

UC Davis

UC Davis Previously Published Works

Title

Dementia caregiver intervention development and adaptation in the Vietnamese American community: A qualitative study

Permalink

<https://escholarship.org/uc/item/03w066mq>

Journal

Dementia, 19(4)

ISSN

1471-3012

Authors

Meyer, Oanh L

Fukurai, Mihoka

Ho, Janis

et al.

Publication Date

2020-05-01

DOI

10.1177/1471301218792704

Peer reviewed



Published in final edited form as:

Dementia (London). 2020 May ; 19(4): 992–1008. doi:10.1177/1471301218792704.

Dementia Caregiver Intervention Development and Adaptation in the Vietnamese American Community: A Qualitative Study

Oanh L. Meyer, PhD, MAS¹, Mihoka Fukurai, BAS², Janis Ho, BS¹, Pim Limtiaco³, Hedda Hieu Nguyen, BA², Jennifer Dang, BA⁴, Nolan Zane, PhD², Ladson Hinton, MD¹

¹University of California, Davis, School of Medicine

²University of California, Davis

³Sacramento Community College

⁴University of the Pacific

Abstract

Objectives: The purpose of this study was to obtain input and feedback on a proposed intervention to reduce stress and enhance the health of Vietnamese dementia caregivers.

Methods: Sixteen semi-structured, in-depth interviews and two focus groups were conducted with a total of 21 key stakeholders (i.e., family caregivers, professionals, and community leaders).

Results: Several themes emerged from the data, and these themes fell into two major domains: the first domain was recruitment and engagement into the intervention: (1) importance of faith-based institutions, (2) inclusion of multiple family members in the intervention, (3) community empowerment/ownership, and (4) importance of credibility and trust. The second domain included themes on intervention content: (1) education about Alzheimer's disease and dementias and (2) tailoring the intervention to caregivers' needs.

Conclusions: Findings indicate that the proposed intervention could be very beneficial to caregivers, but slight modifications needed to be made.

Keywords

Dementia caregiver; culture; diverse; intervention adaptation; minority

INTRODUCTION

Caring for a family member with dementia or Alzheimer's disease (AD) is stressful, as caregivers are more likely to experience anxiety and depression and to report lower levels of life satisfaction (Cooper, Katona, Orrell, & Livingston, 2008; Herrera et al., 2012; Schulz et al., 1997). Chronic levels of stress increase caregivers' susceptibility to psychiatric ailments, accelerated physical decline, and decreased quality of life (Chan, 2010). 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/ethnic minority group in the U.S. (Pew Research Center, 2012). As this population grows and ages, the number of individuals with AD and related dementias and their family caregivers will also increase (Fact Sheet: Selected Caregiver Statistics, 2012). In the U.S., Vietnamese are the fourth largest Asian subgroup, following Chinese, Asian Indian, and Filipino. Of these subgroups, Vietnamese seem to be at highest risk for poor health. Most Vietnamese arrived in the U.S. in the mid-late 70's as political refugees. Vietnamese refugees lacked the usual financial resources and social networks that prior Asian immigrants had. They suffered much trauma during their escape, and their harsh experiences make them vulnerable to psychological problems (Tran, Tran, & Hinton, 2006). For instance, 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 then cause delays in diagnosis. Also, Vietnamese may be less likely to seek formal support because of accessibility issues or a lack of culturally and linguistically appropriate services. Even when services are available, caregivers may not seek help because they believe it is their obligation to care for their family member with dementia (Brodsky, Thomson, Thompson, & Fine, 2005). This duty is known as filial piety, wherein younger family members take on the responsibility of caring for older family members (Santoro et al., 2016; Wang, 2012), which may lead to greater caregiver stress and burden. Given that Vietnamese caregivers face greater health and mental health disparities because of lack of knowledge of AD, inappropriate services, and existing socioeconomic and health care disparities, there is a critical need to intervene in this population.

An ongoing challenge in the field is the development of culturally tailored, sustainable caregiver interventions. Currently, there are effective interventions for ethnically diverse caregivers (Napoles, Chadiha, Eversley, & Moreno-John, 2010), however, these interventions rarely sample Asian Americans, and none involve Vietnamese. Thus, there is a large gap in evidence-based interventions for Vietnamese dementia caregivers. Several models exist for adapting interventions for use in diverse communities, including ones by Napoles et al. (2013), Rescinow et al. (1999), and Barrera and Castro (2006). Although there are idiosyncrasies to each model, an overarching theme is utilizing a community-based participatory research model to obtain input on the intervention from the intended audience, thus ensuring its relevance. Another central tenet is considering the sociocultural, psychological, and historical context of the target population. Our study used a combination of approaches from these models to adapt Savvy Caregiver and REACH 2 (Resources for Enhancing Alzheimer Caregivers' Health) for use in the Vietnamese community (Gitlin et al., 2003; Hepburn, Lewis, Sherman, & Tornatore, 2003). Thus, the purpose of this article is to describe the process of adapting a dementia caregiver intervention by presenting research findings from key stakeholders. Qualitative methods provide an in-depth opportunity to explore the perspectives and experiences of dementia caregivers and community leaders in working to reduce dementia caregiving disparities.

The Current Study

Previously, we conducted formative work to understand the lived experiences of Vietnamese dementia caregivers. We identified key stressors and coping strategies (Meyer et al., 2015) and these findings, along with previous work on models of stress and coping, were used to develop the proposed intervention. The intervention is a six-week multicomponent program, structured into weekly two-hour sessions and is meant to reduce stress and promote culturally sensitive 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. Our preliminary work indicated that there are often multiple family members involved in the care of a family member with dementia (Meyer et al., 2015). Based on this interdependence and the collectivistic values of Vietnamese, 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. We elicited perspectives and recommendations on our intervention through individual interviews and focus groups. Interviews allowed for a more in-depth discussion while focus groups took participants through a mock intervention.

METHODS

Fifteen semi-structured individual interviews ($n = 16$, one interview had two participants) and two focus groups ($n = 9$) were conducted with a total of 21 key stakeholders in the larger Sacramento and bay areas. The individual interview guide explored the following topics: (1) personal background and experience with dementia in the Vietnamese (or Asian American) population, (2) ideas about how Vietnamese view dementia and how they cope with caregiving, and (3) perspectives on the intervention (interview and focus group guides included in Appendix). The goals of the focus groups were to (1) describe the modified intervention (that was updated following interview input), (2) take participants through a brief mock intervention (30 minutes of the first class), and (3) obtain additional feedback. For both the individual interviews and focus groups, we asked stakeholders about recruitment and retention strategies, the content of the proposed intervention, and potential barriers of intervention participation. Interviewers used the guide, but had the flexibility to explore topics in any order if it flowed naturally. Most of the individual interviews (14/15) were conducted by the lead author (OM), a PhD-level researcher, and one trained research assistant (either undergraduate-, Bachelor's degree-, or graduate-level), and ranged from 45 minutes to 1.5 hours (one interview was conducted with two research assistants). Interviews with caregivers were conducted in either the person's home or in a public place while interviews with professionals occurred at their place of work. All professional interviews were conducted in English with some Vietnamese dispersed throughout, while 3 of the 6 caregiver interviews were conducted predominantly in Vietnamese. Information gathered from the interviews was used to ask more specific questions about the intervention in the focus groups, which were held about 3–6 months after the interviews were completed. We conducted two focus groups – one in English (with four participants) and one in Vietnamese (with five participants). Both groups included caregivers and professionals and were split based on language proficiency. The English language focus group was led by a bilingual Vietnamese clinician licensed in marriage and family therapy. The Vietnamese language

focus group was led by a community worker and by the lead researcher (OM). Each group lasted approximately two hours.

Sample

Participants included Vietnamese dementia caregivers, professionals (e.g., therapists, social workers, community-based organization staff), and community leaders. Participants for both the interviews and focus groups were recruited through the local Alzheimer's Association, community partners (two Asian-specific organizations in the Sacramento area), and word-of-mouth. Those who participated in the individual interview were told that if they were interested, we would follow up with them later to participate in the focus group. Following written informed consent, participants completed a demographic questionnaire. Caregivers were self-identified, Vietnamese, at least 18 years old, and spoke either English or Vietnamese. Professionals and community leaders were individuals familiar with the experiences of Vietnamese (or Asian American) caregivers and their families. Participants received monetary compensation for participating in the individual interview and additional compensation if they participated in the focus group later. Four of the individuals from the interviews also participated in the focus groups; five were new individuals recruited as mentioned above. This study was approved by the Institutional Review Board of the University of California.

Data Analysis

Individual and focus group interviews were audio recorded and transcribed verbatim immediately afterwards. Vietnamese language interviews were transcribed, then translated into English for coding and analysis. Because we wanted to generate knowledge that would specifically inform intervention modification and implementation, a descriptive approach was used (Neergaard, Olesen, Andersen, & Sondergaard, 2009). For the individual interviews, analysis was done in tandem with data collection: as salient and interesting themes emerged from the interviews, relevant questions were added to the interview guide. After the first several interviews, the research team, all whom were bilingual, underwent an open-coding process that involved independently reading the transcripts and labeling phrases and sentences. Codes were assigned based on the important concepts that emerged from the interviews (Strauss & Corbin, 1990). Then the team met to discuss emergent codes and through a consensus process, a revised coding scheme was developed. Everyone read through all transcripts a second time to code based on the revised coding scheme and to highlight any new emerging themes. After the second round of coding, an initial codebook was developed. For subsequent transcripts, two team members coded each interview based on the initial codebook, which was revised as new themes emerged from the data. The next step involved axial coding where codes were condensed and/or combined into larger categories to reflect the major themes. The entire team, along with the lead author, met regularly to discuss codes, categories, and themes to resolve discrepancies and decide upon final themes. Previous transcripts were then recoded if new themes emerged in subsequent transcripts (until data saturation was reached). For the focus group, the team independently read through transcripts and made note of pragmatic suggestions and recommendations from participants. The lead author independently reviewed all interview and focus group transcripts when all data had been coded to organize themes and recommendations (Morse,

2015). All interviews were prepared for analysis using Dedoose qualitative software (Version 4.5, 2013).

RESULTS

Table 1 displays the demographic characteristics for study participants. All dementia caregivers ($n = 6$) were female, married, born in Vietnam, and lived with their care recipient. Half of the caregivers worked full-time. The mean age was 50 years, and ranged from 44 to 60. Four caregivers were taking care of their parent/parent-in-law, one caregiver was taking care of her older sister, and one was caring for her husband.

The majority of the professional participants ($n = 15$) were female ($n = 12$), married ($n = 8$), and employed full-time ($n = 12$). Most ($n = 11$) had a formal education equivalent to or greater than 16 years. Several themes emerged from the data, and they have been organized into two major domains: recruitment and engagement into the intervention and intervention content. Along with salient themes, specific recommendations about the intervention are described within certain themes.

Recruitment and Engagement into the Intervention

Themes that emerged from recruitment and engagement into the intervention included the importance of faith-based institutions, the inclusion of multiple family members in the intervention, community empowerment/ownership, and the importance of credibility.

Faith-based institutions—Stakeholders highlighted the multiple ways that faith-based institutions, including both churches and temples, were important to the intervention. They were helpful in terms of engaging and recruiting from the Vietnamese population since a large majority attended church or temple. In the Vietnamese culture, the two predominant religions are Buddhism and Catholicism, although religious practices can often overlap. That is, one can espouse Judeo-Christian beliefs but also participate in ancestor worship. Regardless of the religion caregivers ascribed to, praying and attending church or temple helped stressed caregivers find emotional support. One caregiver discussed the fact that over the last couple of years of caring for her mother, she had become less stressed because of her volunteer role at the temple; it helped her to feel happy and fulfilled. She also mentioned that talking to the Buddhist monks helped her because they encouraged her to have “tra hieu,” which translated, means filial piety. Reminding her of this cultural value helped her in caring for her mother.

Another caregiver described her feelings of sadness and depression because of her sister’s dementia. She coped with this sadness by praying and going to the temple. She often brought her sister to the temple as well, “Going to the temple and connecting with the Vietnamese community and her [sister’s] friends, it relaxed her and made me happy (60-year-old female caregiver).” The idea of faith-based institutions as a means of coping with the disease was helpful for another caregiver who said that if she could overcome the stress and struggle of caring for her husband with dementia, she might be rewarded in a different life. “I do the best I can, so that my next life will be better. That’s what I think about (63-year-old female caregiver).” Additionally, “buy-in” from local religious leaders was

important because they could promote the intervention and normalize the idea for their congregations. Thus, caregivers' faith and faith-based institutions emerged as a salient theme throughout the interviews because they helped caregivers to cope with caregiving and were important in engaging the community.

Inclusion of multiple family members—The collectivistic and interdependent nature of Vietnamese families impacts caregiving, in that the self is not separate from others. For example, it was often the case that there were multiple caregivers involved in caring for a family member with dementia, not just a single caregiver. “There’s no older son anymore, they work together...Vietnamese families tend to be... like, grandparents, parents, and grandchildren, and they kind of talk together... it is different from the Western culture...usually the wife will go ahead if the husband has Alzheimer’s, the wife most likely makes the decision, but I think because they [Vietnamese] live together, they eat together, they do it together at the table (52-year-old female professional)...” Thus, caregivers and professionals both felt that having multiple family members involved in the intervention was necessary.

A professional noted, “One family that I am working with...my client has dementia... I thought it was really interesting because each child is assigned a different task, so if it’s something that pertains to medical appointments, it will go to one child. If it’s something like rehab support or following up with her desire to go to this Buddhist monastery, and in terms of transportation, it will be another child (32-year-old male professional).” Several participants noted the delineation of responsibilities that all family members had in caregiving, not just the oldest son or daughter. Thus, the interventionist needed to have a solid understanding of who family members were, how they were involved in caregiving, and the dynamics of the family. Because family members each enacted different roles and responsibilities in the caregiving, it was important to understand and address multiple family members in the intervention.

Community empowerment/ownership—The idea of community empowerment and ownership was another salient theme that cut across both domains of recruitment and engagement and intervention content. Both caregivers and professionals believed that there should continue to be a space for intervention participants to meet after the six-week intervention was over. The role of the interventionist was to facilitate a group that would over time, be sustainable and self-functioning. Thus, community empowerment and ownership of the intervention would help the intervention’s effectiveness and sustainability. A professional mentioned that even when there were Vietnamese-specific programs in an area with a large Vietnamese population, people did not attend. Thus, it was not a matter of availability of culturally and linguistic appropriate services (even though those were rare), she suggested there needed to be momentum and initiative from the community and a demand for services- “It’s got to be- I think grassroots, right? We did try, we built this social day program...and no one came. I feel like there needs to be a momentum from the community that says, “Yes! We acknowledge this is a condition that we are all affected by and here’s what we want and this is what we need (44-year-old female professional).”

The idea of taking ownership of the intervention was shared by another participant who suggested that that the intervention should not consist of just interventionists and researchers imparting knowledge in a didactic manner to caregivers. Participants recommended that caregivers have the opportunity to share what they wanted in the intervention – what types of information they would learn and techniques they might use. The idea of having it be participant driven was a strong and consistent theme. Participants suggested we set the tone from the very beginning – that this was a program owned by the community and the interventionist was there only to facilitate the connections among caregivers.

“Have the facilitator throw out some ideas, like, ‘Here’s how to address caregiver stress so that’s one thing we could talk about that,’ or have the facilitator say, ‘You know, in my other group, we talked about caregiver stress...but I want it to be your group.’ Because I think that can be empowering for them...empower the caregiver to take charge of their group because they’re going to be in this thing together for six weeks, and hopefully develop a relationship and continue to support each other after the class (31-year-old female professional).”

Participants expressed the importance of maintaining support for caregivers long after the six-week intervention was complete.

Importance of credibility and trust—Given the sociopolitical history of Vietnam, participants felt that it would often be the case that caregivers could be guarded with outsiders. When asked about what qualities the interventionist should possess, participants felt that it should be someone who spoke Vietnamese well, who knew the culture, and had education and training that would give him/her credibility. Therefore, it would take someone very skilled, like a clinician who could build rapport and work with caregivers and their families. “They have to build a relationship with someone already and have that trust in that agency or that person to attend something like this. Because there’s some fear of meeting new people and also talking about their emotions, too. They have to have a good relationship with the person facilitating the group (32-year-old female professional).”

Participants discussed the idea that credibility had to be established very early on for caregivers to buy into the intervention. Another part of establishing the credibility of the intervention was providing caregivers with something tangible and new. Many echoed that the intervention had to provide caregivers with some new piece of information they had not known previously. A professional who had worked with many Vietnamese families suggested that we had to meet a tangible need first, like when she would help her clients understand their phone bill before engaging them in therapy. “In the beginning, depending on the client’s personality... I have to build that rapport first by doing something that makes sense to them (32-year-old female professional).” Another professional discussed the idea of meeting an immediate need for caregivers - “Don’t tell me something [that will help] three years down the road...they can see it now...they can see the benefit right away (63-year-old male professional).” It was suggested that in the first session, caregivers should feel that a tangible need would be met, and that would help establish the credibility of the intervention and the interventionist.

Intervention Content

Themes that emerged in the domain of intervention content included education about AD and dementia and tailoring the content to caregivers' needs.

Education about Alzheimer's and dementia—A salient theme that emerged from the transcripts was the importance of teaching caregivers about AD and related dementias and educating them on the disease. Participants stressed the lack of AD knowledge that was prevalent in the Vietnamese community. Oftentimes, individuals believed dementia and associated memory and behavioral problems were a normal part of aging, a disagreeable personality, or part of a mental health syndrome. Participants felt like if caregivers did not understand that repetitive questioning was a part of AD, they would just get annoyed at their family members, and not realize there were strategies they could use to deal with these behaviors. “The caregiver is still trying to reason with the patient, ‘I fed you already three times! Why are you still asking if I fed you or why do you keep asking me these things over and over again?’ So [it’s] not just the lack of education, but even once they understand the disease, it’s hard to act on it, right? So guiding or coaching these caregivers to know how to respond to these behaviors (52-year-old female professional).”

Several participants discussed the need to not only educate caregivers in the program, but also the larger community and other professionals such as Vietnamese medical doctors who saw a large number of older Vietnamese. Both caregivers and professionals felt that some physicians and their staff did not seem to have much knowledge about dementia or AD. Non-health professionals described experiences of referring caregivers to the family’s physician, only to be disappointed in the outcome.

“The physician or the physician’s office just didn’t seem to have as much knowledge about dementia and Alzheimer’s...So as we’re trying to encourage the family to seek a diagnosis and they go to their Vietnamese doctor, this small little practice, and the doctor says, ‘it’s normal aging,’ then we’re kinda stuck in- ‘no it’s not, you need to go somewhere where there’s a better understanding of it (44-year-old female professional).”

The lack of education and awareness was salient for our participants, but discussed more by the professionals than by caregivers.

Tailoring the intervention to the caregivers’ needs—The theme of tailoring the intervention to the needs of caregivers closely resembled the community empowerment/ownership theme discussed in recruitment and engagement. Both themes were reflected in participants’ comments about being personally engaged and having a voice in the intervention. A suggestion that emerged from the data was tailoring the intervention to what the participants needed, such as asking people if they want to do Tai Chi or some other stress management technique. Some participants felt that Tai Chi might be too time intensive for caregivers who were already stretched thin. It was suggested that we take the time to carefully assess caregiver needs at the beginning, perhaps this might be done by a social worker or someone who could get to know each person first and assess their immediate needs, before the intervention started. Similar to the theme of community empowerment and ownership of the intervention, caregivers suggested we present the six possible class options

to participants in the beginning and ask them what they want to learn first. For example, originally, the six-week intervention had one class on local resources, which covered the various types of community resources for caregivers and where they could access them, which was discussed in Class 4. Focus group participants felt that we should move this class up, because they felt like caregivers wanted to have something tangible, some new piece of information they did not have before, right away.

DISCUSSION

To ensure that our intervention addressed critical factors to meet the needs of Vietnamese families and promote long-term sustainability, we used a community-engaged approach to the development and adaptation of the intervention. Through the individual interviews, we identified several themes that had direct relevance for our intervention and the focus groups provided specific recommendations for adapting our intervention, seen in Table 2. Stakeholders were generally supportive of the proposed intervention but had recommendations related to recruitment and engagement of the community and intervention content. For example, after input that practical strategies and education about AD was important for caregivers, we added more education to each class and translated the behavioral strategies used in REACH 2 into Vietnamese and added these to the caregiver notebook. The importance of faith-based institutions emerged in two ways- first, as a means of helping caregivers to cope with the stress of caregiving, and second, as a means of building credibility and engaging the community. Several studies have shown the importance of religion and spirituality for helping Asian American caregivers manage the stress of caregiving (Chan, 2010; Hinton, Tran, Tran, & Hinton, 2008). Partly because of the spiritual teachings of Confucianism, Buddhism, and Taoism, the collectivistic cultures of East Asia espouse a set of values and beliefs that promote maintenance of harmony with individuals and with the environment. Some caregivers suggested that suffering in this life would mean a reward in the next life. This fits into the Buddhist notion that living is a struggle and requires patient endurance (Wangmo & Valk, 2012). Additionally, monks and priests, as well as those who regularly attend faith-based institutions, play important roles as they encourage caregivers to seek support for their loved ones and have the credibility to promote the intervention among their congregations. As a result, outreach and recruitment strategies for the actual intervention will have a focus on engaging local churches and temples.

The idea of multiple caregivers being involved in caring for a family member was a predominant theme that has been found in previous work (Meyer et al., 2015). In the case of multiple caregivers, it is important to help everyone come to a shared understanding of caregiving tasks and to address some of the disagreements that siblings and parents can have about dementia. Including family members is critical to the success of managing and treating dementia (Gallagher-Thompson et al., 2006; Tran et al., 2006). However, arguments among family members about the disease or what the patient is capable of doing or not doing are common in Vietnamese and ethnic minority families (Turner et al., 2015) and requires support (Meyer et al., 2015). Thus, the more that several caregivers can be involved in the intervention, the more unified family members can be about shared caregiving tasks. Nevertheless, how we involve a secondary caregiver will depend on each family, their dynamics, and their work obligations. Caregiver intervention models for the Vietnamese, and

potentially other minority populations, should be re-evaluated if a dyadic intervention is not the most culturally appropriate for this group.

Community empowerment and participant driven themes were continually stressed throughout our interviews as a method for ensuring effectiveness and sustainability. As seen in Table 2, we edited several pieces of the intervention. For example, in the first class, the course content and schedule will be presented to caregivers and feedback will be requested regarding their preferences. The importance of trust and credibility was a salient theme, although much more so with the professionals than with caregivers. Although not unique to the Vietnamese community, there is a lack of trust in government or seemingly government-related institutions. Thus, for our intervention to have credibility, language and background of the interventionist was important. Credibility can be provided by “gift-giving” early on in the intervention, that is, by the interventionist providing caregivers with a new skill or new knowledge that will practically help them care for their family member (Sue & Zane, 2009).

In our previous study Meyer et al. (2015), we found that lack of knowledge of dementia was a significant source of stress for caregivers, as has been found with other populations in general (Ayalon & Arean, 2004; Wang, 2012). Interview and focus group data both validated the idea that education about AD and dementia should be a key component of the intervention. The lack of awareness or education about AD and dementia in the Vietnamese community is pervasive and extends all the way from families to family physicians and the broader community. Often, primary care providers either do not have the knowledge about AD required to make a diagnosis, or they feel that because there is no cure, it is better to not “worry” families (Hinton et al., 2007). For the intervention, education on dementia and support services for caregiving is critical in ensuring caregivers are well-informed and aware of available community resources.

Study limitations include the small number of participants in just one region of the United States, limiting the generalizability of findings to non-Vietnamese dementia caregivers outside California. Second, although our sample included a decent number for qualitative research (N = 21), only six participants were dementia caregivers. A larger sample size might have allowed for additional important themes to emerge from the caregiver perspective. At the same time, we include a variety of other perspectives, and our findings support and extend results from other qualitative work on Vietnamese dementia caregiving (Hinton et al., 2008; Liu, Hinton, Tran, Hinton, & Barker, 2008; Tran et al., 2006). A major strength of this study was engaging the community via the in-depth exploration of dementia caregiving and a potential strategy for reducing stress in a vulnerable and understudied population.

Overall, while our proposed intervention was evaluated positively by stakeholders, suggestions were made regarding having the flexibility to tailor our intervention according to participants’ needs. That is, although a set protocol for the intervention was created, it may need to change depending on characteristics and preferences of caregivers. For example, a specific suggestion from the focus group was to change the follow-up assessment to three instead of six months. Moving forward, the revised intervention (which is currently being piloted) will still allow for opportunities for feedback: at the initial meeting when

caregivers are assessed and consented, and during the first group session- to allow caregivers to change the order of the classes (e.g., what they want to learn first). Our study adds to the literature by elucidating the process of adapting and refining a culturally-tailored intervention for an underserved population of dementia caregivers as well as the important factors in implementing the intervention in a diverse population. We engaged dementia caregivers, community leaders, and community-based organizations in discussions regarding the intervention. In retrospect, our process would have been enhanced by reaching out to family physicians that treat older Vietnamese and their families. Vietnamese physicians are key stakeholders in dementia care, and future research with this and other underserved populations should involve family physicians in intervention work.

Thus far, interventions for the Asian American population of dementia caregivers are minimal. Given this rapidly growing population, it will be crucial for those in the field to consider the important issues surrounding diversity and cultural tailoring in intervention development, adaptation, and implementation in this community.

References

- Ayalon L, & Arean P (2004). Knowledge of Alzheimer's disease in four ethnic groups of older adults. *International Journal of Geriatric Psychiatry*, 19(1), 51–57. [PubMed: 14716699]
- Barrera M Jr., & Castro F (2006). A heuristic framework for the cultural adaptation of interventions. *Clinical Psychology: Science and Practice*, 13, 311–316.
- Braun KL, & Browne CV (1998). Perceptions of dementia, caregiving, and help seeking among Asian and Pacific Islander Americans. *Health and Social Work*, 23(4), 262–274. [PubMed: 9834879]
- Brodady H, Thomson C, Thompson C, & Fine M (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, 20(6), 537–546. doi:10.1002/gps.1322. [PubMed: 15920707]
- Center, P. R. (2012). The rise of Asian Americans. Retrieved from Washington, DC:
- Chan SWC (2010). Family caregiving in dementia: The Asian perspective of a global problem. *Dementia and Geriatric Cognitive Disorders*, 30(6), 469–478. [PubMed: 21252540]
- Collins KS, Hall A, & Neuhaus C (1999). U.S. minority health: A chartbook. New York: Commonwealth Fund.
- Cooper C, Katona C, Orrell M, & Livingston G (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23(9), 929–936. doi:10.1002/gps.2007 [PubMed: 18383189]
- Dedoose Version 4.5, Web application for managing, analyzing, and presenting qualitative and mixed method research data. (2013). Los Angeles, CA: Sociocultural Research Consultants, LLC Retrieved from www.dedoose.com
- Fact Sheet: Selected Caregiver Statistics. (2012). <https://www.caregiver.org/fact-sheets>
- Gallagher-Thompson D, Rabinowitz Y, Tang PC, Tse C, Kwo E, Hsu S, . . . Thompson LW (2006). Recruiting Chinese Americans for dementia caregiver intervention research: suggestions for success. *American Association for Geriatric Psychiatry*, 14(8), 676–683. doi:10.1097/01.JGP.0000221234.65585.f9
- Gitlin LN, Belle SH, Burgio LD, Czaja SJ, Mahoney D, Gallagher-Thompson D, . . . Ory MG (2003). Effect of multicomponent interventions on caregiver burden and depression: the REACH multisite initiative at 6-month follow-up. *Psychology and Aging*, 18(3), 361–374. doi:10.1037/0882-7974.18.3.361 [PubMed: 14518800]
- Hepburn KW, Lewis M, Sherman CW, & Tornatore J (2003). The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. *The Gerontologist*, 43(6), 908–915. [PubMed: 14704391]

- Herrera AP, Mendez-Luck CA, Crist JD, Smith ML, Warre R, Ory MG, & Markides K (2012). Psychosocial and cognitive health differences by caregiver status among older Mexican Americans. *Community Mental Health Journal*, 49(1), 61–72. doi:10.1007/s10597-012-9494-1 [PubMed: 22311331]
- Hinton L, Franz CE, Reddy G, Flores Y, Kravitz RL, & Barker JC (2007). Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. *Journal of General Internal Medicine*, 22(11), 1487–1492. doi:10.1007/s11606-007-0317-y [PubMed: 17823840]
- Hinton L, Tran JN, Tran C, & Hinton D (2008). Religious and Spiritual Dimensions of the Vietnamese Dementia Caregiving Experience. *Hallym Int J Aging*, 10(2), 139–160. doi:10.2190/HA.10.2.e
- Liu D, Hinton L, Tran C, Hinton D, & Barker J (2008). Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of Cross-Cultural Gerontology*, 23(3), 283–299. doi:10.1007/s10823-008-9075-5 [PubMed: 18665444]
- Meyer OL, Nguyen KH, Dao TN, Vu P, Arean P, & Hinton L (2015). The sociocultural context of caregiving experiences for vietnamese dementia family caregivers. *Asian American Journal of Psychology*, 6(3), 263–272. doi:10.1037/aap0000024 [PubMed: 26617956]
- Morse JM (2015). “Data were saturated . . . “. *Qualitative Health Research*, 25(5), 587–588. doi:10.1177/1049732315576699 [PubMed: 25829508]
- Napoles AM, Chadiha L, Eversley R, & Moreno-John G (2010). Reviews: developing culturally sensitive dementia caregiver interventions: are we there yet? *American Journal of Alzheimers Disease and Other Dementias*, 25(5), 389–406. doi:10.1177/1533317510370957
- Napoles AM, Santoyo-Olsson J, & Stewart A (2013). Methods for translating evidence-based behavioral interventions for health-disparity communities. *Preventing Chronic Disease*, 10, E193.
- Neergaard MA, Olesen F, Andersen RS, & Sondergaard J (2009). Qualitative description - the poor cousin of health research? *BMC Med Res Methodol*, 9, 52. doi:10.1186/1471-2288-9-52 [PubMed: 19607668]
- Pinquart M, & Sorensen S (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *The Gerontologist*, 45(1), 90–106. [PubMed: 15695420]
- Resnicow K, Baranowski T, Ahluwalia JS, & Braithwaite RL (1999). Cultural sensitivity in public health: defined and demystified. *Ethn Dis*, 9(1), 10–21. [PubMed: 10355471]
- Santoro MS, Van Liew C, Holloway B, McKinnon S, Little T, & Cronan TA (2016). Honor thy parents: An ethnic multigroup analysis of filial responsibility, health perceptions, and caregiving decisions. *Research on Aging*, 38(6), 665–688. doi:10.1177/0164027515598349 [PubMed: 26282571]
- Schulz R, Newsom J, Mittelmark M, Burton L, Hirsch C, & Jackson S (1997). Health effects of caregiving: The Caregiver Health Effects study: An ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine*, 19(2), 110–116. [PubMed: 9603685]
- Strauss A, & Corbin J (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Sue S, & Zane N (2009). The role of culture and cultural techniques in psychotherapy: A critique and reformulation. *Asian American Journal of Psychology*, 5(1), 3–14.
- Tran J, Tran C, & Hinton L (2006). Working with Vietnamese American families In Yeo G & Gallagher-Thompson D (Eds.), *Ethnicity and the dementias*. New York: Routledge.
- Turner R, Hinton L, Gallagher-Thompson D, Tzuang M, Tran C, & Valle R (2015). Using an emic lens to understand how Latino families cope with dementia behavioral problems. *American Journal of Alzheimer's Disease and Other Dementias*, 30, 454–462.
- Wang DS (2012). Caregiving for dementia in Asian communities: Implications for practice. *Journal of Ethnic & Cultural Diversity in Social Work: Innovation in Theory, Research & Practice*, 21(3), 249–273. doi:10.1080/15313204.2012.700496
- Wangmo T, & Valk J (2012). Under the influence of Buddhism: The psychological well-being indicators of GNH. *Journal of Bhutan Studies*, 26, 53–81.

Table 1.

Sample Characteristics	Variable	n or %
Caregivers		
Female gender		6
Mean age; range 44 to 60		50.2
Marital status		
Married		5
Education (in years)		
11 (incomplete)		1
12 (high school diploma)		1
16 (college degree)		2
Primary language(s)		
English		2
Vietnamese		1
English and Vietnamese		2
Mean years in the U.S.; range 25 to 37		33.5
Religion		
Buddhist		3
None		2
Employment		
Full-time		3
Retired/Unemployed		2
Relationship to care recipient		
Spouse		1
Child		4
Sister		1
Care recipients		
Mean age; range 69 to 83		75.2
Female gender		5
Health/Mental Health Professionals and Community Leaders		
Female gender		12

Variable	n or %
Mean age; range 29 to 63	39.9
Marital status	
Single/Divorced	5
Married	8
Education (in years)	
16 (college degree)	11
Primary language(s)	
English	7
Vietnamese	3
English and Vietnamese	3
Mean years in the U.S.; range 20 to 60	32.8

Note. Numbers do not add up to total participants because of some missing data. Five participants were in the health/mental health professions, and seven were in administrative professions. One participant was in a legal profession.

Table 2.

Intervention and Adaptation

Session	Element	Content	Adaptations/Revisions
1	Introduction Education about dementia Effects of caregiving stress Signal Breath activity	<ul style="list-style-type: none"> Introduce participants and staff Introduce program purpose and timeline Background on dementia and Alzheimer's Disease Discuss effects of stress and stress-reduction techniques Introduce Signal Breath technique 	<ul style="list-style-type: none"> Include caregiver notebook with specific problem behaviors and strategies to cope Obtain input on order of classes
2	Debrief Behavior problems associated with dementia Community Resources Stages of Alzheimer's disease Signal Breath activity	<ul style="list-style-type: none"> Participants discuss progress/changes since last session Discuss behavior problems among participants Solutions and strategies to minimize behavior/issue Respite care options Review stages of Alzheimer's Disease and strategies for each stage Participants practice signal breath exercise 	<ul style="list-style-type: none"> Information on community resources was moved from Session 4 to 2 Add more education on dementia
3	Debrief Culture and dementia Stress Management Seeking formal and informal support Tai Chi or Stretching Exercise	<ul style="list-style-type: none"> Participants discuss progress/changes since last session Discuss acculturation and how Vietnamese cultural beliefs can influence participants' understanding 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 Tai Chi or stretching exercise 	<ul style="list-style-type: none"> Add more education on dementia Replace Tai Chi with breathing meditation in this and all subsequent classes
4	Debrief Pleasant events for care recipient Pleasant activities for caregivers Tai Chi or Stretching exercise	<ul style="list-style-type: none"> Participants discuss progress/changes since last session Identify activities care recipients enjoy doing Identify activities participants enjoy doing and managing self-care Participants practice Tai Chi or stretching exercise 	
5	Navigating care/healthcare decision Tai Chi or Breathing Exercise Review Sessions	<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.) Participants practice Tai Chi or breathing exercise Review material from previous sessions 	
6	Support Group Tai Chi or Breathing Exercise	<ul style="list-style-type: none"> Arrange support group for participants after the program's end Participants practice Tai Chi or stretching exercise 	