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The Sociocultural Context of Caregiving Experiences for Vietnamese Dementia Family Caregivers

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Abstract

The goal of this qualitative study was to describe the beliefs and experiences of Vietnamese caregivers caring for a family member with dementia and to elicit their ideas about promising interventions. We recruited 10 caregivers from support groups, the Alzheimer's Association, and local community-based organizations in Northern California. We conducted semi-structured in-depth interviews with all caregivers, as well as a focus group to obtain ideas about supportive strategies. Several themes emerged from the data: (1) Filial piety was influential in caregiving; (2) A sense of loss/grief or trauma was pervasive; and (3) Caregivers had clear sources of stress and sources of support. An overarching theme underlying these three topics was that cultural beliefs, values, and expectations impacted the caregiving experience. Suggestions for promising interventions included education, language-congruent and/or telephone support groups, case management, inclusion of the care recipient in the intervention, and importance of credibility of the intervention. It also may be valuable to include an understanding of cultural values and promotion of spirituality and religion as key components. Findings highlight targets for dementia caregiver interventions to reduce burden and distress in an understudied population.

Keywords

dementia caregiving; Vietnamese; caregiver burden; acculturation; family conflict

Introduction

Asian Americans are the fastest growing racial/ethnic minority group in the U.S. (Center, 2012). Accompanying this rapid growth is the number of individuals diagnosed with Alzheimer's disease and related dementias (ADRD) and their family caregivers ("Fact Sheet: Selected Caregiver Statistics," 2012). Compared to non-Hispanic Whites, Asian Americans and other ethnic minorities are more likely to take on the burden of caregiving for patients with ADRD and less likely to place their family members in assisted living facilities (Connell & Gibson, 1997; Dilworth-Anderson, Williams, & Gibson, 2002). Caregiving is accompanied by several challenges that place caregivers at risk for significant mental health problems (Schulz et al., 1997; Yaffe et al., 2002). The paucity of research on Asian American dementia caregivers suggest that they might be at higher risk for depression compared to non-Hispanic White caregivers (Pinquart & Sorensen, 2005). Therefore, it is imperative we understand what factors influence caregiver experiences and how to reduce caregiver burden in Asian Americans.

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). Cultural values and level of acculturation are important factors to consider for Asian Americans. Acculturation is a process in which members of one cultural group adopt the beliefs and behaviors of another group. It involves acquiring the language, attitudes, values, and roles of the dominant society, and the process of adjusting to these changes (Berry, 2005). Although the endorsement of cultural values varies by acculturation level, there is typically a greater value on the collective or group rather than the individual in Asian cultures, including the Vietnamese population. 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). It is typical for individuals in Vietnamese families to defer to the goals of the group. In Vietnam, this orientation towards the group or family is reinforced by the practice of having multiple generations in a family live together (Braun, Takamura, & Mougeot, 1996). Allegiance to parents, or filial piety, is strongly valued in traditional Asian cultures (Uba, 1994; Zane & Yeh, 2002), and is a part of Vietnam's heritage influenced by Chinese culture (Yeo, Tran, Hikoyeda, & Hinton, 2002). Filial piety is characterized by respect, honor, fidelity, devotion, dutifulness, and sacrifice on the part of children for their parents (Chen, 1982). The importance of deference and obligation of younger towards older family members is also reinforced by the practice of ancestor worship, which is based on the idea that a family unit transcends time and space (Yeo et al., 2002). Practicing filial piety means that children unquestionably obey their parents and respect their needs and wishes, even into adulthood. This sense of obligation or reciprocity may put some Asian American caregivers at greater

risk for caregiver burden, stress, and depression (Wang, 2012). In this qualitative study, we examine the experiences of Vietnamese caregivers of older adults with dementia.

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 and mental health. They are more likely to rate their health status as poor or fair compared to members of other Asian subgroups (Collins, Hall, & Neuhaus, 1999). Data from the 2007 California Health Interview Survey indicated that the poorest self-rated health and highest disability rate were found in older Vietnamese (Kim et al., 2010). Older Vietnamese have limited personal resources, including the lowest levels of educational attainment, household income, and English language proficiency (Kim et al., 2010). Experiences of war trauma, post-traumatic stress disorder (PTSD), and resettlement challenges may contribute to depression with prevalences as high as 49% in the Vietnamese population (Mollica et al., 1998).

In addition to health and socioeconomic disparities, there are distinct barriers in seeking mental health services and a lack of knowledge about dementia among Vietnamese (Tran, Tran, & Hinton, 2006; Tran & Yeo, 2004). Among many Vietnamese, symptoms of dementia are usually attributed to normal aging, physiological, psychological, or spiritual/religious causes (Yeo et al., 2002). A number of key idioms or labels are used to describe someone with dementia, including *lân*, which translates as “confusion.” Traditional Vietnamese views of health may be influenced by moral/religious traditions that stem from Taoism, Confucianism, and Buddhism (Yeo et al., 2002). Often, spiritual or folk beliefs about dementia overlap with causes from the biomedical model of dementia (Hinton, Franz, Yeo, & Levkoff, 2005). Depending on etiological perceptions, some time may pass before family members seek help for the patient’s dementia, adding to caregiver stress and burden and reducing the likelihood of treatment effectiveness for symptoms that start earlier in the dementia (Hinton, Franz, & Friend, 2004).

Stigma surrounding dementia also may prevent families from discussing their patient’s dementia (Liu, Hinton, Tran, Hinton, & Barker, 2008; Tran et al., 2006). Even for families that seek formal help, many are left unsatisfied with care they receive in primary care settings, where most individuals initially go. Problems typical in primary care settings include underdiagnosis, lack of information about diagnosis, and inadequate examinations. These problems may be exacerbated for Asian Americans because of language barriers, lower health literacy, and lack of culturally appropriate care (Hinton et al., 2005). As seen here, only a handful of studies have described the Vietnamese dementia caregiving experience (Braun & Browne, 1998; Hinton et al., 2005; Hinton, Tran, Tran, & Hinton, 2008; Scharlach et al., 2006; Yeo et al., 2002); thus, more are needed to understand how cultural values might impact the caregiving experience and to inform the development of culturally appropriate interventions to reduce distress for caregivers.

Currently, there are effective caregiver interventions for diverse ethnic minority 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 the Vietnamese population. Culturally-tailored

interventions for Vietnamese caregivers need to be implemented to contribute to the overall health of this group and other underserved communities. This study represents one of the few attempts to examine Vietnamese caregivers' experiences of caring for a family member with dementia, coping strategies, as well as attitudes about interventions. In doing so, it will inform the development of effective and culturally-relevant interventions in a population that is at-risk for health disparities.

Methods

Sample and Data Collection

An informal adult caregiver was defined as a family member responsible for taking care of a spouse or parent who had been diagnosed with dementia or who was having memory problems. Caregivers had to self-identify as Vietnamese, speak English or Vietnamese, and be at least 18-years-old to be included in the study. Two caregivers came from the same family. Participants were recruited through local Alzheimer's Associations, caregiver support groups, and snowball sampling methods. Ten caregivers participated in semi-structured, in-depth individual interviews and five of these caregivers also participated in a focus group. Caregivers received monetary compensation for their participation in the individual interview and additional compensation if they also participated in the focus group. This study was approved by the Institutional Review Board of the University of California, San Francisco and the University of California, Davis. All participants provided written informed consent via an English language consent form which was verbally reviewed in both English and Vietnamese for research participants.

For the individual interviews, we developed an interview guide with open-ended questions about participants' attitudes, experiences, and practices in caregiving for a family member with memory problems/dementia. Domains in the interview guide included family structure and immigration, beliefs about dementia, experiences with caregiving, coping strategies, help-seeking and service utilization, and identity and culture. The first half of the interviews was conducted by one PhD-level researcher (OM, KN) and one Bachelor's-level (TD) or Master's-level (PV) trained research assistant (all were bilingual and bicultural). The latter half of the interviews was conducted by both research assistants (one interview had only one research assistant). Each interview lasted approximately 1.5 hours and had a primary interviewer, with the second research staff as an observer taking notes. Interviewers used the semi-structured guide, but had the flexibility to explore domains and topics in any order as long as it flowed naturally. Most of the interviews were conducted in the participant's home. Interviews were recorded using a digital voice recorder and transcribed verbatim immediately after the interview by research assistants (PV, TD). All 10 interviews began in English with Vietnamese dispersed throughout several interviews. Two of the interviews were conducted mostly in Vietnamese. These interviews were transcribed directly into English. Researchers reviewed the first four interviews and further refined the interview guide to ensure relevant concepts were explored in subsequent interviews. Demographic information was collected in the form of questionnaire.

After the 10 interviews were completed, all caregivers were invited to participate in a focus group. The purpose of the focus group was two-fold: to discuss and validate findings that

emerged from the in-depth interviews and potential interventions that caregivers believed would be helpful for Vietnamese caregivers. Subsequently, the focus group guide included presenting the most frequently discussed sources of stress as well as coping/management strategies that emerged from the interviews. Participants were asked whether they agreed or disagreed with these stressors and coping strategies, and probed to discuss their responses. In the second half of the focus group, participants were presented with a list and description of current dementia caregiver interventions, including psychoeducation, cognitive-behavioral therapy, problem solving therapy, counseling/case management, support groups, and a combination of these interventions. They were asked to discuss their thoughts on these interventions as well as other ideas they had for treatments to reduce caregiver distress. OM and PV led the focus group with the five caregivers who could attend. Most of the focus group was conducted in English, with some Vietnamese included when needed. The discussion lasted for almost two hours and was recorded using a digital voice recorder and transcribed verbatim immediately after the meeting.

Data Analysis

Each interview and the focus group was coded by a two-person team consisting of one principal investigator (KN, OM) and one research assistant (PV, TD). Each coder read through each transcript line by line and highlighted key concepts or ideas that were salient. Each coder then developed an initial set of codes, from these concepts/ideas and then met with a team member to discuss and develop a new coding scheme based on consensus. The new coding schemes were reviewed and refined by KN and OM. The lead author (OM) then sorted these initial code categories and subcategories. OM and KN developed definitions for each category/subcategory, and through subsequent analyses of the transcripts, identified the interrelationships between categories and subcategories (axial coding)(Charmaz, 2006) All interviews were prepared for analysis using Dedoose qualitative software (Version 4.5, 2013).

Results

Characteristics of the Sample

Table 1 shows the characteristics of caregivers and care recipients. The median age for the 10 caregivers was 55 years. The majority of caregivers ($n = 7$) were female, were born in Vietnam ($n = 9$), and were employed full-time ($n = 7$). All caregivers had at least a high school diploma or equivalent, with the majority ($n = 8$) having at least a college degree (see Table 1). All caregivers had lived in the U.S. for at least 19 years, with a median length of 33 years. Age at immigration (derived from caregiver age and years lived in the U.S) ranged from three-years-old to 66-years-old, with a median of 28 years. Eight caregivers were taking care of a parent/parent-in-law or a grandparent; five of these caregivers lived with the care recipient, two caregivers had a care recipient living in an assisted living facility; and one had a care recipient who lived with her sibling because she worked full-time. Two were spousal caregivers: one lived with his wife and the other had her husband in an assisted living facility because she worked full-time. Thus, all caregivers who had spouses/parents living in a facility were working full-time. Five caregivers from the individual interviews participated in the focus group. The mean age of this group was 57 ($SD = 4.0$). The majority

in this group were female ($n = 4$), were born in Vietnam ($n = 5$), were employed full-time ($n = 3$), and were taking care of a parent with dementia ($n = 4$).

Overview

Several themes and sub-themes emerged from the transcripts: (1) Filial piety was influential in caregiving; (2) A sense of loss/grief or trauma was pervasive; and (3) Caregivers had clear sources of stress and sources of support. Underlying these three themes was the idea that cultural beliefs, values, and expectations impacted the caregiving experience. Thus, an overarching theme was the influence of cultural orientation in understanding the illness and the caregiving experience. Culture is defined as a set of shared symbols, beliefs, and customs that shape behavior and provide guidelines for behaving, interpreting, and evaluating one's actions and reactions in life (Goodenough, 1981). In measuring how culture might influence thoughts and behavior, researchers have turned to the concept of acculturation (Betancourt & Lopez, 1993). Depending on when caregivers immigrated to the U.S. and the context of their resettlement in the U.S., varying levels of acculturation existed across caregivers and within families, and this was apparent in most of the themes. We now describe each of these themes.

Filial Obligation

Filial responsibility has long been the focus of caregiving studies among racial/ethnic minority groups in the U.S. and is generally endorsed as a supportive behavior in caregiving and a social capital within these communities. In our study, most participants acknowledged *hiếu* or filial piety as a motive for caregiving for their parents or close family member.

“I was raised in Vietnam [where] the family relationship is very strong. I was taught when I was young that we have to have *tra hieu* [repay a moral debt or filial piety]. That is our responsibility. We have to take care of our parents when they are old. Do not put them in a nursing home.” (*Female, 53*)

hiếu was such a deeply ingrained obligation that participants assumed the caregiving role without engaging in any significant decision-making process when their family member became impaired and in need of assistance. Caregivers described how being Vietnamese or having a traditional cultural orientation influenced how they took care of their family member, and contrasted this with being Americanized. For example, a caregiver whose husband was White described his family and their role in helping.

“...they are very nice, but, in a way, I feel like there is a limit. You cannot ask for help a lot. That's all they can do. Whatever they can do, they do it, but doing the American way – they might think, ‘Oh, I've done enough’ ... But with the Asian feeling or Asian way of life, we feel like the family nucleus is always there and always we need the support from family.” (*Female, 53*)

All but three participants provided care for their family member in their home or at another relative's home. All three of these caregivers had a full-time career and had been in the U.S. for at least 25 years and therefore quite acculturated. For most caregivers, placing a loved one in a nursing home was an “American” thing to do and went against the values of respecting and honoring elders in Vietnamese culture.

“One of the things that the Viet, the Asian, when we put them in the nursing home, your friends would laugh at you too...They would laugh at it and say, ‘why you do that, why don’t you take care of your dad?’” (*Female, 61*)

We found participants’ conceptualizations of filial obligation more complex than whether or not an individual felt a personal sense of responsibility for his/her parents. There were varied attitudes towards caregiving. Some participants conveyed a greater willingness to take on the caregiver role and expressed sentiments that suggested they were motivated to care out of love and affection. However, there were attitudes that emphasized reluctance even as they accepted their obligation.

“It was just a lot of resentment. Like, you do it out of guilt and obligation and because, it wasn’t a question at all for us if we would take care of our mom. It’s like, of course. We need to always take care of her, no matter what.” (*Female, 33*)

Caregivers often reported mixed emotions about caregiving. They felt positively about fulfilling their role expectations but also found caregiving to be difficult. The majority described caregiving as a sense of reciprocity or way to give back to parents who cared for them as children (i.e., to repay a debt to parent for their sacrifices).

Sense of Loss/Grief or Trauma

Related to the sense of filial obligation was the reciprocity caregivers felt they needed to enact because of the sacrifices their parent or spouse had made for them, especially following the war. Most caregivers implicated past trauma and/or loss related to the war or immigration experience. Caregivers recounted stories of family members who had been involved in wartime conflict for most of their life in Vietnam, or who had gone from serving as a high-ranking military official in Vietnam to facing a loss of status after emigrating to the U.S. In some cases, caregivers felt that these traumatic experiences might have been the cause of the care recipient’s dementia. One caregiver mentioned that upon visiting his dying father in the re-education camp in Vietnam, he and his mother were not allowed to see his father until after he had died, and that this might have affected his mother’s mental health and partially contributed to her dementia. Often, it was other family members who directly experienced trauma and loss, and not the actual care recipient. However, because of the interdependent nature of Asian families, the self is not separate from others. Thus, the family members’ traumatic experiences and mental health were seen as potential contributing to the care recipient’s dementia.

A spousal caregiver relayed stories of his imprisonment in the re-education camps in Vietnam and how his wife had to take on the burden of caring for their entire family while he was in prison.

“After being imprisoned by Communists, I feel that everything I do now is nothing [in comparison]. After I got out of the camp, I saw that my family’s life was even more difficult because the Communists stripped everything from you. So my life right now, I try my hardest to live so I can take care of my wife.” (*Male, 81*)

Even though his imprisonment was challenging, this caregiver was saddened that his family’s life had also been heavily impacted. This story, like others, describes the trauma

and sense of loss caregivers felt due to the war and refugee experience. Subsequently, caregivers felt a stronger obligation to care for the care recipient because of his/her difficult life and sacrifices.

Sources of Stress

Overwhelming Nature of Caregiving—In all of the interviews, participants noted how difficult it was to care for their family member with dementia. They described the physical as well as mental exhaustion they faced and the constant need to supervise care recipients who might wander or inadvertently hurt themselves. Caregiving affected all aspects of participants' lives, including their psychological and physical health, marriage quality, relationship with other family members, job choices, and living situations. In addition to desiring respite, caregivers wanted others to be able to understand their situation.

“I want to go out! I want someone to help take care so I can go out! That’s it. I want people who see to be able to understand and empathize – that’s one thing. And every so often, for me to take off to relax and ... one or two weeks for me to go out with my friends to relax and then I can return home re-energized to work more.” (*Female, 60*)

Many times, stress occurred because caregivers were trying to balance their obligation to take care of their family member with their obligation to their own jobs and self-care. Additionally, participants contrasted the physical versus emotional challenges of caregiving and described how the psychological and behavioral symptoms were often more difficult to deal with than the physical tasks.

“It’s hard because, it’s not because of physical work, I don’t mind to do all the cooking, cleaning, right? It’s hard when she start yelling at me and accusing me [of] things.” (*Female, 51*)

Family as a Source of Stress—In our study, family could be both a source of support and stress. Family members had to make adjustments in their time and priorities in order to meet the demands of caregiving (e.g., communicate with extended family members) and work together to care effectively. The majority of caregivers indicated that although shared caring responsibilities with family members helped relieve the burden, family conflicts were frequent and had substantial negative effects on caregivers' ability to cope. One caregiver mentioned, “...the dynamics of caregivers is just as hard as doing the caregiving.” (*Female, 33*)

The process of becoming caregivers caused major turmoil in families, particularly in the beginning, as it disrupted family roles and lifestyles. Some families were ill-equipped to cope with these changes, particularly if members had poor communication skills to deal with intrafamilial difficulties. One participant described how the caregiving situation forced significant interaction among her adult siblings and since they had yet to develop effective coping and communication strategies, struggled in their relationship.

“...We reverted to childhood behaviors a lot. We would yell at each other and get really upset with things. We just played the roles we played as kids, you know. It wasn't healthy.” (*Female, 33*)

The sources of family discord varied. Typically, conflicts arose from different expectations about the level of support and involvement in caring for the recipient including disagreement on the division of caregiving tasks. A few participants complained that they often shouldered the bulk of the caregiving because other members were not doing enough, resulting in feelings of burden, resentment, and fatigue. Caregivers recognized how acculturation differences impacted how other family members' responses differed from their own in regards to caregiving.

“For my sister, she came from Vietnam later than me, so she's still very Vietnamese. She doesn't know how to cope with all of the stress. She [was] just upset all the time...” (*Female, 53*)

Although most participants discussed negative family experiences involving siblings, conflict also stemmed from intergenerational and acculturation differences in beliefs about dementia and approaches to caregiving. Family conflict arose from caregivers feeling that there was a lack of knowledge of dementia in older generations. Caregivers felt that this lack of understanding of dementia caused ill-informed family members to be angry with or treat the care recipient harshly, which upset caregivers who understood that behavioral symptoms were merely a part of the dementia. Often, more acculturated caregivers had beliefs about dementia that stemmed from a biomedical model of illness whereas other less acculturated and/or older family members believed dementia stemmed from a personality disposition or folk explanation of the illness. Folk model explanations of care recipients' dementia or memory problems involved the perception that dementia symptoms were a normal part of aging and stereotyping older adults as being forgetful. Differences in beliefs about the causes of the dementia or how to take care of the care recipient were related to caregiver stress. A caregiver described how her father, because he was not very acculturated, believed that dementia could be cured through Chinese medicines.

“...he was on his search for the Chinese herbal cure for it and hoping that someday she'll just come back and be normal again...” (*Female, 33*)

A lack of knowledge about and stigma associated with dementia caused family members and friends to stay away from the care recipient, leading to negative feelings from caregivers.

“...Uncles and aunts, because of her problem now, they don't even come over. It's kinda sad you know. Because this is pretty new for Vietnamese people. They don't understand what is dementia or Alzheimer's. All they see is, 'Oh she's crazy,' you know. And I explained to them, but they don't believe it. My aunt-she get like scared, so she barely come over.” (*Female, 51*)

Caregivers acknowledged that one of the barriers to extended family members' involvement might be due to lack of knowledge and acculturation differences.

“...I think, maybe that's part of the cultural thing too, is we don't understand how Asian culture works, and how people maybe don't talk about it out of respect not

because they don't care. But the way we interpret it, it's just like, wow, you know, you don't really care about our mom you don't make the effort...I think that's the thing, is that to educate, like community wise, you don't have to feel sorry for people or families that are going through this. Find practical things that you can do to help." (*Female, 33*)

Sources of Support

Family as a Source of Support—Care recipients, primarily elderly parents, lived in the homes of the participants or of their siblings, and in a few cases, adult children lived together in a single household with the care recipient to facilitate caregiving. For example, two participants from the same family described the life-changing decision among their four siblings to buy a house, relocate (one from a different country), and live together with their ill mother with the intention of providing her with 24-hour care. Though that family situation was atypical, other participants also described extensive arrangements for sharing caregiving duties with their siblings. In the few instances where the care recipient was in an assisted living facility, caregivers continued to be heavily involved in caregiving.

"So my sisters and I still take turns. She go to visit her on Mondays and Wednesdays, and I do Tuesdays and Thursdays, and we drop in whenever we can and bring food or take her for a walk. So at least someone's always there for a short period of time each day..." (*Female, 39*)

In general, cooperative arrangements among family members were perceived as beneficial. Caregivers had a strong desire to involve extended family members not only because caregivers wanted help, but because they felt that only family members could provide the type of support that was best for care recipients. Most caregivers believed that although paid caregivers might technically be better able to help care recipients (because of their specialized training), only family members could provide the type of care that would emotionally benefit care recipients.

"...When you care for someone, you feel like you devoted 100% of your time and also your love toward that person – to care for that person – make sure that person has all the basic needs that you can provide, that- a caregiver can do. A professional, trained person can do the same thing – sometimes even better than a family person. But by doing it, you [feel] rest assured...because of the love, because of the bond." (*Female, 53*)

Support from Individuals in Similar Situations—Regardless of acculturation level, almost all caregivers relied on some type of informal support, particularly relying on friends who were in similar caregiving situations.

"I got a friend at work... I think the caregiver needs to talk. Sometime you keep so quiet in your heart, you [get] so stressful, you might get sick." (*Female, 61*)

Religious/spiritual support—Caregivers also found relief through religious and spiritual activities such as praying and attending church. Approximately half of the caregivers

identified themselves as Catholic and the other half as Buddhist, although spiritual beliefs were usually a mixture of the two religions.

“So at church, you get the support from the people, the church, maybe not direct support, to taking care of my dad, but then I can talk with them, I can share with them. I can have fun there. Every time you go to church, you sing hymn notes and you hear the sermon, so all of that help me to adjust [to] whatever that I think is wrong in my life.” (*Female, 51*)

Formal support—Interview and focus group data pointed to a number of formal support services that caregivers used and/or desired. Caregivers who were more acculturated were more likely to seek formal support services for their stress, such as support groups provided as part of the Alzheimer’s Association or a hospital/clinic, whereas less acculturated caregivers seemed reluctant to use these services, although there was quite a bit of variation even within similarly acculturated individuals. Caregivers who participated in support groups valued not only the emotional support of hearing from others with similar experiences, but they found the information and resources that were available to caregivers helpful.

“Going to these support groups, I found it so incredibly helpful for me, just because to hear about other people. They might not have memory loss, but just the fact that they’re care providers for their parents or a father and the issues that they deal with and that you know, bureaucracy that they have to deal with to figure out how to navigate [getting in-home or other types of supportive services for care recipient] ...” (*Female, 39*)

One caregiver recognized how culture and/or acculturation level might influence whether or not caregivers who were distressed sought help.

“Like I say, I’m very Americanized, so I’m different you know. For them [Vietnamese caregivers], go to a meeting, especially to talk about your mom or your dad’s problem is something like, usually they don’t want other people to know. They don’t realize that when you go to the support group, this is confidential.” This same caregiver also stated, “now I think I deal with it better than before I went to the support group. I was a mess, but now at least I can walk away. It’s better, but still it’s hard. You know like I say, I pray a lot, and I cry a lot.” (*Female, 51*)

Caregivers who utilized support groups attended only the English speaking ones because they were not aware of any Vietnamese language support groups. Some caregivers seemed open to attending formal support groups, but mentioned that language and time were both barriers.

“...For Vietnamese people, they don’t speak English, it’s tough for them to go to support groups or things like that. They don’t speak English. And I think those people feel very alone, so that’s why I wish we’re gonna have a Vietnamese support group, for dementia or Alzheimer’s.” (*Female, 51*)

During the focus group, many caregivers expressed that formal support services such as therapy (e.g., cognitive behavioral, problem-solving) would not be helpful for them because they believed Vietnamese individuals shouldn't disclose their problems to a stranger. Caregivers that hadn't used any formal support services discussed their desires/needs for distinct support services (or interventions) they thought would be appropriate and helpful. Besides language congruent support groups, some caregivers liked the idea of multicomponent interventions, which were described as including general support, case management, and caregiver skills training. Focus group results also suggested that any intervention to help caregivers should include the care recipient because caregivers could not leave the care recipient alone and/or caregivers felt better if care recipients were also being helped.

“The most important [thing] is, how my mom can join the group right? We need the Vietnamese group.” (*Male, 60*)

This caregiver talked about wanting his mother to have some socialization with other Vietnamese speaking older adults. Another caregiver who was employed full-time mentioned:

“The support group, let's say we got the group, not meeting [in person], but we have the group on the phone maybe. Support group on the phone, we call, we ask for opinion.” (*Female, 61*)

Thus, language and time were major barriers to caregivers' formal help-seeking. Even for caregivers who were willing to seek support, many were not aware of available resources. Caregivers wanted to know about the resources (e.g., in-home support services, how to look for nursing homes, etc.) that existed for caregivers and how to plan for the future.

“I think also understanding the disease is important...what to anticipate or expect and that help[s] the caregiver. I think understanding the disease...what [are] the consequences from there?” (*Female, 53*)

During the focus group, one caregiver asked us to put together a list of resources that we could then distribute to the entire group. Caregivers were not aware that there were Vietnamese language support groups or Vietnamese hotlines to call when one needed immediate support. Another salient topic that emerged in terms of ideas for interventions was the idea of credibility of the researchers and the intervention.

“Because in the Vietnamese culture, age is important, ranking is important... reputation is important.” (*Female, 53*)

In conclusion, data suggest that filial piety was influential in caregiving; a sense of loss/grief or trauma was pervasive; and caregivers had clear sources of stress and sources of support. Moreover, family was an important contributor of stress as well as support. An overarching theme underlying these three ideas was that cultural beliefs, values, and expectations impacted the caregiving experience.

Discussion

The current and projected growth of Asian Americans in the older adult population makes understanding caregivers' experiences and views of dementia critical. In our study, caregivers struggled with the constant need to supervise their family member with dementia. This feeling of being overwhelmed or trapped has been noted in previous studies of dementia caregivers (Chan, 2010). The nature of caring for someone with ADRD is challenging because caregivers have to deal with not only the physical tasks of caregiving, but the emotions that accompany care recipients' psychological and behavioral symptoms (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Although caregivers desired respite, many were not willing to leave the care recipient in the care of anyone else except a family member or relative. They trusted that only family members could care for their loved one appropriately. Thus, it became stressful for caregivers when family members were seemingly unwilling to provide support.

One of the most difficult aspects of caregiving was figuring out how to navigate relationships with other family members. Family conflict was a common occurrence and poor family relations exacerbated caregiver burden and stress. It has been posited that including family members is critical to the success of managing and treating dementia, and that most racially/ethnically diverse older adults prefer to be treated within their family units (Gallagher-Thompson et al., 2006; Tran et al., 2006). So although family could serve as a source of support for Vietnamese caregivers, as was the case for our caregivers who discussed detailed caregiving shifts, it also became a source of major stress. Family conflict may arise from differences in family members' level of acculturation.

Similar to previous research on Vietnamese Americans (Yeo et al., 2002) and Korean Americans (Jang, Kim, & Chiriboga, 2010), variation in acculturation level among family members impacted beliefs about dementia and caregiving. More acculturated caregivers recognized that acculturation and intergenerational differences affected the way family members saw the disease and were aware that it may be culturally acceptable to avoid, possibly out of respect, discussing the dementia. However, they still had a difficult time dealing with discrepant perspectives and lack of support by family members. For example, caregivers mentioned that relatives who were once close to the care recipient failed to call or visit once the disease progressed. Interview and focus group data indicate that caregivers wanted family members and individuals in their community to understand and empathize with their situation. A lack of knowledge about and stigma associated with dementia caused family members and friends to stay away from the care recipient, leading to negative feelings from caregivers (Liu et al., 2008).

Among family members, acculturation often proceeds at different rates, and with different goals, sometimes leading to an increase in conflict and stress (Berry, 2005). The acculturation of younger family members and the influence of Western culture has been reported as a stressor for Chinese Canadian caregivers (Ho, Friedland, Rappolt, & Noh, 2003), and although less is known for Vietnamese caregivers, research suggests acculturation conflict might also be stressor in Vietnamese caregiving families (Trinh & Ahmed, 2009), as was the case in our study. Individuals who immigrate later in life may

have different opinions and beliefs about illness and disease (Hinton et al., 2004; Ho et al., 2003; Zhan, 2004) compared to those who immigrate at younger ages. Thus, it is important to recognize that even within the same family and generation, acculturation differences may impact family dynamics and caregiving strategies.

Almost all of our caregivers recounted stories in which their care recipients faced some sort of trauma that either contributed to their dementia and/or placed the caregivers in a position of reciprocating because of the care recipient's sacrifice. Research has shown that refugees carry immense trauma from war or concentration camps, which often results in insomnia, nightmares, and startle reactions. Many of these symptoms may fuel, or be amplified by symptoms of dementia, including memory loss, disorientation, and impaired judgment (Boehnlein & Kinzie, 1995). Thus, the sense of loss and trauma from the Vietnam War adds another level of complexity to dementia and caregiving in the Vietnamese population (Wang, 2012).

Although many caregivers did not use formal support strategies, they relied on talking to friends in similar situations and religion/spirituality to help them cope. Several studies have shown the importance of religion and spirituality for helping Asian American caregivers manage the stress of caregiving (Chan, 2010; Hinton et al., 2008). Partly due to 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. These ideas, along with doctrinal beliefs about purpose behind God's will in Catholicism, helped caregivers to cope.

Caregivers who initially seemed closed to the idea of using support groups or nursing homes (possibly because of the lack of familiarity with them) seemed open to getting information from others during the focus groups. In fact, the dynamics in the focus group were similar to that of a support group. All focus group members used the time to vent their frustrations with caregiving and to exchange ideas about resources and caregiving strategies. Despite the notion of stigma around dementia, caregivers spoke freely with one another to ask about experiences of using in-home support services or how to start the process for obtaining services. It appeared that the major barriers to these resources were cost, time, and language, and less so cultural beliefs. Caregivers who felt like they did not have enough time to come to a support group meeting thought a telephone support group might be a feasible option.

Practical Implications

Results of this study have implications for the development of interventions to reduce caregiver stress and burden and increase psychological well-being in Vietnamese dementia family caregivers. Because lack of knowledge of dementia was a significant source of stress for caregivers in our study and the Asian American population in general (Ayalon & Arian, 2004; Wang, 2012), a key component of any intervention should include education about specific types of dementia, symptoms, the course of illness, etc. This component should also include resources and linkages with community and state agencies that can support the caregiver. Previous research supports the notion that Asian Americans may often be looking for concrete and tangible assistance rather than therapy or assistance with coping with caregiving (Sue & Zane, 1987; Wang, 2012). An innovative psychoeducation intervention

might also discuss intergenerational and cultural differences as they relate to dementia caregiving. Although this wasn't explicitly expressed by caregivers, considering that family could sometimes serve as a major source of stress for caregivers, it may be important for differentially acculturated family members to understand each other's differing cultural values and norms. This might help caregivers and family members to empathize with one another, thereby reducing family conflict and encouraging supportive behaviors (Ying, 2007). This is especially important since many of the caregivers felt that only family members/loved ones could take care of the care recipient the way they need to be cared for. Other research has similarly advocated for the strengthening of families' social networks as a useful strategy to reduce caregiver burden (Chan, 2010). Future research should examine how to help caregivers capitalize on their social networks, for example, having extended family or trusted friends who can help care for the care recipient.

Psychoeducation around the mental health impact of trauma could also be beneficial to caregivers, who may not only be better able to empathize with their care recipient, but may also have experienced war and displacement themselves and will be motivated to address their well-being. Other interventions that might help Vietnamese caregivers include ways to encourage religious/spiritual coping for individuals who find these methods helpful, or to promote secondary control strategies such as such as accommodating to and accepting a situation rather than acting to actively change the stressor (Rothbaum, Weisz, & Snyder, 1982; Weisz, Eastman, & McCarty, 1996). Several caregivers mentioned praying or attending church to help them cope with stress. Caring for a loved one with dementia is unlike most other diseases, in which there is no way to prevent or cure the illness. When certain situations do not lend themselves to personal control, adopting the use of secondary control (e.g., praying to be more accepting of the situation and calm) may be conducive to well-being (Rothbaum et al., 1982). Social and cultural psychology emphasize that well-being may not be solely affected by proactive strategies directed at the stressor, as is the view in many Western cultures, but also by alternative strategies that emphasize regulating one's emotional response to stressful events.

Because of the interdependent nature of Asian families, the self is not separate but instead is a collective self that is interdependent with other family members, including the care recipient. That is, how the care recipient fares strongly affects caregivers. Thus, it may be beneficial and culturally appropriate for interventions targeted towards reducing caregiver stress and burden to also have a component (e.g., physical activity intervention) that includes the care recipient, as our focus group findings suggest. Also, our caregivers stressed the importance of credibility in any caregiver intervention. Thus, individuals delivering the intervention should be aware of the cultural norms and values of Vietnamese caregivers. Lastly, interventions should occur in easily accessible settings that are culturally congruent, such as in community-based agencies or churches and temples (Sayegh & Knight, 2013), and with bilingual and bicultural staff/researchers (Trinh & Ahmed, 2009).

We had some important limitations in this study. First, participants represent a non-random sample of Vietnamese caregivers from one geographical area in California, thus caution must be used in thinking about how results apply to individuals of other Asian subgroups and races/ethnicities. Second, our sample included only 10 caregivers. A larger sample size

might have allowed for additional important themes to emerge from the interview and focus group data. At the same time, findings from this study support and extend results from other qualitative work on Vietnamese dementia caregiving (Hinton et al., 2008; Liu et al., 2008; Tran et al., 2006). Also, our sample had moderate to high levels of English proficiency and education. Thus, caution must be used in thinking about how our findings extend beyond those who have higher socioeconomic status and thus, better access to resources and potentially lower caregiver burden. Future research should include individuals who are monolingual Vietnamese (and/or less acculturated) as their beliefs about dementia, experiences with caregiving, and likelihood of accessing supportive services may be different from bilingual (and bicultural) Vietnamese caregivers. Lastly, although we use acculturation level as an explanation for intragroup variation in caregiving beliefs and experiences, we realize that acculturation is a much more complex construct that can be conceptualized and measured in multiple ways (Betancourt & Lopez, 1993). Despite these limitations, a major strength of this study was the in-depth exploration of dementia caregiving in a vulnerable and understudied population. Our study adds to the literature by elucidating potential strategies and interventions to reduce caregiver distress and burden. We also highlight ways in which trauma and loss in this refugee population might affect the dementia caregiving experience. Lastly, a methodological strength was the use of the focus group to validate the individual interview findings on stressors and coping strategies.

Conclusions

Dementia caregiving is an overwhelming and challenging experience for family caregivers. For Vietnamese caregivers who often have lived a life of chronic stress and adversity, coming into their role as caregivers can be even more stressful. The themes that we have outlined here may not be unique to Vietnamese caregivers; however, the context in which the stress occurs and the types of interventions that might be seen as culturally valid are novel. Given the life course stressful experiences that many Vietnamese caregivers have faced, there is an urgent need to create, implement, and evaluate culturally relevant interventions that include multiple components (e.g., education, tangible support, adopting secondary coping strategies) to reduce burden in this understudied population. This qualitative study elucidates the experiences of Vietnamese dementia caregivers and their ideas for supportive interventions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1Characteristics of Caregivers and Care Recipients ($N = 10$)

Variable	<i>n</i>
Caregiver	
Mean Age (<i>SD</i>); range: 37–86	55 (14.7)
Female Gender	7
Marital Status	
Single	2
Married	7
Divorced	1
Education (in years)	
12 (high school diploma)	1
13 – 14 (some college)	1
16 (college degree)	8
Primary Language(s)	
Vietnamese	4
English and Vietnamese	6
Country of Birth	
United States	1
Vietnam	9
Mean Years in the U.S. (<i>SD</i>); range: 19–38	29 (7.5)
Religion	
Buddhist	5
Catholic/Christian	3
None	2
Employment	
Full-time	7
Unemployed	1
Retired	1
Relationship to Care Recipient	
Spouse	2
Child*	8
Care Recipient	
Mean Age (<i>SD</i>); range: 69–91	79 (8.7)
Female Gender	6

Note. Two participants did not list their years in the U.S. and one did not indicate employment status. *SD* = Standard deviation.

* One caregiver was an adult grandchild.