

Why is it Difficult to Recruit/Retain Asian American Family Caregivers in a Virtual Intervention?

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Abstract

Background: Virtual interventions using computers and mobile devices have increasingly been developed and tested among racial and ethnic minorities in recent years. Yet, few virtual interventions have been developed for Asian American midlife women who are family caregivers of persons living with Alzheimer's disease (AD). Furthermore, little is known about the feasibility of recruiting this specific group of racial/ethnic minority midlife women to a virtual intervention study.

Objective: The purpose of this paper is to discuss practical issues in recruiting and retaining this specific group of racial/ethnic minority midlife women for a virtual intervention study.

Methods: The ongoing parent study is to develop and test a preliminary version of a virtual intervention for this specific population. During the research process, the research team had regular meetings to have discussions on recruitment and retention issues and each team member wrote research diaries. A content analysis was conducted with the written records including the research team's research diaries and meeting minutes.

Results: The issues were: (1) an extremely small pool of Asian American midlife women who were family caregivers of persons living with AD; (2) competitions with other studies, (3) practicality of inclusion/exclusion criteria, (4) lack of time and interests in research participation, and (5) negative perception of small monetary incentives.

Conclusion: Future researchers need to consider the unique cultural and social dynamics of this specific population, foster trusted connections with the communities before initiating the study, and obtain feedback from potential gatekeepers and the communities in advance.

Keywords

research subject recruitment, retention, research design, virtual intervention, Asian American, middle aged, women, family caregivers

Virtual interventions using computers and mobile devices have increasingly been developed and tested among racial and ethnic minorities. Indeed, virtual interventions have been widely accepted by various groups including general populations, patients with specific conditions, healthcare providers, and researchers.^{1,2} A drastically increasing number of virtual interventions aiming to change health behaviors have recently been developed and tested among different groups of users.^{3,4} Recent studies have shown that virtual interventions are effective for mental health conditions, particularly depression, as well as for managing chronic diseases, supporting dementia caregivers, alleviating the burden on cancer survivors, helping to improve individuals' quality of life, and promoting healthy behaviors.^{5–8} Studies have supported that virtual interventions are welcomed and accepted especially by those with low resources regardless

of race, ethnicity, gender, and/or age.^{1,2} Furthermore, the recent COVID-19 pandemic has made virtual interventions more widely accepted, especially among racial and ethnic minorities.^{9,10}

Despite their popularity and acceptability,^{1,2} virtual programs have rarely been developed and tested among Asian American midlife women who are family caregivers of persons living with Alzheimer's disease (AD). Although the incidence rate of AD is the lowest among Asian American

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older adults compared to other racial and ethnic groups,¹¹ the prevalence rate of AD in this specific population is anticipated to increase in the future as the number of Asian Americans aged 65 and older is expected to increase to 26.6 million, or 34% of older adults, by 2040.¹² Furthermore, the caregiving situation of Asian Americans is not positive. Asian Americans have the lowest percentage of caregivers and spend the least on caregiving among racial/ethnic minority groups,¹² which indicates their high need for support including virtual information and coaching/support interventions. However, little is known about the feasibility of recruiting this specific group of racial/ethnic minority midlife women to a virtual intervention study. Even in a PubMed search with combined keywords of online/virtual, Asian American midlife women, family caregivers, and AD (without a time limitation), no articles were retrieved. Further, with an extensive PubMed search with keywords of Asian American midlife women, family caregivers, and AD (without a time limitation), only one article was retrieved.¹³ Actually, the article was about a long-term meditation program, not a virtual program, among home-based caregivers of older adults with AD in two South Asian cities,¹³ not among Asian Americans.

Purpose

This paper aims to discuss recruitment and retention issues in a virtual intervention program targeting Asian American midlife women who are family caregivers of persons living with AD and to make suggestions for future recruitment and retention of this specific group in virtual intervention studies. First, the ongoing parent study is described in short, and the approach to find supporting evidence for discussion points is described. Then, the recruitment and retention issues are presented. Finally, some suggestions are made for future recruitment and retention of this specific group in virtual intervention studies.

The Parent Study and Approach

The purpose of the ongoing parent study is to preliminarily evaluate a virtual information and support/coaching program in supporting Asian American midlife women who are family caregivers of persons living with AD. The study includes two phases: (1) Phase 1 with an expert review and a usability test; and (2) Phase 2 with a small randomized clinical trial among 60 Asian American midlife women who are family caregivers of persons living with AD. The study is conducted under the approval of the Institutional Review Board of the institutes where the study is being conducted. The expert review was conducted among five self-identified experts in family caregiving for persons living with AD. All the experts reviewed the program for 2 weeks and provided their feedback via email. The usability test was conducted over a 1-month online forum with 11

Asian American midlife women who were family caregivers of persons living with AD. Overall, the participants agreed that the program would be helpful and useful for Asian American midlife women in similar caregiving roles. They found the program well-organized and easy to follow. Several suggestions were made regarding the content and online logistics of the program. Based on feedback from both the expert panel and the usability test, the program was refined.

The ongoing Phase 2 is a small randomized clinical trial, and the recruitment for Phase 2 is in progress. The study has been announced through online and offline communities/groups for Asian Americans. Once potential participants visit the study website and are checked against the inclusion/exclusion criteria, they are automatically randomized into either (1) an intervention group or (2) a control group. The objective of our recruitment practice has been to ensure the inclusion of representative Asian American midlife women who are family caregivers of a person living with AD. Multifaceted recruitment strategies have been adopted: (1) outreach activities through community centers specific to Asian Americans, religious organizations (eg, churches and temples), official Asian organizations, nursing homes, and healthcare facilities; (2) participation in gathering events such as cultural festivals; (3) the use of social media platforms for prompt communication; (4) targeting ethnic-specific student organizations in universities to reach out to local communities linked to ethnic-specific organizations; (5) identifying and reaching out to key community leaders; and (6) utilizing culturally sensitive materials to build trust and rapport with potential participants.

The intervention group uses the virtual information and coaching/support program for caregiving and the Alzheimer's Association (AA) website on caregiving while the control group uses only the AA website. The components of the intervention include: (1) educational modules related to AD and caregiving; (2) online resources related to AD and caregiving (with video clippings including 360-degree videos); and (3) two sub-ethnic-specific social media sites with chat function. Group coaching/support is provided through the sub-ethnic-specific social media sites with educational modules and online resources. Individual coaching/support is provided weekly via a chat function. At three points in time (pretest, post-1-month, and post-3 months), the participants complete the questionnaire. The target population is self-reported Chinese or Korean American women who are 40-60 years old; whose parents and grandparents are of Korean or Chinese descent; who can read or write in English, Chinese, or Korean; and who live in the United States, have access to the Internet using computers or mobile phones, and are family caregivers of persons living with AD.

Once a visitor visits the project website, the person is asked to review and sign the informed consent on the website and is screened against the inclusion/exclusion criteria. When the participant passes the screening process, the

participant is automatically linked to the pretest survey questionnaire on the Research Electronic Data Capture (REDCap) tool. Then, the participant is automatically randomized into either the intervention or control group. Both groups are asked to use the intervention and/or the AA website via a link on the project site. Furthermore, the study includes multiple instruments to assess the participants' background characteristics, health and menopausal status, caregiving experience, care recipients' health outcomes, and caregivers' health outcomes. The instruments have established reliability and validity in Asian American populations, with Cronbach's alpha over 0.80. All the participants are reimbursed with \$150 electronic gift cards (\$50 per time point).

During the second phase of the study (specifically during the recruitment phase), research team members wrote research memos on issues in participant recruitment and retention. The team has held weekly group discussion meetings, and the meeting records have been maintained. Individual research team members have written 1-3 pages of weekly research memos (9 members \times 1-3 pages per week \times 4 weeks \times 4 months = 288 pages), and they have discussed emerging issues/concerns through Microsoft Teams. All the research team members were provided with detailed instructions for journaling, recording the key search terms, collecting contact information, and noting any challenges they faced during the searches. All of them have been engaged in directly contacting the organizations, identifying key community figures, and promoting the study at ethnic-specific events.

By the end of the fourth month of participant recruitment, the research memos, weekly meeting records, and Microsoft Teams messages were analyzed using the simple content analysis by Weber¹⁴ to identify practical issues in participant recruitment and retention. Using individual words as the unit of analysis, all written records were coded through line-by-line coding by all authors of this paper. Then, the categorization of all generated codes was done; through reviewing, re-reviewing, and comparing the categories and the codes, idea categories reflecting the recruitment and retention issues were extracted. Finally, themes were identified to support the discussion points related to recruitment and retention issues.

Findings: The Issues

The issues included: (1) an extremely small pool of Asian American midlife women who were family caregivers of persons with AD; (2) competition with other studies; (3) practicality of inclusion/exclusion criteria; (4) lack of time and interests in research participation; and (5) negative perception small monetary incentives (Table 1).

An Extremely Small Pool of Potential Participants

Despite widespread announcements of the study, virtually no participants were recruited during the first 3 months. The

research team had a series of discussions with community gatekeepers and experts. Essentially, there was an extremely small pool of potential participants due to several reasons. First, cultural stigma attached to cognitive impairment was noted in this study; dementia was viewed as a stigmatizing condition, and the local terminology used to describe it carried negative connotations. Indeed, in the literature, Korean Americans report the stigma of pity linked to the notion of dishonor and their tendency to avoid individuals with AD and their family members.¹⁵ In addition, Chinese Americans report family embarrassment and social avoidance related to AD, which frequently prevents them from seeking help within their communities.¹⁶ Furthermore, the literature was clear that Asian Americans tended to view cognitive disorders as a family sin or karma and were often reluctant to reveal the condition even within their family members.¹⁷ The case was more severe among Chinese Americans compared to other Asians; dementia was regarded as a stigmatized mental illness. Approximately one out of four elderly Chinese Americans considered AD a mental disease.¹⁸ Consequently, Chinese Americans were unwilling to be diagnosed with AD and did not seek healthcare providers' help even when family members started to recognize cognitive impairment. According to a qualitative study, caregivers felt ashamed to reveal their family member's AD.¹⁹ The diagnosis of AD was typically based on the severity of cognitive impairment, often determined by specific scores on the Mini-Mental State Examination.²⁰ Thus, if patients were unwilling to report the severity of their cognitive impairment, the diagnosis could not be made in a timely manner.

Second, in this study, lack of knowledge of AD was noted as a reason for delays in the diagnosis and treatment process, which subsequently hid them in the communities. In the literature, a lack of knowledge and misconceptions about AD were reported as barriers to AD-related care.^{16,21} In most Asian cultures, memory loss was viewed as an inevitable part of aging, and this misconception frequently deterred Asian Americans from seeking treatment.¹⁶ Notably, among major Asian sub-ethnic groups residing in the US, Koreans had the highest level of concern about becoming a caregiver for a person with AD, rather than developing the disease themselves.²¹ Moreover, they reportedly had the least negative attitudes toward placing individuals with AD in nursing homes.²¹ The literature clearly suggested that there would be fewer Korean family caregivers who would be available for research projects, which was confirmed in this study.

Third, like other immigrant groups, many Asian Americans with AD faced difficulties in finding culturally and linguistically proper services at long-term care facilities. As reported in the literature, these difficulties led many of them to move back to their countries of origin for more affordable nursing home care, supported by the government.^{17,19} Moreover, they experienced language barriers, struggled to find bilingual healthcare providers to communicate effectively, and had limited trust in their healthcare providers as reported in the literature.¹⁰ This could frequently

Table 1. A Summary of Recruitment and Retention Issues and Suggestions for Future Research.

Issues	Suggestions
An extremely small pool of AAFCA	<ul style="list-style-type: none"> The unique cultural backgrounds and social situations of Asian American midlife women need to be considered in the study design and research process.
Competitions with other studies	<ul style="list-style-type: none"> It would be essential to establish trusted relationships with potential gatekeepers and communities/groups for Asian Americans before starting a study.
The practicality of inclusion/exclusion criteria	<ul style="list-style-type: none"> The practicality/feasibility of inclusion/exclusion criteria needs to be carefully examined in advance through multiple ways. Getting feedback on inclusion/exclusion criteria from experts and gatekeepers before planning a study could be one way to determine the practicality/feasibility.
Lack of time and interest in research participation	<ul style="list-style-type: none"> Highly creative and innovative strategies need to be developed to motivate this specific population to participate in research.
Negative perception of small monetary incentives	<ul style="list-style-type: none"> The optimal monetary incentives need to be examined with multiple stakeholders, including potential participants and gatekeepers in the planning stage. Highly creative and innovative strategies need to be developed to motivate this specific population to participate in research.

Abbreviation: AAFCA: Asian American family caregivers of persons with Alzheimer's disease.

lead to difficulties in understanding medications¹⁰ and might have resulted in fewer Asian American patients with AD and their caregivers seeking help in the US.

Competitions with Other Studies

The potential participants the research team recruited in the first phase of the study (for the usability test and the expert review) through establishing relationships with multiple organizations/groups totally disappeared when the recruitment for Phase 2 was started because of the time delay due to a grant transfer. Then, the organizations/groups who were willing to help during the first phase could not help the study anymore because they were bound by other research projects and other research institutions. The trust that the research team originally established had been broken due to the time delays, and other competitors provided a great incentive to them.

With a limited number of communities/groups of Asian American family caregivers of people living with AD, all researchers possibly target the same communities/groups for recruiting research participants. As a result, the research team experienced difficulties connecting with organizations/communities that were already closely connected with other research teams targeting the same population. About 45% of Asian Americans in the US (about 9.8 million) are residing in the West, and most Asian American Alzheimer's support groups and organizations are located in the West.²² Community leaders could help announce the study broadly and help potential participants to understand the study process.²³ However, since this study is a national virtual study, the research team frequently had difficulties in connecting with community leaders or gatekeepers in different states. Although attending ethnic-specific culture fairs or events would be helpful in recruiting Asian Americans, the research team could not easily attend those fairs or events happening

in other states. Yet, having community consultants who were insiders of the communities in other states helped shorten the distance between the research team and the specific communities.

Practicality of Inclusion/Exclusion Criteria

Community consultants and gatekeepers mentioned the practicality of the inclusion/exclusion criteria that the research team set for the study, which might make recruitment more difficult. First, the criteria requiring only "family caregivers" did not work for this population. According to a previous study, more than 50% of patients with AD were cared for by their relatives, friends, and non-family members.^{17,24} Thus, the definition of "family" caregivers needed to be extended. Second, the criteria related to "non-paid" caregiving was also problematic because most family caregivers received some subsidies from the government for caregiving.²⁵ Therefore, limiting the participants to "non-paid" caregivers further restricted the availability of potential participants. Third, one of the inclusion criteria, which required more than 4 h of direct assistance to persons living with AD, also caused a practicality issue and it was eliminated after consulting with the funding agency. Since middle-aged caregivers usually had their jobs and had to manage other responsibilities such as raising a family and handling financial obligations, it was difficult for them to meet the requirement of 4 h of direct assistance. Indeed, family caregivers of patients with AD reportedly had a varied range of hours for caregiving, with 20.5% spending 4-6 h per week, 11.5% less than 4 h per week, and 27.5% spending 10-20 h per week.^{23,24}

The second-generation Asian American immigrants were also different from the first-generation Asian American immigrants due to their high level of assimilation to the host culture and Americanized lifestyles. Among Asian Americans, there was a shift toward single-generation households with

gradual changes in lifestyle and perception toward filial piety.^{26,27} Thus, unlike the first-generation immigrants, most of the second-generation immigrants no longer provided direct care for their family members with AD.²⁶ However, second-generation Asian American immigrants still considered caregiving for their elderly family members as their duty, which often made them feel guilty for not fulfilling the traditional value of filial piety.¹⁹ Subsequently, even when they did not provide direct, time-intensive care for their family members with AD at home, they still played an active role in caregiving by hiring and monitoring assistants.²⁸ This generational difference could be another reason why it was difficult to find potential Asian American caregivers who provided direct care in this study.

Lack of Time and Interests in Research Participation

Most of the potential participants who were contacted indicated their lack of time and interest in research participation as the major reason for declining to participate in this study. In the literature, even though caregivers often felt proud to be responsible for their family members with AD,¹⁹ some caregivers of individuals with AD reported poor quality of life and strained relationships with the patients.^{24,28} They frequently described feelings of exhaustion and emotional distress,¹⁰ and even experienced mental health issues due to the demands of caregiving.^{17,19} These reasons could cause their reluctance to engage in this study. Furthermore, some caregivers had very busy schedules as they also cared for their own families alongside their parents with AD.^{19,24} Thus, their multiple roles as workers, spouses, mothers, and caregivers kept them busy in their lives,²⁹ which deterred them from participating in a research study. Originally, the research team considered computers and mobile devices as an excellent medium to provide the intervention with flexible schedules, allowing participants to join the study at their convenience. However, some Asian American midlife women were not familiar with operating mobile devices such as sending emails, creating accounts on the study website, and logging into the website. Furthermore, their busy schedules took up most of their time, leaving them with little energy or less time to learn how to navigate an unfamiliar website. Thus, some were hesitant to participate in this virtual study. Moreover, a gatekeeper mentioned that Asian American caregivers would participate in a study only if it could significantly benefit their family members with AD. Therefore, it was necessary to emphasize the direct benefits of the study to potential participants.

Negative Perception of Monetary Incentives

The research team set the amount of monetary incentives for research participation considering potential ethical issues

and the cost of Internet connections to participate in this study. Although participants did not directly express their opinions about monetary incentives, two possible types of responses were inferred from the research team's interactions with the participants. First, some Asian American caregivers indicated it was their duty to take full responsibility for family members with AD, even to the extent of turning down job promotions to focus on caregiving. Therefore, the caregivers often viewed accepting monetary incentives for their research participation as conflicting with these values, believing that caregiving and related activities should not be monetized as reported in the literature.³⁰ Indeed, there existed fear about how accepting payment for research participation could be perceived by others in their communities.^{30,31} On the other hand, many caregivers of this study felt that the small amount of monetary incentives trivialized their contributions and experiences, leading to a sense of disrespect or devaluation, although the literature was clear that monetary compensation was not a deciding factor for their research participation.³² Furthermore, there existed mistrust among potential participants regarding the research process and motives. They questioned whether the study was genuinely beneficial or simply trying to obtain their participation at a low cost. This suspicion could stem from historical instances where research involving minority populations was conducted unethically and exploitatively in the past.³³

Suggestions for Future Recruitment and Retention

Based on the issues, the following suggestions are made for future research targeting Asian American midlife women who are family caregivers of persons living with AD. First, the unique cultural backgrounds and social situations of Asian American midlife women need to be considered in the study design and research process. In this study, despite the difficulties in recruiting and retaining Asian American family caregivers of persons living with AD, it was obvious that the caregivers clearly had a desire for culturally tailored support programs; they consistently sought online-based support training for new information and frequently used online platforms to communicate with other caregivers and discuss their challenges. Moreover, many of them, especially Korean Americans, mentioned that their patients with AD faced difficulties in finding culturally and linguistically suitable services. Thus, the recruitment and retention difficulties might not be related to a lack of needs among the population. Rather, the difficulties might be due to a lack of consideration for the unique cultural background and social situations of the population.

Second, establishing trusted relationships with potential gatekeepers and communities/groups for Asian Americans before starting a study would be essential for future research recruitment of this specific population. Due to the limited

pool of potential participants, there was intense competition among researchers wanting to work with this specific population. Without establishing trustworthy relationships with potential gatekeepers and communities/groups for Asian Americans, this competition could pose a significant hurdle for future research efforts.

Third, the practicality/feasibility of inclusion/exclusion criteria needs to be carefully examined in advance through multiple ways. Getting feedback on inclusion/exclusion criteria from experts and gatekeepers before planning a study could be one way to determine practicality/feasibility. The inclusion/exclusion criteria for this study were set based on a literature review and research team discussions. Yet, obviously, the team did not have enough experience with this specific population to foresee the issues that were encountered during the recruitment/retention process.

Finally, the optimal monetary incentives need to be examined with multiple stakeholders including potential participants and gatekeepers in the planning stage. Also, highly creative and innovative strategies need to be developed to motivate this specific population to participate in research. The research team set the amount of monetary incentive based on their previous experience in virtual intervention studies among Asian Americans, but the perceived adequacy of the amount was different in this specific population from that in other groups of Asian Americans. As discussed, this specific population tended to be heavily burdened in their daily lives with additional caregiving responsibilities, which could influence their perceived adequacy of the monetary incentive differently from that of other groups of Asian Americans. Also, this specific population was extremely busy with multiple responsibilities and rarely willing to participate in research due to their cultural values and attitudes, which need to be considered in future recruitment and retention plans.

Conclusion

In this paper, the challenges in recruiting and retaining Asian American midlife women who are family caregivers of persons with AD in a virtual intervention study are discussed. Based on these challenges, several suggestions are made for future recruitment and retention of this specific group in virtual intervention research. Recruiting and retaining racial/ethnic minority groups of family caregivers of persons living with AD in research is not an easy task. The suggestions provided in this discussion paper could be helpful for future researchers planning studies among this specific population.

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Author Contributions

Dr Wonshik Chee is the Principal Investigator (PI) of the parent study who designed the study and wrote the manuscript. Dr Eun-Ok Im is the contact PI of the parent study who co-designed the study, reviewed, and provided feedback on the manuscript. Seulgi Ryu, Jianing Quan, and Dongmi Kim are research assistants of the parent study who wrote, reviewed, and provided feedback on the manuscript.

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IRB Approval

The IRB of the University of Texas at Austin approved the parent study (STUDY00004808).

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