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Community-engaged research with Vietnamese Americans to pilot-test a dementia caregiver intervention

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Abstract

Caring for a family member with Alzheimer's disease (AD) or a related dementia is stressful, and this may especially be the case for racial/ethnic minority caregivers. This study examined the feasibility and acceptability of a pilot intervention for Vietnamese American dementia caregivers. A secondary, exploratory aim was to examine post-intervention effects on AD knowledge and psychosocial outcomes. Of the 87 individuals contacted, 32 met inclusion criteria. Of this number, 14 enrolled in the study with 11 caregivers completing the intervention, and 10 of the 11 completing 3-month follow-up data. Caregivers provided positive feedback on the intervention and had higher scores on AD knowledge and self-efficacy in seeking support services post-intervention, with the effect on self-efficacy maintained at 3-month follow-up. Recruitment for the intervention was difficult; however, once caregivers came to the first session, they were engaged and found the classes informative. Recommendations for a future intervention are discussed.

Keywords

Alzheimer's disease; diversity; disparities; culture; ethnicity

Introduction

An estimated 34.2 million adults in the U.S. provide unpaid care for a family member or other loved one (National Alliance for Caregiving, 2009). As the older adult population in the U.S. continues to grow in size and longevity, the likelihood that more adults will be

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caring for a family member with dementia or Alzheimer's disease (AD) increases (Caregiver Statistics, 2012). Dementia caregiving is stressful, as caregivers are more likely to experience anxiety, depression, and to report poorer quality of life and lower levels of life satisfaction (Chan, 2010; Cooper, Katona, Orrell, & Livingston, 2008; Schulz et al., 1997). They are also more vulnerable to mental health problems and accelerated physical decline. The experiences of ethnic minority caregivers may be even more challenging because of the existing health and healthcare disparities that exist for these groups (Pinquart & Sorensen, 2005).

Asian Americans are the fastest growing racial minority group in the U.S. today (Pew Research Center, 2012). In the U.S., Vietnamese are the fourth largest Asian subgroup, following Chinese, South Asian, and Filipino. Of these large subgroups, Vietnamese seem to be at highest risk for poor health and mental health (Tran, Tran, & Hinton, 2006). Older Vietnamese are more likely to rate their health status as poor or fair compared with members of other Asian subgroups (Collins, Hall, & Neuhaus, 1999). Studies show that Vietnamese tend to view memory problems as a normal part of aging (Braun & Browne, 1998; Meyer et al., 2015) which may subsequently cause delays in diagnosis and care. Given that Vietnamese caregivers face greater health and mental health disparities, potentially exacerbated by the stress of caregiving, there is a critical need to intervene in this high-disparity population.

The development of effective and sustainable caregiver interventions remains an ongoing challenge in the field. More pressing is the need for caregiver interventions that are appropriate for ethnically and culturally diverse caregivers. Currently, there are effective interventions for diverse caregivers, which aim to improve caregivers' psychosocial functioning and caregiving skills (Napoles, Chadiha, Eversley, & Moreno-John, 2010); however, these interventions rarely sample Asian Americans, and no large randomized trials involve Vietnamese Americans. Thus, there is a tremendous gap in evidence-based interventions for Vietnamese dementia caregivers. A central tenet underlying cultural adaptation of caregiver interventions is considering the sociocultural, psychological, and historical context of the target population.

Aranda and Knight's *sociocultural stress and coping model* suggests that cultural factors within ethnic/racial minority populations may influence caregivers' beliefs, attitudes, and experiences of caring for their family member (Aranda & Knight, 1997; Knight & Sayegh, 2010). Although the endorsement of cultural values likely varies by acculturation level, or the adoption of American values for Vietnamese, there is typically a greater value on the collective or group rather than the individual in Vietnamese culture. The roles in Asian American families may be highly interdependent and an expectation of all family members is to avoid bringing shame and loss of face to the family (Kim, Atkinson, & Umemoto, 2001; Zane & Yeh, 2002). Filial piety, wherein family members take on the responsibility of caring for older family members (Wang, 2012) may lead to greater caregiver stress and burden.

With these values in mind, the intervention is a six-week multicomponent program, structured into weekly two-hour sessions and is meant to reduce stress and promote

culturally appropriate coping strategies. The goal is to enhance the well-being of Vietnamese dementia caregivers and their care recipients through education, support, skills training, and stress management in a group setting. Based on the theoretical perspective of interdependence and the collectivistic values of Vietnamese, as well as our own preliminary work indicating that there are often multiple family members involved in the care of a family member with dementia (Meyer et al., 2015), the intervention is unlike typical dementia caregiver interventions in that it involves several family members as a collective target for the intervention, not just the primary caregiver. As shown in Table 1, the sessions covered various concerns salient to Vietnamese dementia caregivers, including education on dementia and AD, relevant community resources, strategies for providing better care, discussion of how culture impacts views on dementia and caregiving responsibilities, and stress management. As mentioned, many Vietnamese caregivers believe that memory loss is a normal part of aging (Braun, Takamura, & Mougeot, 1996) and are not aware that AD is a neurodegenerative disease (Meyer et al., 2015), thus incorporating additional education on dementia and the different stages of AD was crucial to provide caregivers with a better understanding of their family member's symptoms, behaviors, and disease progression. The major stress management component used in the intervention was the signal breath exercise from REACH 2 (Gitlin et al., 2003). In addition, short stretching exercises were incorporated into the classes and caregivers were encouraged to use these stress management techniques and other REACH 2 exercises at home (e.g., planning for self-care). Unique to the intervention was our goal to include a secondary caregiver in the intervention, as previous studies have indicated the importance of multiple family members in the Vietnamese caregiving context (Meyer et al., 2015; Wang, 2012).

Several models exist for adapting interventions for use in ethnically diverse communities, including ones by Napoles, Santoyo-Olsson, and Stewart (2013), Resincow and colleagues (1999), and Barrera and Castro (2006). Although each model has a slightly different focus, an overarching theme is utilizing a community-based participatory research process to obtain input on the intervention from the intended audience, thus ensuring its relevance. In a previous study, we conducted formative work to understand the lived experiences of Vietnamese dementia caregivers. We identified key stressors and coping strategies and these findings (Meyer et al., 2015) along with previous work on sociocultural models of stress and coping, were used to inform and adapt the intervention. Then, a qualitative study was conducted to further refine the pilot intervention as well as to seek community input before implementation; this process has been described elsewhere (Meyer et al., 2018).

The intervention borrowed the structure from The Savvy Caregiver Program—six two-hour sessions—and adapted the content from the Resources for Enhancing Alzheimer Caregivers' Health II (REACH II: Gitlin et al., 2003; Hepburn, Lewis, Sherman, & Tornatore, 2003) intervention. Stirman and colleagues (2013) detailed a framework for intervention adaptation based on a review of 32 articles, specifying 12 ways that content modifications can occur: tailoring/tweaking/refining, adding elements, removing elements, shortening/condensing, lengthening/extending, substituting elements, re-ordering elements, integrating another approach into the intervention, integrating another intervention into the approach, repeating elements, and loosening structure. Our study used this framework to adapt REACH II for use in the Vietnamese community in Northern California (see Table 2).

Pilot studies are important to assess the feasibility of implementing a complex intervention such as a full-scale randomized trial (Craig et al., 2008). This pilot study used a single-arm, pretest-posttest design to examine the feasibility and acceptability of implementing the caregiver intervention. Although not a main objective, an exploratory aim was to assess preliminary efficacy on caregivers' AD knowledge and psychosocial outcomes. This study was approved by the University's Institutional Review Board and registered in [ClinicalTrials.gov](https://clinicaltrials.gov) (Study ID: NCT03218982).

Participants and Methods

Sample and Recruitment.

We began recruiting dementia caregivers in December 2016, approximately six months prior to starting the first intervention cohort. We partnered with local community organizations in Sacramento to place fliers at their agencies and to obtain referrals. In addition, recruitment was conducted at several community events, including the lunar new year festival, health fairs, and Vietnamese doctors' offices throughout the Sacramento area. Also, Vietnamese language media (e.g., newspapers, television, etc.) as well as traditional forms of American social media (e.g., Facebook, Youtube, Instagram, Yahoo) were used. To increase awareness of AD and recruit for our intervention, we conducted nutrition and brain health presentations at several community events.

Inclusion criteria.—Caregivers were eligible to participate if they a) self-reported as Vietnamese, b) were over age 21, c) provided hands-on care to a family member with AD or cognitive impairment related to AD, d) spoke Vietnamese or English, e) were physically able to participate, and f) expected to stay in the Sacramento area during the duration of the study. Caregivers could indicate they were the primary (provided the most hands-on care) or secondary caregiver (helped the primary caregiver). Although care recipients did not have to have an official diagnosis, caregivers had to report their family member had dementia or problems with memory loss. Additionally, care recipients' level of cognitive impairment was assessed by administering screening measures.

Exclusion criteria.—Caregivers were excluded if they were primary caregivers but not related to the care recipient.

Procedures.

Trained bilingual research assistants met with participants in their homes or at the community partner organization to conduct consent and baseline assessments of the psychosocial measures. These were mostly done in Vietnamese; however, a couple of caregivers preferred English versions of the assessments. In addition, a short caregiver appraisal was completed which asked about the care recipient's level of impairment and the most pressing need for the caregiver.

Our pilot intervention included three cohorts that went through the intervention approximately 6 months apart. The same interventionist, a Vietnamese bilingual licensed clinical social worker, facilitated all three cohorts. The first cohort consisted of five

caregivers, which included four primary caregivers and one secondary caregiver ($n = 5$). The second cohort consisted of two families with two primary caregivers and one secondary caregiver ($n = 3$); the third cohort had three primary caregivers ($n = 3$). This was done as a process to continue to adapt and refine the intervention protocol after each cohort. Sample demographics are reported in Table 3.

For all three cohorts, the intervention was held once a week at a local community center. Before each class, Vietnamese food was catered and caregivers, care recipients, and research staff all ate dinner together briefly; then caregivers separated to the intervention class. During each session, respite care for care recipients was provided by trained research assistants. Depending on the care recipients' severity of dementia, research staff provided socialization activities like singing Vietnamese songs, led light physical exercises, or played board games with care recipients during the two hours. Of the 11 caregivers, seven consistently brought their family members to respite care. The classes were divided into five main parts: checking in and caregivers sharing about how the week went (15–25 minutes), didactic information (30–40 minutes), caregiver responses to the information (30–40 minutes), stress management exercises (10 minutes), and goals for the week (10 minutes).

Post assessments were conducted about a week after the last session, and three months after the last session. We also used these opportunities to obtain feedback about the acceptability of and satisfaction with the intervention. Caregivers and care recipients were compensated with gift cards for their participation in the study.

Measures.

All assessments were completed in English or Vietnamese with trained research assistants at participants' homes or at a community partner organization. All English measures that had not been previously administered to Vietnamese populations were translated by the university's medical interpreting and translation services, and then checked for readability and clarity by the study's research team and community advisory board; these included the Quality of Life in Alzheimer's Disease (QOL-AD) measure (Logsdon, Gibbons, McCurry, & Teri, 2002); Informant Questionnaire on Cognitive Decline in the Elderly (Jorm & Jacomb, 1989; Jorm, 1994); the Alzheimer's Disease Knowledge Scale (AKDS) (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009), the Zarit Burden Inventory (Bedard et al., 2001), and the Caregiver Self-efficacy Scale (Fortinsky, Kercher, & Burant, 2002).

Feasibility and Acceptability.—Feasibility was assessed via standard criteria (Leon, Davis, & Kraemer, 2011), including the number of caregivers who were recruited, enrolled, and completed the intervention, as well as retention and inclusion of a secondary caregiver in the intervention. We also assessed the feasibility of the administration of study measures in terms of percent of baseline, post-intervention and 3-month assessments completed as well as homework compliance after each session. Acceptability was assessed via a short qualitative interview post-intervention.

Screening Measures.—Caregivers completed the IQCODE (Jorm, 1994) to report on their care recipients' level of cognitive functioning. The 16-item IQCODE asks caregivers to compare care recipients' current memory and cognitive abilities to 10 years prior. The scale

ranges from 1 (*Much improved*) to 5 (*Much worse*); scores are averaged, and higher scores indicate worse cognitive functioning. The original version of the IQCODE contains 26 items and has high test-retest reliability (Jorm & Jacomb, 1989). This shorter version shows similar reliability. Trained research staff administered the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005), a common measure of care recipients' global cognitive function. The total score is 30, and a score lower than 26 suggests cognitive impairment. The IQCODE and MoCA were both completed at baseline.

Caregiver measures.—The 13-item QOL-AD measure (Logsdon et al., 2002) assesses caregiver reports of care recipients' overall functioning. On a scale from 1 (*Poor*) to 4 (*Excellent*), caregivers rate their family member's physical and psychological health, as well as overall satisfaction with different aspects of their lives. Higher scores indicate better quality of life in family members. The same measure was administered to caregivers and care recipients by a trained staff member. However, upon administering the QOL-AD to care recipients, it was clear that the questionnaire was not understood by care recipients because their level of impairment, so only caregiver reports of quality of life were used. Reliability for the QOL-AD is high ($\alpha = .83 \sim .90$).

The ADKS (Carpenter et al., 2009) is a 30-item true/false scale assessing caregivers' knowledge of AD and dementia patients' behaviors, including risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment and management ($\alpha = .71$).

The Zarit Burden Interview short version (ZBI: Bedard et al., 2001) contains 12 items and assesses caregivers' levels of burden. Sample questions include, "Do you feel angry when you are around your relative?" and "Do you feel that your health has suffered because of your involvement with your relative?" Higher scores indicate more burden. Reliability for the short version is high ($\alpha = .92 \sim .97$).

The 10-item Perceived Stress Scale (PSS: Cohen, Kamarck, & Mermelstein, 1983) measures caregivers' stress levels within the past month on a scale from 0 (*Never*) to 4 (*Very often*). Sample questions include, "In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?" and "In the last month, how often have you been able to control irritations in your life?" Higher scores indicate more stress, $\alpha = 0.72$.

The 10-item Caregiver Self-Efficacy Scale (Fortinsky et al., 2002) assesses caregivers' ability and confidence in managing dementia. The two subscales include self-efficacy in symptom management (5 items; $\alpha = .77$) - "How certain are you right now that you can handle any problems that might come up in the future with your relative's care?" and self-efficacy in using community support services (4 items; $\alpha = .78$) - "How certain are you right now that you can get answers to all of your questions about these services?"

Data Analysis—Feasibility outcomes were summarized as frequencies and percentages, as well as via reading notes made by the interventionist after each session. Acceptability was assessed via short interviews with participants post-intervention and at 3-month follow-up. The lead author (OM) conducted multiple readings of the post-intervention short answers

from all participants to familiarize herself with the data. Notes were taken of answers that specifically addressed what participants enjoyed the most about the intervention and their recommendations for improving the intervention. These notes were reviewed with other members of the research team. Based on these discussions and using a consensus approach, data were compiled and included in the results. Nonparametric Wilcoxon signed ranks tests were conducted to assess the effect of the intervention on AD knowledge, stress, burden, self-efficacy, and future intention to seek services.

Results

Feasibility.

Figure 1 summarizes our recruitment and retention. Through outreach efforts, 87 total individuals were contacted and 32 (37%) were determined eligible. The majority came from our community partner agency ($n = 22$), the Lunar New Year festival ($n = 12$), community presentations ($n = 10$), and the remaining from referrals or word-of-mouth. Of the 32 who were eligible for the intervention, over half declined because they were too busy or changed their minds. Fourteen participants were consented and enrolled in the study, but only 11 attended the intervention. All 11 participants came to five of the six sessions. Ten of the caregivers completed all baseline, post-, and 3-month follow-up assessments; one caregiver's family member passed away soon after the last class, so she did not complete follow-up data. Only 2 of the 11 primary caregivers had a secondary caregiver join the intervention. Based on qualitative notes from the interventionist, the majority of the participants in Cohort 1 and 2 did not complete their homework. Thus, homework was not required in Cohort 3.

Acceptability.

Acceptability was measured based on a series of short answers post-intervention and at 3-month follow-up. Caregivers were queried about their experiences in the intervention – including what they found most and least helpful, and what they enjoyed the most and the least. Overall, participants provided positive feedback regarding the intervention and their experiences with research staff and the classes. All caregivers reported that they learned a great deal from the intervention, mentioning that the intervention was necessary, helpful, and “eye-opening.” Participants indicated that they gained more knowledge about AD and dementia and better understood their family members' behaviors, which reduced misunderstandings and improved communication. Caregivers described feeling more sympathy towards the care recipient and this helped them to be more patient. Over half of the participants appreciated the opportunity to connect with caregivers who were also Vietnamese and hear about others' challenges, as well as to share their experiences as a group. Other intervention components that participants reported to be helpful were the breathing exercises, information regarding community resources, respite care, and the “friendly research team”.

At the 3-month follow-up visit, several caregivers reported that their family member's symptoms had gotten worse, and that caregivers were experiencing more stress and exhaustion, getting less sleep, and wanting to cry more often. However, almost all caregivers reported that the information and support they received during the intervention were still

very helpful. Many caregivers reported still utilizing the stress management techniques that they learned. Furthermore, three of the care recipients expressed that they “had fun” and wanted to come back.

As part of acceptability as well as preparing for the randomized controlled trial, we obtained feedback and suggestions for improving the intervention. Some recommendations from the participants were: longer or more sessions, categorizing sessions by severity of AD, reducing time for sharing experiences and focusing on information about AD, and having a support group after the intervention. When participants were asked the question, “What would you say to other Vietnamese caregivers who wanted to know about this program?” specific examples of participants’ responses were, “I would highly recommend this program to Vietnamese caregivers”, and “They [other caregivers] will learn a lot; there’s no doubt.” Other descriptions of the intervention included, “necessary,” “informative,” and “important.”

Exploratory Outcomes.

Table 4 shows the pre-, post-, and three-month follow-up means and standard deviation outcomes from Wilcoxon signed ranks tests. Caregivers’ AD knowledge increased post-intervention (20.90 vs. 22.55, $p = .031$), as did self-efficacy in utilizing support services (2.82 vs. 6.00, $p = .004$). In addition, the intervention effect on self-efficacy was maintained at 3-month follow-up ($p = .004$). Although non-significant, results also showed increases in caregivers’ report of care recipients’ quality of life (1.95 vs. 2.05, $p = .42$) and caregiver self-efficacy in symptom management (5.48 vs. 6.53, $p = .06$), and decreases in caregiver burden (23.64 vs. 21.82, $p = .43$), stress (15.00 vs. 12.23, $p = .08$), and intention to use support services (4.09 vs. 3.77, $p = .19$).

Discussion

We had a priori hypotheses that the intervention and its components would be effective based on prior work with Vietnamese caregivers as well as other evidenced-based interventions that have been conducted with racial/ethnic minority and immigrant populations (Gitlin, Marx, Stanley, & Hodgson, 2015; Meyer et al., 2015; Parker, Mills, & Abbey, 2008). However, it was unclear whether Vietnamese American caregivers would participate in the intervention and furthermore, find it useful. Overall, the feasibility results are quite nuanced. We found that recruitment was challenging and resource-intensive. To illustrate, it took an average of 6–7 months outreaching in the community and advertising locally to recruit an average of 4 caregivers for each cohort.

This could be due to a variety of reasons. First, individuals had to know their family member had dementia or at the very least - problems with memory. Individuals who saw the recruitment announcement but did not realize or understand their family member had dementia may not have ever considered the intervention. In addition to the limited knowledge on AD and its symptoms (Meyer et al., 2015), other factors such as shame and stigma about dementia (Yeo, Tran, Hikoyeda, & Hinton, 2002), and a smaller number of Vietnamese in the Sacramento area also may have contributed to the recruitment challenges. Second, caregivers had to have the time and desire to commit to six class sessions. We found that this was challenging as 32 caregivers were initially interested but because of time

constraints, did not feel like they could participate. Less than half of this number actually participated in the intervention. Despite the fact that recruitment was challenging, retention in the class was 100%.

Once caregivers participated in the first class, they completed the intervention and found it useful and informative. Post-intervention and three-month follow up interviews with caregivers demonstrated how valuable caregivers felt the program was. Caregivers expressed how much more empathy they had towards their family member once they understood AD and its symptoms. They also found it encouraging and comforting to be in a supportive environment with other Vietnamese caregivers. The fact that the intervention provided caregivers with concrete strategies and solutions to problems they encountered during caregiving was helpful. One caregiver pointed out that joining an intervention focused on the caregivers as opposed to the person with dementia made him feel less isolated. Additionally, we found out that although the idea of having a secondary caregiver being involved in the intervention was important; it was practically challenging as only 2 of the 11 primary caregivers had a secondary caregiver accompany them to the intervention. These caregivers cited time constraints as a reason they were not able to participate. The intervention was very acceptable to the 11 caregivers who participated. They found it useful and informative, and highly recommended the program to others.

Although we were not powered to explore intervention effectiveness, exploratory analyses show significant increases in AD knowledge and self-efficacy of using support services for caregivers. Given the low knowledge of AD in the Vietnamese population, providing caregivers with a better understanding of AD gives them specific skills (e.g., using short simple sentences when communicating with the care recipient) and reduces stigma that current exists in many Asian American populations (Yeo et al., 2002). Self-efficacy is important because it is directly related to stress, burden, and depression in caregivers (Cheng, Lam, Kwok, Ng, & Fung, 2013; Mausbach et al., 2011). Ironically, although caregivers felt more efficacious and confident in being able to use support services post-intervention, caregivers also reported (although not significant) that they were less likely to use services post-intervention. This could be because they felt more confident in being able to take care of their loved one (self-efficacy in symptom management trended towards significance). In fact, the first cohort of caregivers met as a support group for months after the intervention was over. An absence of significant changes in stress and burden might be explained by the fact that the study did not actively recruit people who met criteria for high stress and burden at baseline, implying that perhaps there was less opportunity to change on these outcomes.

The study was not without its limitations. First, the sample size was small. Although the aim was to conduct a pilot trial to assess feasibility and acceptability, future studies need to include larger sample sizes and a control group to ensure greater statistical power and true intervention effects. Moreover, the intervention was limited to one geographic area, potentially limiting the generalizability of study findings. Although the main content of the intervention did not change among the cohorts, we included more information regarding local resources and legal and medical care for caregivers in the 2nd and 3rd cohort, which may have differentially affected the results. Also, only 2 of the 11 secondary caregivers

joined the intervention. Thus, we were not able to witness family dynamics in action, or assess whether empathy for one another increased after the intervention. The goal of having two caregivers was for everyone to be on the same page about dementia and caregiving responsibilities. In the future, we will still not require a secondary caregiver be involved in the intervention, but will find an alternative means of contacting the secondary caregiver to share the intervention content with them. Lastly, this was a multicomponent intervention and it isn't clear which component was the most effective or "drove" the intervention effects. However, we were able to partly address this through the post-intervention interviews, which suggested that education on AD was one of the most valuable components of the intervention.

Future Research Recommendations

Even though the intervention was successful in terms of increasing knowledge about AD and the confidence caregivers had in seeking help and support, there are opportunities to do things differently in the future randomized trial. For example, it would be important to have the Vietnamese community in general be more aware of and knowledgeable about brain health and AD. Although we attempted to do this through our brain health presentations, many local faith-based institutions would not allow us the time to do 20-minute presentations. Spending more time on the radio or television might be helpful in empowering the community and helping them to be ready for intervention studies (Love & Tanjasiri, 2012). Additionally, a future trial may offer caregivers the option of participating in an abbreviated version of the intervention. One caregiver mentioned that he initially did not want to participate because the idea of a six-week long commitment was too much for him. However, after the first class, he knew he had made the right decision to join the intervention. This caregiver suggested giving people the option of a shorter intervention, with the possibility of increasing the length of the intervention after the first or second class, when people were already engaged, invested, and had experienced the benefits of the class. Lastly, we also learned that over half of the people ineligible for the intervention were interested in brain health information and/or had concerns about their own cognition. However, they were not caregivers. In the future, this speaks to the need for education and providing services to the Vietnamese community who want to know about their own cognitive aging, but lack the resources and access to services needed.

Our intervention fills a gap in the current caregiving literature by involving a group that has been woefully under engaged in aging and dementia research. This pilot study involved a systematic, theory-driven, iterative process of culturally adapting a dementia caregiver intervention while engaging community partners. It represents an important contribution to the literature since it proves that it is feasible to implement a 6-week intervention with monolingual Vietnamese caregivers and their family members. In doing so, we provide preliminary evidence that a culturally sensitive intervention can help Vietnamese families caring for a family member with AD.

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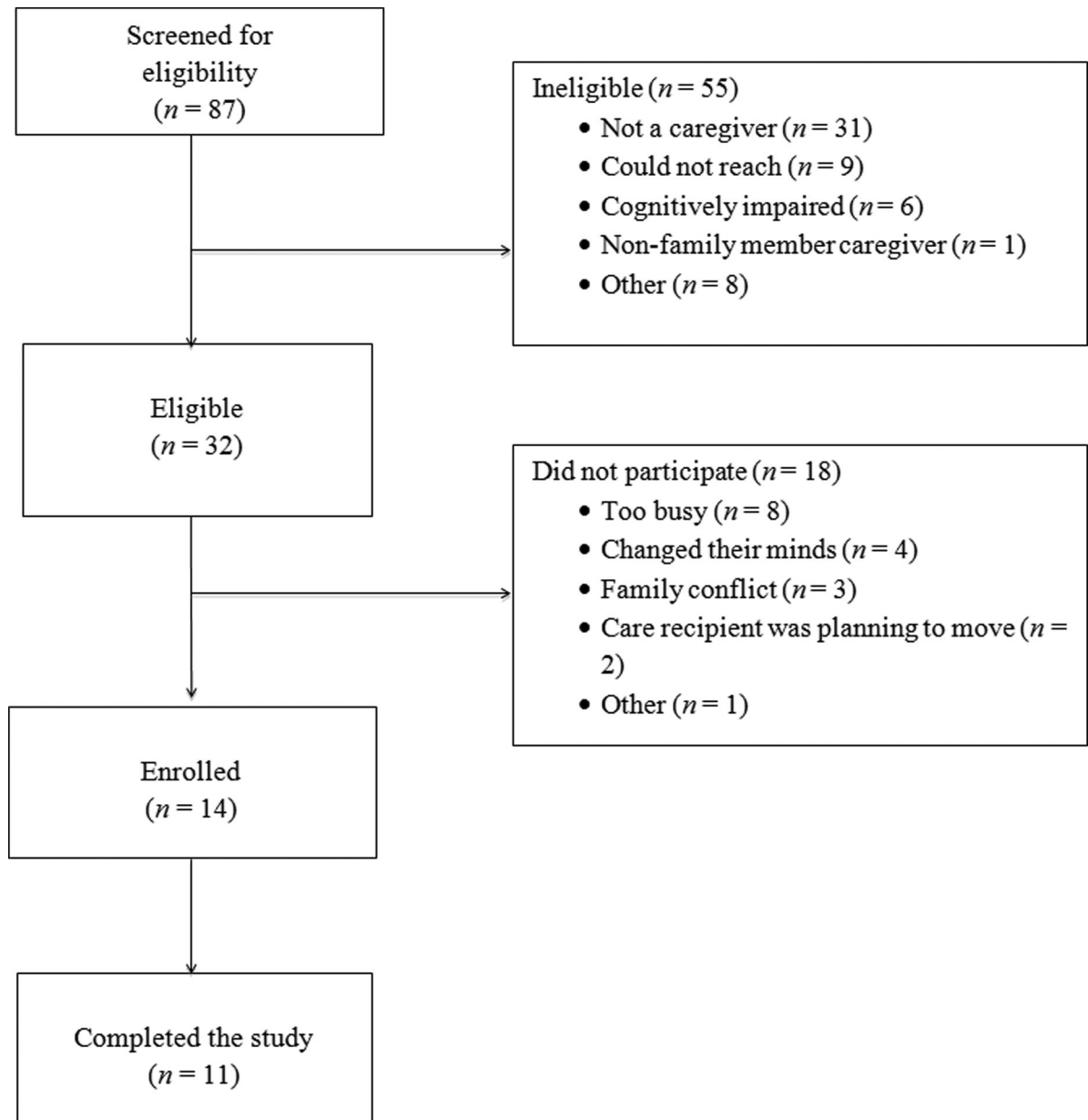


Figure 1.
Recruitment flow chart

Table 1.

Intervention description

Session	Elements	Content
1	<p>Introduction Education about dementia Effects of caregiving stress Signal Breath activity Caregiver Notebook Caregivers' input</p>	<ul style="list-style-type: none"> • Introduce participants and staff • Introduce program purpose and timeline • Provide background on dementia and Alzheimer's disease • Discuss effects of stress and stress-reduction techniques • Introduce Signal Breath technique • Introduce the Caregiver Notebook which contains specific dementia problem behaviors and coping strategies • Obtain caregivers' input on the order of sessions
2	<p>Debrief Additional education about dementia Behavior problems associated with dementia Community Resources Stages of Alzheimer's disease Signal Breath activity</p>	<ul style="list-style-type: none"> • Participants discuss progress/changes since last session • Provide additional information on dementia and Alzheimer's disease • Discuss behavior problems among participants • Provide solutions and strategies to minimize behavior/issue • Provide respite care options and other community resources • Review stages of Alzheimer's disease and strategies for each stage • Participants practice signal breath exercise
3	<p>Debrief Additional education about dementia Culture and dementia Stress Management Seeking formal and informal support Breathing meditation or stretching exercise</p>	<ul style="list-style-type: none"> • Participants discuss progress/changes since last session • Provide additional information on dementia and Alzheimer's disease • Discuss acculturation and how Vietnamese cultural beliefs can influence participants' understandings of dementia • Discuss physical, psychological, and social effects of stress • Identify family members, friends, social services, or support groups for emotional support and assistance with caregiving • Introduce breathing meditation
4	<p>Debrief Pleasant events for care recipients Pleasant activities for caregivers Breathing meditation or stretching exercise</p>	<ul style="list-style-type: none"> • Participants discuss progress/changes since last session • Identify activities that care recipients enjoy • Identify activities participants enjoy doing and managing self-care • Participants practice breathing meditation or stretching exercise
5	<p>Navigating care/healthcare decision Breathing meditation</p>	<ul style="list-style-type: none"> • Communicate with healthcare provider about major problems/concerns • Discuss legal issues (e.g. advanced directives, power of attorney, etc.)

Session	Elements	Content
6	Review sessions Support group Breathing meditation or stretching exercise	<ul style="list-style-type: none"> • Participants practice breathing meditation
		<ul style="list-style-type: none"> • Review material from previous sessions • Arrange support group for participants following the intervention's end • Participants practice breathing meditation or stretching exercise

Note. A version of this table was previously published in (Meyer et al., 2018).

Table 2.

Content Modifications from REACH II

Tailoring	<ul style="list-style-type: none"> Delivered all materials in Vietnamese language instead of English Delivered intervention in a group format instead of one-on-one sessions Changed the delivery format to all in-person sessions at a community center from phone and in-home sessions Tailored the pleasant activities module by prompting caregivers to reflect and try pleasant activities that they enjoy doing with their care recipients and alone, while caregivers in REACH II were prompted to only reflect and try pleasant activities that they enjoy doing alone
Adding elements	<ul style="list-style-type: none"> Meditative breathing component in addition to the signal breath activity under the stress management module Discussion of differences in cultural beliefs about dementia Provided information on culturally appropriate resources in the community Education and assistance on navigating the healthcare system, health care decisions, and the legal system
Removing elements	<ul style="list-style-type: none"> Music in stress management module Mood management module Online social support group
Shortening	<ul style="list-style-type: none"> Shortened the overall intervention to six sessions from 12 sessions Shortened the problem behaviors activities
Lengthening	<ul style="list-style-type: none"> Extended the education related to dementia, Alzheimer's disease, and dementia caregiving Extended the education on the effects of stress on physical and psychological well-being
Re-ordering elements	<ul style="list-style-type: none"> Re-ordered the delivery of most content, except for introducing The Caregiver Notebook during the first session Sought the perspective of caregivers regarding the order of the sessions
Loosening structure	<ul style="list-style-type: none"> Loosened and shortened the check-in and closure formats of each session

Table 3.Sample demographics at baseline ($N = 11$)

Variable	<i>n</i>
Caregiver	
Female Gender	9
Mean Age (<i>SD</i>); range: 50–74	60.91 (9.31)
Marital Status	
Married	11
Mean Education in Years (<i>SD</i>); range: 6–18	14 (3.74)
Mean Years of Caregiving (<i>SD</i>); range: 1–14	6.14 (4.27)
Relationship to Care Recipient	
Spouse	63 (100%)
Child/Child's Spouse	30 (0%)
Sibling	10 (0%)
Friend	10 (0%)
Care Recipient	
Female Gender	5
Mean Age (<i>SD</i>); range: 52–85	74.64 (10.54)

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Table 4.Means (*M*) and standard deviations (*SD*) of outcome data (*N*=11)

	<i>Baseline</i>		<i>Post-Assessment</i>		<i>3-Month Follow-Up</i>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Caregivers						
Burden	23.64	9.88	21.82	8.76	18.90	12.39
Self-efficacy						
Symptom management	5.48	2.24	6.53	1.69	6.22	1.14
Support services	2.82*	1.65	6.00*	1.75	6.18*	1.52
Knowledge of Alzheimer's disease	20.90*	2.42	22.55*	2.07	22.20	2.57
Perceived stress	15.00	5.98	12.23	6.86	13.10	5.88
Intention to use services	4.09	.45	3.77	.56	3.48	.47
Care recipients						
Quality of life	1.95	.45	2.05	.48	2.11	.29
MOCA	8.0	4.90				
IQCODE	4.60	.49				

* $p < .05$. One caregiver missed follow-up data. Only 7 care recipients had MoCA scores.