Appropriate

Participants described several strategies to engage VAs into research. *“Especially the elderly now they can use iPad to go on YouTube, so I think if you can advertise on YouTube, on a regular channel, people can subscribe to that channel”* (Male, mid 50’s, English-speaking). Another participant mentioned, *“For the elderly or middle-aged group, I see my grandpa read newspapers a lot and my mom watch YouTube and TV”* (Female, early 30’s, English-speaking). Radio was also suggested as another potential outreach method- *“Middle aged people and retirees listen to the radio [and] to the talk shows a lot”* (Male, early 50’s, English-speaking).

Participants’ responses indicated that different approaches were needed for younger compared to older participants. One participant spoke about this tailoring, *“We need to announce via TV, radio, social media or community programs”* to engage different populations (Male, early 70’s, Vietnamese-speaking). Similarly, another participant said, *“For the young generation, we can advertise on social media,”* (Male, mid 50’s, English-speaking). Many participants shared that older members of Vietnamese communities do not find technology as accessible for engagement and offered potential solutions. Websites should be *“easy to use and navigate,”* however *“Elderly people may not know how to use”* them so they might not be as effective when targeting this older demographic (Female, mid 50’s, Vietnamese-speaking). A participant also suggested that *“instead of calling it a registry, maybe calling it a list”* may make it easier *“for the Vietnamese or older population to understand,”* (Male, early 30’s, English-speaking).

Across ages, participants suggested that cultural events were great opportunities for outreach and community engagement. For the VA community, this includes events like Lunar New Year or the Mid-Autumn Moon Festival, which participants mentioned gather many VA individuals (Male, mid 50’s, English-speaking). Weekly religious events like Sunday mass at church or temple were also suggested (Male, early 30’s, Vietnamese-speaking). Participants proposed that religious leaders at those events could mention opportunities to participate in research, appealing to the importance of culturally appropriate recruitment and the necessity of trustworthy and credible figures to promote initiatives (Male, late 60’s, Vietnamese-speaking).

Importance of Monetary Incentives

Although it did not spark as much endorsement as the previous themes, monetary incentives were discussed throughout the focus groups. One participant mentioned, *“I think a lot of people also look at that [incentives] as well to weigh their options... like money. What can I get right now when I sign up?”* (Female, late 20’s, English-speaking). Another participant mentioned, *“If you give them a gift card or something, they will be more interested in enrolling in research”* (Male, early 50’s, English-speaking).

Themes by Age

The most dominant themes among the younger (49 years and younger) group were *motivations to participate in research for the family* and the *need for trustworthy spokespersons*. The most dominant themes among the older (50 years and older) group were *motivations to participate in research for oneself* and *need for trustworthy spokespersons*. Thus, in both groups, the need for trustworthy spokespersons was salient.

DISCUSSION

The CARE registry is unique in its broad focus on aging research (e.g., asks about many health conditions) and its exclusive focus on improving AANHPI representation. In this paper, we report the findings of three focus groups conducted with VAs that elicited their perspectives about culturally appropriate recruitment approaches regarding research participation. Themes that emerged included (1) motivations to participate in research to gain knowledge: for oneself, for family's benefit, and for the VA community as a whole; (2) necessity of trustworthy and credible individuals to promote the research initiative; (3) recruitment strategies that are age-specific and culturally appropriate, and (4) importance of monetary incentives.

Although there are similarities between this paper and our focus group paper on overarching themes for all focus group participants (10), this paper reports a more in-depth analysis and the subsequent themes that emerged for VAs that are more nuanced. For example, in this paper, providing monetary incentives was a prominent finding that emerged as its own unique theme, but was not specifically mentioned in the overarching paper. Findings from the current paper are supported by other research that similarly indicate the importance of financial incentives for Chinese Americans (13). There were similarities and differences in motivations to participate in research. Here, we found that participants were motivated to participate for themselves, their family and community, and to learn more about detection and prevention of ADRD, which also emerged as important subthemes for the overarching paper. One aspect to the theme of motivation that was discussed in the overarching focus group paper was related to the importance of caregiving, but this was not an emergent theme for the current paper. Overall, the motivations to participate in research with our Vietnamese American focus group participants are consistent with previous research in other Asian American studies showing that a major motivation to participate in research was giving future generations hope and better treatment options. Having incentives was also a motivating factor in previous studies (17).

Finally, a theme in this paper was the necessity of involving trustworthy and credible individuals to promote the research initiative (i.e., CARE registry). While this was mentioned as an example in the overarching paper, it was not a prominent finding. Instead, it was mentioned within the context of culturally/linguistically appropriate outreach (i.e., theme #1), which does line up with previous work (14, 15). A recent study in Latino participants also indicated that trusted local organizations was important for increasing research engagement (18). However, our focus on just the VA groups provides a more nuanced idea of the trust needed for research participation. Given the social and historical context of VAs and the Vietnam War, it is logical that credibility and trustworthiness

of persons is important for healthcare and research with groups like VAs who have a complicated history with and in the U.S (16). Importantly, this theme emerged in both older and younger VAs.

Results from this study lend themselves to specific recommendations, outlined in Table 3. First, outreach and recruitment strategies targeting VA participants should consider that they may be motivated to gain knowledge- for themselves and also for their family and for their community. Thus, education during the course of outreach and throughout the research process is very important, as is being candid with participants that the research may not benefit them directly now, but it may benefit future generations of Vietnamese Americans in terms of bringing education and awareness to these individuals and the community. Second, we recommend that recruitment strategies be targeted. Older Vietnamese may have and prefer a different medium for receiving information than younger Vietnamese, and regardless of the strategy, there is a need for trustworthy and credible spokespersons- people who can advocate for the research and are a trusted source in the community. Finally, we recommend that research studies budget well – so that participant compensation is sufficient to engage Vietnamese persons. Recommendations for funding agencies and community partner organizations are also listed in Table 3.

Limitations

This study had limitations. There was a relatively small sample size; however, this is not atypical in qualitative studies. Our findings provide a deeper and more nuanced understanding of perspectives of outreach and research engagement in an underserved group. Additionally, many participants reported having some college or a college education; thus, findings may not be generalizable to VAs with lower educational attainment or VAs in other parts of the country. We were unable to explore potential differences in focus group findings by language of focus group (English vs. Vietnamese) given that the latter was confounded with modality (i.e., because of the pandemic, all English language groups were held via zoom while the Vietnamese group was held in person). However, both the digital/English language and in-person/Vietnamese focus groups appeared to have the same amount of participant involvement – in terms of recruitment and engagement during the focus group. Future research should ensure the inclusion of perspectives of diverse VAs with wide variability in education level, age, geography, and spoken language.

Conclusions

This study provides an in-depth examination of important barriers and facilitators to the inclusion of VAs in research. To engage VAs and other diverse groups, research recruitment must consider motivations to participate, the necessity of trustworthy and credible individuals to promote the research, strategies that are age-specific and culturally appropriate, and the importance of financial incentives. Our results show that when research is culturally and linguistically appropriate, VAs were glad to be invited and eager focus group participants who wanted their voices to be heard. Findings from this study are being used to guide community engagement and recruitment into the CARE registry. Results may also be informative for other registries and research aiming to diversify their participant samples, especially those from AANHPI populations.

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Data Availability:

All data generated or analyzed during this study are included in this article. Further inquiries can be directed to the corresponding author.

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Table 1.

Focus Group Guide for CARE

Section 1. Knowledge, attitudes and experiences with research participation	
1.a	What does “research” or “clinical studies” mean to you?
1.b	Have you participated in a research study before?
	- If yes, what are the reasons that motivated you to participate? What kind of research studies were these?
	- If no, what motivated you to participate in today’s research study?
1.c	What does “Aging, Caregiving, and/or Alzheimer’s and dementia research” mean to you?
Section 2. Knowledge, attitudes and experiences with research registries	
2.a	What does a “research registry” mean to you?
2.b	Have you enrolled or signed up in a research registry before?
	- If yes, what are the reasons that motivated you to enroll or sign up for the research registry? What kind of a research registry was it? A research registry (or potential participant registry) is a repository (or list) of potential participants (or individuals) who have expressed their willingness to be contacted about studies for which they may be eligible to participate in.
Section 3. Perspectives, experiences, and suggestions with various recruitment methods for research participation and research registry enrollment	
	Now, we would like to ask you about your perspectives, experiences, and suggestions with various recruitment methods for research participation and research registry enrollment. First, we would like to ask you about recruitment strategies. What do you think are the best ways to recruit [add community such as Chinese, Vietnamese, Korean, Asian Indian, Filipino, Samoan, etc.] to enroll or sign-up on CARE’s research registry? [Probe accordingly to the discussion; some recruitment strategies include flyers, social media, ethnic media, email, texting, workshops (e.g., regular vs. culturally appealing such as using Korean dramas)]
Section 4. Insights on how to frame messages on research participation and research registries for [add community such as Chinese, Vietnamese, Korean, Asian Indian, Filipino, Samoan, etc.]	
	What are your thoughts and/or ideas about how to frame the recruitment messages for CARE’s research registry for [add community such as Chinese, Vietnamese, Korean, Asian Indian, Filipino, Samoan, etc.]? [Probe accordingly to the discussion; some talking points include messages’ content (e.g., personal health; help research; cure Alzheimer’s), length (e.g., brief, descriptive), culturally specific to the community or general to Asian American and Pacific Islander, etc.]
Section 5. Insights on how the research registry website should look.	
	What are your thoughts and/or ideas about how CARE’s registry website should look like for [add community such as Chinese, Vietnamese, Korean, Asian Indian, Filipino, Samoan, etc.]? [Probe accordingly to the discussion; some talking points include registry’s look, registry’s content, registry’s function, culturally specific to the community or general to Asian American and Pacific Islander, etc.]
Section 6. Insights on participant incentives for enrolling in our research registry for [add community such as Chinese, Vietnamese, Korean, Asian Indian, Filipino, Samoan, etc.]	
	What are your thoughts and/or ideas about providing a participant incentive for CARE’s research registry for [add community such as Chinese, Vietnamese, Korean, Asian Indian, Filipino, Samoan, etc.]? [Probe accordingly to the discussion; some talking points include whether a participant incentive needs to be provided, amount of a participant incentive (e.g., \$0, \$5, \$10)]
Section 7. Next steps	
	After we complete all of our focus groups, we will develop a survey about the various recruitment methods and messaging. Then, we will have additional focus groups to review the survey before conducting the survey with some members of [add community such as Chinese, Vietnamese, Korean, Asian Indian, Filipino, Samoan, etc.] Please let a staff member know if you would be interested in participating again in a focus group or in completing the survey.
Section 8: Summary	
8.a	What are your recommendations to outreach to the [add community such as Chinese, Vietnamese, Korean, Asian Indian, Filipino, Samoan, etc.] about potentially enrolling in our CARE research registry for Asian Americans and Pacific Islanders?
8.b	At last, let’s go around the room and have everyone share some final comments about this topic or today’s discussion.

Table 2.

Sociodemographic Characteristics of Focus Group Participants (N= 21)

Characteristics	n	(%)
Mean Age*	41 years (SD 17.9; range 18–73)	
Sex		
Female	9	(42.9)
Male	12	(57.1)
Marital status		
Single	7	(33.3)
Married or have a partner	13	(61.9)
Divorced/Separated	1	(4.8)
Widowed	0	(0.0)
Employment		
Employed	11	(52.4)
Unemployed or Homemaker	1	(4.8)
Retired or Disabled	2	(9.5)
Student	6	(28.6)
Other	1	(4.8)
Education		
Less than high school	2	(9.5)
High school graduate or G.E.D.	1	(4.8)
Some college or	15	(71.5)
College graduate		
Graduate degree	3	(14.3)
Income		
\$25,000 or less	7	(33.3)
\$25,001 to \$75,000	8	(38.1)
\$75,001 to \$150,000	5	(23.8)
\$150,001 or more	1	(4.8)
Nativity		
US-born	3	(14.3)
Non-US born	18	(85.7)
Mean years in US	15.8 years (SD 12.6; range 3–50)	
English fluency		
Native or Fluent	12	(9.5)
Some	8	(38.1)
Do not speak	1	(4.8)
Previous participation in research		
Yes	4	(19.0)
No	17	(81.0)
ADRD caregivers	1	(4.8)

Table 3.

Recommendations for Engaging Vietnamese Americans

For researchers
1. Consider motivations of potential participants during outreach (to gain knowledge for themselves, their family, and community)
2. Recruitment strategies should be targeted and culturally appropriate for older vs. younger participants
3. Rely on trustworthy and credible spokespersons and advocates for the study
4. Budget studies well so that participants can be compensated for their time
5. Establish partnerships with trusted community organizations
For funding agencies/sponsors
1. Include grant announcements targeting underrepresented groups like Vietnamese Americans in research
2. Target and invest in early career investigators interested in studying underrepresented groups
3. Allow budgets to compensate study participants well
For community organizations
1. Connect with local researchers who have a lived experience or history of working with population of interest
2. Collaborate on health education and research programs that will benefit both partners

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