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Featured Article

Promising results from a pilot study to reduce distress in Vietnamese American dementia and memory loss caregivers

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Abstract

Introduction: This study developed and examined the feasibility of a culturally tailored, evidencebased skill-building program to reduce stress and depression of Vietnamese American dementia caregivers.

Methods: This pilot randomized controlled trial included pretest and posttest measures using the Center for Epidemiologic Studies-Depression Scale and the Revised Memory and Behavior Problems Checklist. The intervention (n = 30) group participated in a culturally tailored, 4-week Vietnamese-language cognitive-behavioral skills evidenced-based program (Our Family Journey); caregivers in the control condition (n = 30) received dementia-related educational materials (education control condition).

Results: Our Family Journey caregivers showed significantly lower somatic scores on the Center for Epidemiologic Studies-Depression Scale and reported lower frequency of care recipients' disruptive behaviors. However, they also reported being more stressed by their care recipients' depressive symptoms on the Revised Memory and Behavior Problems Checklist compared to caregivers in the education control condition.

Discussion: These promising results suggest that a culturally adapted program can benefit Vietnamese dementia caregivers. Additional research is needed to develop and evaluate stronger, more impactful interventions for this underserved group.

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Keywords: Vietnamese; Dementia caregiving; Caregiver intervention; Health disparities; Mental health

1. Introduction

In 2015, more than 15 million family members and other unpaid caregivers (CGs) provided care to persons suffering from Alzheimer's disease (AD) and other dementias [1]. "Caregiving" is caring for a loved one's health needs above and beyond what is typical in the family. It generally includes assistance with one or more activities of daily living (e.g., bathing) and instrumental activities of daily living (e.g., paying bills) [1]. Most dementia CGs are unpaid family members/friends/other loved ones [1]. Compared with non-CGs, the adverse mental health (MH) consequences of caregiving include higher rates of depression, stress, and other MH problems [2–4].

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Little is known about dementia and caregiving among Vietnamese Americans, a relatively recent immigrant group [5] with lower English proficiency and educational attainment compared with other U.S. populations [6]. Asian Americans in general tend to underutilize MH services despite the demonstrated need [7] (e.g., Vietnamese Americans have high rates of MH problems such as posttraumatic stress disorder [8,9].

Vietnamese Americans' experience with war-related trauma and other refugee-related barriers (e.g., low socioeconomic position) compound their MH risk as CGs [10,11]. Caregiving for a person with dementia is expected—rooted in long-held cultural beliefs and practices such as Confucianism and Buddhism that are still important today. Filial piety and normalization of memory loss in old age are also very common [11,12]. Lack of extended family members in the United States to help care for a person with dementia puts even greater stress on Vietnamese American CGs [12]. These factors may cause Vietnamese American CGs to be reluctant to use formal support or long-term care, consequently affecting their health [10].

Research has indicated the appropriateness and effectiveness of cognitive-behavioral therapies and principles for Asian Americans [13], but work with Vietnamese American dementia CGs have not yet been carried out. This study sought to address this gap. We first culturally tailored the program by Gallagher-Thompson et al. [14] (see Methods for program description) by interviewing MH professionals who worked directly with Vietnamese Americans [11]. Then, we conducted a pilot study to examine the feasibility of a culturally tailored, evidence-based skill-building program to reduce stress and depression for Vietnamese American dementia CGs. "A pilot study can be used to evaluate the feasibility of recruitment, randomization, retention, assessment procedures, new methods, and implementation of the novel intervention" [15]. We hypothesized that CGs in the intervention will (1) show greater reduction in depressive symptoms and (2) greater reduction in CG-related burden compared to CGs in the control condition. To our knowledge, this is the first pilot study of an evidence-based dementia caregiving program that was adapted for use with Vietnamese Americans. At the time of the study's inception, we were unaware of systematic efforts from local or national service agencies to engage Vietnamese American dementia CGs. Three of the authors are Vietnamese professionals who do research, provide clinical services, and social services to the Vietnamese American community; they expressed a need for this kind of program and provided considerable support throughout its development and implementation. Moreover, there are no systematic data at a national level reporting the use of services provided by this group nor on the number of older Vietnamese persons who seek or obtain dementia diagnoses.

2. Methods

2.1. Study design and procedures

This study was a pilot randomized controlled trial with 60 CGs, including 30 in each of the intervention (Our Family Journey [OFJ]) and control (educational control condition [ECC]) conditions. Participants learned about the study through Vietnamese media (33.9%), community organizations (27.4%), word of mouth (19.4%), social services agency (5%), providers (5%), and unknown (9%). Trained bilingual/bicultural Vietnamese staff screened potential participants to determine their eligibility. Inclusion criteria were as follows: (1) self-identified as Vietnamese American; (2) were able to read, write, and speak Vietnamese and/or English; (3) \geq 18 years old; (4) were CGs for a family member/loved one with dementia/neurocognitive disorder for >6 months; (5) provided care for >12 hours/week at the time of screening; (6) were screened positive for depression/stress; (7) agreed to random assignment to conditions; and (8) resided in the San Francisco Bay Area. This region, which includes San Jose (the city with the largest Vietnamese American population), is home to an estimated 200,000 Vietnamese [5].

A total of 112 interested persons contacted the research staff including 88 individuals who were eligible to participate. Of these 88 individuals, 28 did not participate due to the following reasons: were unable to be contacted (15); felt "too stressed" to participate (7); because of a family conflict (i.e., did not want them to talk about their CR having dementia) (2); could not drive to the sessions (2); their CR passed away (1); or they moved out of the area (1). The remaining 60 eligible participants signed a written informed consent and completed their preassessment during a home visit or at a community center or library. This took 45-60 minutes for the participants to complete. Enrolled CGs were then randomly assigned to either OFJ or ECC. We used a sealed envelope system and the Efron biased coin process for randomization [16]. Each participant received \$100 for his or her participation that was paid at the end of postassessment, which occurred for an average of 3 months after study enrollment. The total recruitment period was 18 months, although about 12 months were "active recruitment" since recruitment efforts halted due to holidays (e.g., Lunar New Year; Christmas) and the Principal Investigator transitioning to a new institution.

2.2. Active intervention condition: Psychoeducational cognitive-behavioral intervention

The intervention was based on Gallagher-Thompson and colleagues' In-Home Behavioral Management Program [14] which had six components: (1) education on dementia and caregiving stress/appraisal/coping; (2) techniques for

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managing troublesome/disruptive behaviors of the care recipient (CR); (3) how to deal with one's own negative feelings/thoughts associated with caregiving; (4) skills to improve communication with other family members and healthcare professionals; (5) behavioral activation techniques to increase pleasurable events in daily lives of CG/ CR; and (6) end-of-life issues. Based on the findings from a qualitative study with Vietnamese MH professionals [11] and input from various community partners, this program was modified to be culturally appropriate for Vietnamese Americans (e.g., examples of pleasant activities included cooking Vietnamese food and singing karaoke). Some content was condensed to be able to offer it in four weekly sessions, with each session lasting two hours. This duration was expected to yield optimal attendance according to a qualitative study with Vietnamese American mental health professionals [11]. Other cultural adaptations included using the Vietnamese language for the intervention delivery and educational materials; adapting the concept of "self-care" to emphasize that by allowing the CG to care for oneself, the CG would, in turn, better be able to care for the CR; and having the focal point of the discussions be on the family unit as well as discussing the roles of filial piety and stigma related to dementia and help seeking. Research staff also developed four brief YouTube videos in Vietnamese with English subtitles to correspond each of the four sessions of the intervention. These videos were intended to supplement the information taught in and were shown in each session to enhance learning.

CGs assigned to the intervention condition participated in four weekly face-to-face sessions in small groups ("cohorts") that were conducted in Vietnamese at a local community organization. Each session lasted approximately 120 minutes. "Action plans" (home practice) were assigned at each session, and a colorful, easy to read workbook encouraged active practice of techniques between sessions that were culturally tailored for this population. On average, postassessment was conducted about 3 months after project enrollment (mean = 96.0 days; standard deviation [SD] = 46.1 days). Although the active intervention was conducted for only 4 weeks, scheduling challenges were common such that the group meetings were not always done in four consecutive weeks. In addition, arranging for in-person interviews at the conclusion of the program (for both OFJ and the ECC) also required flexibility with regard to scheduling. These kinds of issues are commonly experienced in CG intervention research as in the Chinese dementia CG study [14]. See the study by Zarit and Femia [17] for review of this and related methodological issues.

2.3. Control condition—ECC

Educational materials on dementia consisted of Vietnamese and English materials available from the Alzheimer's Association's website [18] including (1) basics of AD—the diagnosis, stages of the disease, what to expect, current treatments, and how your local Alzheimer's Association can help you and your family; (2) safety issues/tips; (3) symptoms of CG stress and ways to be a healthy CG. All materials were provided after the pretests were conducted. CGs in this condition also received information about local resources for AD and MH. On average, postassessment was conducted about 3 months after project enrollment (mean = 85.2 days; SD = 51.2 days).

2.4. Measures

2.4.1. Screening

CGs were screened for depression using the Vietnamese version of the Patient Health Questionnaire-9, which has good reliability and validity [19] and "good convergent validity, good external construct validity, and excellent reliability" with Vietnamese [20]. With a possible score of 0-27, a score of 5 was used as a cutoff score to indicate mild depression. Six questions determined CG stress based on screening used in the Resources for Enhancing Alzheimer's Caregiver Health II, which is a validated CG intervention for other populations [21]. The first four "yes/no" questions asked the CGs about whether they (1) felt overwhelmed; (2) had crying spells or felt like s/he often needed to cry; (3) been angry/frustrated as a result of caregiving; or (4) felt cutoff from family/friends. Question 5 asked them to rate their current level of stress on a 1-10 scale (score of ≥ 6 is a positive response). Question 6 asked them to rate their current health now compared to last year ("better, the same or worse") with a rating of worse categorized as a positive response. To qualify for the study, the CG had to have two or more positive responses [22]. These screening questions were not used as baseline data as there were separate measures for these.

For CGs who were unsure about whether their CRs were suffering from memory loss, the Montreal Cognitive Assessment (MoCA) was administered after obtaining informed consent/assent from the CR/CG. The MoCA is recommended for use with Vietnamese Americans [23] and is a 10minute cognitive screening test with good reliability [24] and translated into Vietnamese [25]. All seven CRs who had the MoCA administered were assessed to be positive for memory loss. Five were randomly assigned to the intervention and two to the control arm.

2.4.2. Sociodemographic questionnaire

It included questions on factors such as gender, age, marital status, education, employment, household income, relationship to CR, living arrangement with CR, and religion.

2.4.3. Primary outcomes

The primary outcomes are as follows: (1) reduction in depressive symptoms (Center for Epidemiologic Studies-Depression Scale [CES-D]); (2) reduction in caregiving-related stress (Revised Memory and Behavior Problems Checklist [RMBPC]). In CG research, the most widely

Table 1 Sociodemographic characteristics of Vietnamese dementia caregivers (n = 60)

Characteristics	Total, N (%)	Intervention, n (%)	Control, n (%)	P value
Gender				1.000
Female	52 (86.7)	26 (86.7)	26 (86.7)	
Male	8 (13.3)	4 (13.3)	4 (13.3)	
Age at recruitment*				.193
Year, SD	57.1, 11.1	58.7, 10.5	55.5, 11.7	
Range (min-max)	(35-81)	(36-76)	(35-81)	
Marital status*				.744
Single/never married	6 (10.2)	3 (10.3)	3 (10.0)	
Married/living together	43 (72.9)	20 (69.0)	23 (76.7)	
Separated/divorced/widowed	10 (16.9)	6 (20.7)	4 (13.3)	
Educational status				.492
Less than high school	15 (25.0)	7 (23.3)	8 (26.6)	
High school diploma/Graduate	14 (23.3)	9 (30.0)	5 (16.7)	
Equivalency Degree				
Some college	7 (11.7)	2 (6.7)	5 (16.7)	
College or higher	24 (40.0)	12 (40.0)	12 (40.0)	
Employment status				.015
Full time	14 (23.3)	2 (6.7)	12 (40.0)	
Part time	13 (21.7)	7 (23.3)	6 (20.0)	
Leave of absence/not employed	22 (36.7)	13 (43.3)	9 (30.0)	
Retired	11 (18.3)	8 (26.7)	3 (10.0)	
Caregiver's household income				.041
Less than \$12,000	9 (15.0)	8 (26.7)	1 (3.3)	
\$12,000 or more	28 (46.7)	12 (40.0)	16 (53.3)	
Missing or declined to state	23 (38.3)	10 (33.3)	13 (43.3)	
Relationship to care recipient*, [†]				.095
Spouse/parent	15 (27.3)	6 (22.2)	9 (32.1)	
Children	30 (54.5)	13 (48.2)	17 (60.7)	
Relative/other	10 (18.2)	8 (29.6)	2 (7.2)	
Living with care recipient				
Yes	38 (63.3)	21 (70.0)	17 (56.7)	.284
No	22 (36.7)	9 (30.0)	13 (43.3)	
Being a member of a formal religion				.519
Yes	48 (80.0)	23 (76.7)	25 (83.3)	
No	12 (20.0)	7 (23.3)	5 (16.7)	

*Missing data.

[†]Six caregivers took care of more than 1 care recipient.

used assessment tool for depressive symptoms is the CES-D [21]. It is a 20-item scale that assesses the presence of depressive symptoms in the past week [26]. Scores range from 0 to 60. Each item is scored 0 (rarely/none of the time), 1 (some/little of the time), 2 (occasionally or a moderate amount of time), or 3 (all of the time) based on the frequency of occurrence. A total score of 16 or greater was used for positive identification of depression status (depression) [27,28]. The CES-D was validated in Vietnamese [29]. It had good internal consistency in the current sample (Cronbach $\alpha = 0.91$), which is comparable to what was reported in its original form (Cronbach $\alpha = 0.85$) [28] and with Chinese dementia CGs (Cronbach $\alpha = 0.93$) [30]. The CES-D domains were also examined: Depressed Affect, Somatic, Positive Affect, and Interpersonal Problems.

To evaluate reduction in CG-related stress/burden, we used the Conditional Bother Subscale from the RMBPC [31]. This measure contains 24 items describing possible troublesome behaviors that the CR might engage in (e.g., losing things). CGs were asked whether each behavior

occurred in the past month (frequency), and if so, to rate on a 5-point scale ("not at all" to "extremely") how much this "bothered or upset" the CGs (reaction). A measure of objective burden was obtained by totaling the number of behaviors reported (frequency). A measure of subjective or CG-related stress was obtained by assessing the degree of upset caused by these behaviors (reaction). The RMBPC domains (items/questions) were memory problems, depression/affective distress, and behavioral problems. The Conditional Bother Subscale had high internal consistency (Cronbach $\alpha = 0.94$), which is similar to what was reported with Chinese dementia CGs (Cronbach $\alpha = 0.93$) [14].

2.5. Translation process and validity

The World Health Organization's process of translation and adaptation of instruments [32] was used to guide the translations of the materials not already available in Vietnamese to attain "conceptually equivalent" Vietnamese language versions of the English materials that were translated

Table 2 Mean within-group differences in CES-D pretest and posttest scores

Statement	Intervention (mean, SD)				Control (mean, SD)			
	Pretest	Posttest	Difference	Effect size	Pretest	Posttest	Difference	Effect size
Total	20.5, 11.9	13.5, 10.4	-7.0, 13.7*	-0.51	18.4, 11.9	16.5, 10.7	-1.9, 10.9	-0.17
Depressed affect	2.1, 2.1	1.4, 1.5	-0.7, 2.4	-0.29	1.8, 2.2	1.3, 1.7	-0.6, 2.0	-0.30
Somatic	4.4, 2.4	2.9, 2.2	-1.5, 2.9*	-0.52	4.1, 2.6	4.2, 2.6	0.1, 2.7	0.04
Positive affect	6.7, 4.1	8.2, 3.4	1.5, 4.5	-0.33	7.0, 3.4	7.0, 3.0	0.1, 4.1	0.02
Interpersonal problems	0.7, 1.1	0.6, 1.2	-0.1, 1.2	-0.08	0.8, 1.4	0.4, 0.8	-0.4, 1.6	-0.25

NOTE. Effect size equation: Cohen's d= (Mean Control-Mean Intervention)/SD Pooled.

Abbreviations: CES-D, Center for Epidemiologic Studies Depression Scale; SD, standard deviation.

*P < .01.

to be cross-cultural and conceptual rather than to be linguistically/literally equivalent [32]. The cultural adaptation procedures began with forward translation, where a Vietnamese bilingual staff performed the translations from English to Vietnamese emphasizing conceptual (vs. literal) translations that are culturally appropriate for the lay community. Then, another Vietnamese bilingual staff and a Vietnamese bilingual social worker examined the forward translation for any inadequate expressions and concepts of the translation and then discussed and resolved any identified discrepancies. Next, another bilingual staff member conducted the back translation: a different person translated the Vietnamese translated materials back to English, with special attention to any words or phrases that do not fully capture the original concept. The final version of the translated materials is the product of all the previous iterations.

2.6. Data analysis

Internal consistencies (Cronbach α 's) were calculated to measure reliability of the CES-D and RMBPC. Descriptive analyses examined the distribution, central tendency, and the dispersion of each variable. With this small sample size, Fisher's exacts test was used to examine the differences among categorical groups. T-tests were applied to examine the differences between pretest and posttest CES-D and RMBPC scores in the study conditions. Since effect size is independent of sample size, we calculated Cohen's d as a standardized score of the mean difference within- and between-subjects analysis [33]. We also calculated bootstrap confidence intervals for Cohen's d as the variable of interest did not have a normal distribution. Each CG was treated as one unit of analysis, regardless of whether they took care of more than one CR. For the RMBPC, the CG responded to only the primary CR. Statistical analyses were performed using STATA, version 15.1 [34].

2.7. Human subjects protection

Institutional review board approvals were obtained from the University of California at San Francisco (#17-22286) and San Jose State University (#F16118).

3. Results

Sample characteristics are presented in Table 1. Most were females (86.7%) and married/living with a partner (72.9%), two of five had a college education (40%), and the majority reported being a member of a formal religion (80%). Average age of the CGs at the time of recruitment was 57.1 years (SD: 11.1 years) with a range of 35-81 years. More than half were caring for parents (54.5%), while 27.3% cared for their spouses/child, and the remaining cared for another relative/loved one (18.2%). Nearly two-thirds lived with their CRs. There were more intervention participants who were retired (vs. controls); and, more controls who were working full time (vs. intervention). There were more intervention participants (vs. controls) who had a household income less than \$12,000/year.

3.1. Findings

Table 2 shows the CES-D pretest and posttest scores within each group. In the intervention (OFJ) group, there was a significant difference in posttest CES-D total mean score (13.5, SD = 10.4) when compared to their mean score at pretest (20.5, SD = 11.9) (P < .01). In addition, the posttest somatic score (2.9, SD = 2.2) was significantly different from the pretest mean score (4.4, SD = 2.4) (P < .01) for this group. In the ECC, there were no significant within-group differences in either total mean CES-D score or scores on the four domains from preintervention to postintervention.

Table 3 shows the RMBPC frequency and reaction pretest and posttest scores within each group. For the OFJ CGs, there was a significant within-group difference in the overall mean frequency of problem behaviors reported from pretest (12.9, SD = 4.5) to posttest (10.9, SD = 4.2) (P < .01). No significant difference was observed for the ECC on this dimension. For the ECC, there was a significant withingroup difference in the mean disruption (total RMBPC reaction/bother) score from pretest (0.54, SD = 0.30) to posttest (0.43, SD = 0.24) (P < .01), but that difference was not observed in OFJ. In short, overall objective burden of care was significantly less after intervention for those in OFJ, whereas overall subjective burden or distress caused by

Statement	Intervention (mean, SD)				Control (mean, SD)				
	Pretest	Posttest	Difference	Effect size	Pretest	Posttest	Difference	Effect size	
Frequency scoring									
Total	12.9, 4.5	10.9, 4.2	-2.0, 3.8*	-0.53	10.7, 6.0	9.9, 5.6	-0.8, 3.6	-0.22	
Memory	5.9, 1.2	5.2, 1.8	-0.6, 2.0	-0.30	4.8, 2.0	4.9, 2.0	0.1, 2.0	0.05	
Depression	3.7, 2.7	3.7, 2.9	0, 2.0	0	3.4, 2.8	2.7, 2.5	$-0.7, 1.8^{\dagger}$	-0.39	
Disruption	3.4, 2.2	2.0, 1.6	-1.4, 2.1*	-0.67	2.5, 2.2	2.3, 2.2	-0.2, 1.8	-0.11	
Reaction scoring									
Total	0.58, 0.21	0.55, 0.40	-0.04, 0.38	-0.11	0.54, 0.30	0.43, 0.24	$-0.10, 0.21^{\dagger}$	-0.48	
Memory	1.18, 1.04	1.17, 0.78	-0.02, 1.08	-0.02	1.30, 1.37	0.88, 0.48	-0.42, 1.40	-0.30	
Depression	0.44, 0.33	0.56, 0.73	0.11, 0.68	0.16	0.48, 0.42	0.31, 0.29	$-0.17, 0.35^{\dagger}$	-0.49	
Disruption	0.45, 0.28	0.29, 0.32	-0.16, 0.31*	-0.52	0.33, 0.28	0.29, 0.28	-0.04, 0.23	-0.17	

Table 3	
Differences in RMBPC mean frequency and reaction pretest and posttest scores.	within groups (intervention and control)

NOTE. RMBPC domains (items/questions): memory (1, 2, 3, 4, 5, 6, 7); depression (12, 14, 17, 18, 19, 20, 21, 22, 23); disruption (8, 9, 10, 11, 13, 15, 16, 24). Effect size equation: Cohen's d= (Mean _{Control}-Mean _{Intervention})/SD _{Pooled}.

Abbreviations: RMBPC, Revised Memory and Behavior Problems Checklist; SD, standard deviation.

*P < .01.

 $^{\dagger}P < .05.$

this set of problems was significantly less after intervention for those in ECC.

Given the pilot nature of this study, we further explored the data by examining differences on the three subscales within RMBPC. On the difficult behaviors subscale, we found a significant within-group difference in mean frequency from pretest (3.4, SD = 2.2) to posttest (2.0, SD = 1.6) (P < .01) and mean reaction from pretest (0.45, SD = 0.28) to posttest (0.29, SD = 0.32) (P < .01) in the OFJ group but no significant differences on that subscale in the ECC. In contrast, for the ECC, there was a significant within-group difference in the mean frequency from pretest (3.4, SD = 2.8) to posttest (2.7, SD = 2.5) (P < .05) and mean disruption from pretest (0.48, SD = 0.48) to posttest (0.31, SD = 0.29) (P < .05) for the depression RMBPC score; that finding was not present for those in OFJ. Finally, there were no significant within-group differences in the mean frequency and reaction for the memory subscale from pretest to posttest in either of the two intervention conditions.

Table 4 shows the pretest and posttest CES-D and RMBPC mean differences between the intervention and control groups. There were no significant differences between the two groups on total scores for these measures, though inspection of the data shows that posttest scores were lower that those of pretest. Since this is a pilot study, we next explored the four domain subscales and found a significant difference between the two groups on the somatic domain only (P < .05). The effect size (Cohen's d) was 0.59 (95% confidence interval [CI]: 0.07, 1.10). The

Table 4

CES-D and RMBPC (frequency and reaction) mean differences in pretest and posttest scores between intervention and control groups

Caregiver depressive symptoms (CES-D) & stress/burden (RMBPC)	Intervention delta* mean, SD	Control delta* mean, SD	Diff	P value	Effect size, 95% CI	Bootstrap result of 95% CI
CES-D						
Total CES-D	-7.0, 13.7	-1.90, 10.87	5.1	.116	0.41 (-0.10, 0.92)	(-0.10, 0.92)
Depressed affect	-0.73, 2.44	-0.56, 2.04	0.16	.776	0.07 (-0.43, 0.58)	(-0.40, 0.55)
Somatic	-1.53, 2.89	0.10, 2.67	1.63	.027	0.59 (.07, 1.10)	(0.06, 1.12)
Positive affect	1.46, 4.51	0.06, 4.11	-1.40	.214	-0.32 (-0.83, 0.19)	(-0.84, 0.19)
Interpersonal problems	-0.10, 1.24	-0.36, 1.58	-0.27	.471	-0.19 (-0.69, .32)	(-0.69, 0.32)
RMB frequency						
Total RMB	-2.0, 3.81	-0.83, 3.62	1.17	.229	0.31 (-0.20, 0.82)	(-0.24, 0.87)
Memory	-0.63, 0.36	0.07, 1.96	0.7	.174	0.36 (-0.16, 0.86)	(-0.13, 0.84)
Depression	0, 2.03	-0.73, 1.84	-0.73	.148	-0.38(-0.89, 0.13)	(-0.87, 0.12)
Disruption	-1.37, 2.09	-0.17, 1.78	1.2	.020	0.62 (0.10, 1.13)	(0.11, 1.13)
RMB reaction						
Total RMB	-0.04, 0.38	-0.10, 0.21	-0.07	.413	-0.21 (-0.72 , 0.30)	(-0.68, 0.26)
Memory	-0.02, 1.08	-0.42, 1.39	-0.41	.211	-0.33 (-0.83, 0.18)	(-0.80, 0.15)
Depression	0.12, 0.68	-0.17, 0.35	-0.29	.042	-0.54 (-1.05, -0.02)	(-0.90, -0.17)
Disruption	-0.16, 0.31	-0.04, 0.23	0.12	.098	0.43(-0.08, 0.94)	(-0.07, 0.94)

NOTE. Effect size equation: Cohen's d= (Mean Control-Mean Intervention)/SD Pooled.

Abbreviations: CES-D, Center for Epidemiologic Studies-Depression Scale; CI, confidence interval; SD, standard deviation; RMBPC, Revised Memory and Behavior Problems Checklist.

*Delta = Posttest score–Pretest score.

bootstraps estimate of the 95% CI for Cohen's d was .06 to 1.12 which was slightly wider than earlier estimate based on the noncentral t-distribution.

Turning again to RMBPC subscales, we found a significant difference in the frequency score for behavior problems between the two groups with the effect size (Cohen's d) being 0.62 (95% CI: 0.10, 1.13). The bootstraps estimate of the 95% CI for Cohen's d was 0.11 to 1.13. In addition, there was a statistically significant difference between the two groups on reaction score of the depression subscale with the effect size (Cohen's d) being -0.54 (95% CI: -1.05, -0.02). In addition, the bootstraps estimate of the 95% CI for Cohen's d was -0.90 to -0.17.

4. Discussion

Results of this exploratory pilot randomized controlled trial study indicate that the OFJ program had several significant impacts on the mental health of CGs who participated. There were (1) significant between-group differences in some CES-D and RMBPC domains; (2) a significant within-group difference in posttest (vs. pretest) CES-D total mean score for the OFJ but not the control CGs; and (3) mixed findings for the within-group differences for the RMBPC in both groups.

Specifically, OFJ CGs reported their CRs as having significantly fewer incidents of disruptive behaviors, which may be a result of their being more likely to tolerate their CRs' behavior and not considering them as "disruptive," hence not reporting them as much as before. It could also mean that they have gained better skills in managing their CRs' disruptive behaviors.

OFJ CGs reported the same level of depressive symptoms for their CRs, but they reported being bothered by the symptoms more (though this was not statistically significant). This may mean that the OFJ CGs became more sensitive and empathic to the CRs' feelings. It may also mean that, as a result of the sharing in the OFJ sessions, OFJ CGs were more sensitive to their own feelings and felt safe enough to report their stress level more accurately. On the other hand, CGs in the ECC reported significantly less depressive symptoms for their CRs and reported being significantly less bothered overall by the CRs' memory and behavior problems. This may be an indication that the control CGs were less sensitive to the needs of their CRs. On the other hand, the educational materials provided to those in the ECC may have been interpreted to mean that such behaviors were "expected" and therefore might have minimized the importance to tend to those symptoms. The information may have "normalized" their experience so they were less likely to be bothered by the common memory and behavior problems. This could be a cultural difference; for example, ethnic minorities such as Vietnamese and African Americans report less distress when faced with these same kinds of memory and behavior problems [12,35].

The study findings also highlight the limited availability of Vietnamese-specific linguistically and culturally appropriate materials on dementia and caregiving [11,12]. The improvements observed for those in the ECC may be due to the impact of having linguistically appropriate materials, whereas the improvements for the OFJ CGs may have resulted from a combination of linguistically and culturally appropriate material and social interactions and support, in addition to the intervention techniques themselves.

Furthermore, social support provided in the OFJ small group sessions may have played a key role in helping participants manage their stress and depression. These CGs shared that as they realized they were not alone on the journey, and as they felt safe in the circle, they started feeling more comfortable with acknowledging their stress and depression, as well as sharing their struggles and looking for ways to take care of themselves without the customary feelings of guilt. This may partially explain the increase in the posttest stress and depression scores for some OFJ CGs.

4.1. Strengths and limitations

Prior literature suggests that this is the first study in the U.S. that uses a culturally tailored, evidence-based intervention to address risk for depression and CG-related stress among Vietnamese dementia CGs. The study created new Vietnamese materials since what currently exists focuses primarily on the disease itself but not on CG-coping skills. It also generated new knowledge about a Southeast Asian American group that has been severely underrepresented in research, which is significant because there are cultural differences in how Vietnamese American families react and care for a CR with dementia.

Similar to other pilot studies, there are some notable limitations. Although a strength of this study included use of a randomized design, the sample size was small, even after over one year of recruitment. This suggests that finding ways to engage Vietnamese Americans in this kind of research is an additional challenge that needs to be addressed so that future studies can enroll sufficient numbers of CGs so that their results can be more definitive. The CES-D and RMBPC questionnaires capture only a snapshot in time, which could be affected by other events in the participants' lives. To counter this limitation, we captured CES-D and RMBPC score at two time points. Nevertheless, a larger sample with more data points will minimize the effect of this limitation. Moreover, the preevaluation and postevaluation tools did not track other external confounding factors that may have influenced self-scoring levels of stress and depression among participants in both groups. For example, some OFJ CGs shared that when their parents went to stay with another sibling (even for a short visit), their level of stress/depression decreased-at least temporarily. It is our hope that the skills taught in the workshop would assist them to cope more effectively when the parent returnedalthough the research design employed did not allow us to explore this issue in depth.

An additional limitation is that administering the MoCA to assess cognitive functioning is not a surrogate for a dementia diagnosis. This pilot study did not collect information about the CR's stage of dementia or years since memory loss started, or level of functional impairment, which may have been helpful in understanding objective burden. These are recommended to include in future research.

Also, there is potential for type I error due to the number of statistical tests that were used. However, because of the small sample size, we were not able to employ a Bonferroni adjustment. To attempt to mitigate this limitation, we provided effect sizes to evaluate the clinical significance of the interventions. We realize this is not a fully adequate solution to the issue but it was the best we could do, given the financial and professional resources available.

Other measures could have been used to assess impact, given the preliminary nature of this research. For example, including a social support scale may have been useful as OFJ was delivered in a small group format, whereas the control condition was "solitary." It is well documented that social support is vitally important to CGs' MH [36] and would have been a viable outcome to assess at this stage of the research development. Moreover, the Perceived Stress Scale [37] that assesses overall stress (not just stress related to caregiving as the RMBPC does) may have been used, as it is possible that the overall levels of stress were different between the intervention and control CGs, and this may have affected the study outcomes. Had such a measure been included, correlation analyses among the key outcomes may have been informative.

4.2. Next steps

A potential next step is to "scale up" and attempt to replicate these findings in a larger and more well-characterized sample. This conclusion seems warranted, given that some effect sizes were at least moderate and suggest benefits from participation in either of these interventions. Future research would do well to study moderator variables (in addition to outcomes) to clarify what CG characteristics are associated with benefits in either intervention. It will also be useful to determine the effectiveness of this program in other Vietnamese American communities across the U.S.

Furthermore, since 17 of the 28 (60.7%) eligible potential participants changed their mind about participating (and never signed the informed consent), there is a need to provide community education to help destigmatize dementia and promote help-seeking behavior. Moreover, Vietnamese Americans need opportunities to learn more about what "research" is and what role their research participation play in ensuring representation of and advancing the needs and perspectives of their community.

In a separate manuscript that reported the qualitative evaluation, study findings indicate an increased level of knowledge in both groups of CGs. Specifically, 50% of the OFJ CGs and 20% of the control CGs indicated an increased knowledge base as a result of their study participation [38]. This research (and its future iterations) holds the promise of increasing not only knowledge but also acquisition of core skills that are effective to reduce burden and empower CGs. This is particularly relevant to family CGs who are faced with the strong expectation that they should care for their elders but have little knowledge of the illness, limited access to resources, and few specific skills to cope with the demands of caregiving for a person with dementia. That knowledge base may also be applied to dementia CGs in similar cultures, especially Southeast Asian American cultures that experience significant health disparities.

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RESEARCH IN CONTEXT

- 1. Systematic review: The authors reviewed the literature using traditional sources (e.g., PubMed) and meeting abstracts and presentations as well as consulted with experts in dementia caregiving in the United States. There have been some dementia caregiving research/programs for some racial/ethnic minorities in the United States but not for Vietnamese Americans.
- 2. Interpretation: Our promising findings suggest that a culturally adapted evidence-based program can benefit Vietnamese dementia caregivers. The study created new Vietnamese materials since what currently exists focuses primarily on the disease itself but not on caregiver-coping skills.
- 3. Future directions: Additional research is needed to develop and evaluate stronger, more impactful interventions for this underserved group. There is a need to provide education to the Vietnamese American community to help destigmatize dementia, promote help-seeking behavior, and learn more about what "research" is and what role their research participation play in ensuring representation of and advancing the needs and perspectives of their community.

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