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“I was confused about how to take care of mom because this disease is different everyday”: Vietnamese American caregivers’ understanding of Alzheimer’s disease

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Abstract

Family members provide the majority of caregiving to individuals living with Alzheimer’s disease (AD) and related dementias. Asian American families are disproportionately impacted by the burden of caregiving due to limited knowledge about the disease in this community. This study explored how Vietnamese American caregivers understand AD and provide care to family members with AD. Twenty caregivers who have provided care to a family member with AD participated in a semi-structured qualitative interview. Data were analyzed using thematic analysis. Several themes were identified in the caregivers’ understanding of AD: (a) *“Now I know:” the disruptions, shocks and surprises leading up to the initial diagnosis;* (b) *The frustrations of managing family members’ cognitive impairments;* (c) *“Going with the flow:” challenges in managing personality and behavioral changes;* (d) *The exhaustion of around-the-clock caregiving;* (e) *“Taking it day by day” in the face of progressively worsening symptoms.* Underlining the participants’ descriptions of AD was a shared understanding of the progressively worsening, complex and unpredictable nature of the disease that makes it challenging for family caregivers on a daily basis. Findings provide important implications for healthcare workers’ outreach to Vietnamese American families to ease the caregiving experience through culturally-responsive education, thereby enhancing the families’ ability to recognize the early symptoms and seek appropriate help.

Keywords

Alzheimer’s caregiving; Vietnamese American caregivers; knowledge about Alzheimer’s disease

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Introduction

More than 16 million Americans in the United States provide unpaid care for individuals living with Alzheimer's disease (AD) and related dementias, and family caregivers are at the forefront of taking on this responsibility (Alzheimer's Association, 2018). Alzheimer's disease is the most common subtype of dementia that impacts an estimated 5.7 million Americans, the majority of whom are 65 years and older (Alzheimer's Association, 2018). As the aging population increases, so will the prevalence of this disease. Alzheimer's disease is characterized by an irreversible, progressive decline in memory, language, problem-solving, and cognitive abilities that interfere with daily activities (National Institute on Aging, 2018).

Caring for a family member with dementia can be stressful and challenging in light of the decline in cognitive, behavioral, and affective functioning associated with the progression of the condition. As such, caregivers' knowledge about dementia has implications for how they provide care to their family members (Andrews et al., 2017). Individuals who are more knowledgeable about dementia are likely to recognize early symptoms and seek appropriate services for support (Ayalon & Arean, 2004). Limited knowledge about dementia can impact caregivers and their loved ones - as it is often associated with delayed diagnosis, underutilization of support services, later onset of appropriate treatment, and caregiver distress (Given, Sherwood, & Given, 2008; Graham, Ballard, & Sham, 1997; Lee & Casado, 2017; Meyer et al., 2015; Wang, 2012).

Despite the prevalence of dementia in older adults and its impact on families, knowledge about the syndrome remains limited, particularly among ethnic minorities (Ayalon & Arean, 2004). Studies have consistently documented the lack of awareness and knowledge about dementia among Asian Americans (Ayalon & Arean, 2004; Cahill, Pierce, Werner, Darley, & Bobersky, 2015; Jang, Yoon, Park, Rhee, & Chiriboga, 2018), yet limited research has explored caregivers' understanding of dementia - within specific Asian American subgroups, particularly Vietnamese Americans - to inform the development of culturally-tailored education and interventions to ease the burden of dementia caregiving in this community. Vietnamese Americans are among the fastest-growing Asian American subgroups, with more than 2 million people residing in the United States (U.S. Census Bureau, 2016). With about 15% of the Vietnamese population over the age of 65, there will be an increase in the number of Vietnamese Americans affected by dementia (Zong & Batalova, 2016). Considering the central role of Vietnamese American family members in providing care to a loved one with dementia, they are likely at risk for experiencing the stress and impact of caregiving when they have a limited understanding of the condition and ways to manage it (Connell & Gibson, 1997; Dilworth-Anderson, Williams, & Gibson, 2002; Yeo, Tran, Hikoyeda, & Hinton, 2002). The purpose of our study was to address this knowledge gap by examining how Vietnamese Americans understand AD, the most common subtype of dementia.

According to the sociocultural stress and coping model, cultural beliefs and values influence the caregiving experiences of diverse groups and their understanding and perceptions of dementia (Aranda & Knight, 1997; Gray, Jimenes, Cucciare, Tong, & Gallagher-Thompson,

2009; Janevic & Connell, 2001; Janevic & Connell, 2001; Knight & Sayegh, 2010; Richardson et al., 2017). Culturally-informed variations in the conceptualization of dementia can impact all aspects of caregiving, including the understanding and interpretation of symptoms, patient and family's treatment preferences and expectations, and help-seeking behaviors (Gray et al., 2009; Napoles, Chadiha, Eversley, & Monero-John, 2010). Depending on level of acculturation, Asian Americans often combine biomedical labels of dementia with explanations that draw upon folk models of illness (Suzuki, Goebert, Ahmed, & Lu, 2015; Yeo, 2001). Persisting folk beliefs about dementia attribute the syndrome to physical, psychosocial stress, spiritual/religious factors, or the process of normal aging (Chan, 2010; Hinton, Franz, Yeo, & Levkoff, 2005; Yeo, 2001). Dementia-related symptoms such as memory loss, forgetfulness, and confusion are most commonly viewed as normal consequences of aging (Lee & Casado, 2017; Sun, Ong, & Burnette, 2012), and in some cases as a mental illness (Hinton, Franz, Yeo, & Levkoff, 2005). Several labels exist in the Vietnamese language to refer to cognitive decline in older adults: the idiom of *lãn* (indicating the loss of mental acuity, forgetfulness, and confusion) used in combination with *lú lãn*, *già lãn*, *lãn rớt*, *lãm lãn*, or *lãn lộn* (Ta Park et al., 2018; Yeo, Tran, Hikoyeda, & Hinton, 2002). This notion of forgetfulness as a natural part of old age, coupled with the lack of knowledge and awareness about dementia, can hinder families' abilities to recognize the early signs and seek help for a family member living with AD. Moreover, traditional Asian cultural beliefs and values, rooted in Confucianism and Buddhist principles, can influence conceptions about and responses to dementia. Fatalism, or the belief in one's destined fate, may guide some families to view their loved one's dementia as part of life (Braun & Browne, 1998; Hinton, Tran, Tran, & Hinton, 2008; Jang, Yoon, Park, Rhee, & Chiriboga, 2018). As such, it is now the caregiver's responsibility to care for their loved one living with dementia in accordance with the virtue of filial piety, or one's duty to care for elders and family members. These culturally-informed conceptions about dementia can pose barriers to early detection and treatment-seeking.

To date, there is limited knowledge on Vietnamese American dementia family caregivers - more specifically individuals providing care to family members living with AD - despite their vital role in the daily care of a loved one impacted by this disease. This was among the few exploratory studies that highlighted the perspectives of individuals impacted by the burden of Alzheimer's disease, and yet, remain largely invisible to the public: family caregivers. In particular, our study provided a richer and deeper understanding of the lived experiences of Vietnamese American family caregivers - whose voices are under-represented in caregiving research. The purpose of this study was to explore how Vietnamese American caregivers understand and provide care to family members with AD. Findings could inform healthcare providers (e.g., physicians, nurses, social workers, clinical psychologists) on culturally- and linguistically-relevant interventions for promoting AD awareness among Vietnamese Americans.

Methods

Participants

Participants included 20 Vietnamese American caregivers of family members living with AD. We used multiple strategies for recruitment. We posted flyers in several local community centers serving Vietnamese Americans in Southern California. We also distributed our flyers in a local non-profit Alzheimer's service organization and local Asian grocery stores to recruit caregivers. A few participants were recruited via snowball recruitment. Potential eligible caregivers either directly contacted the study team or gave our study participants' permission to release their contact information to the study team. This study was approved by the University of California, Irvine, Institute of Review Board (IRB) as Exempt Review for Human Subjects Research Consideration. The signed informed consent was waived by the IRB due to the minimal risk nature of the study protocol.

Eligibility criteria for participation were: 1) aged 18 years or older; 2) currently have a family member who is diagnosed with or have had a family member who was diagnosed with dementia (e.g., Alzheimer's Disease) but died, 3) speak the Vietnamese language or English, and 4) have no significant communication deficits. Participants provided verbal consent on the study information sheet that described the purpose, procedure of the interview, potential risk, benefits, compensation, data security, and research team's contact information. Participants received \$50 cash as appreciation for their time at the end of the interview.

Interview Procedures

Three bilingual research assistants trained by a gerontology-specialized faculty (J.L.) conducted semi-structured interviews in Vietnamese. One participant - who spoke fluent English - was interviewed in English by the gerontology faculty. An interview guide was utilized during the interview that elicited the caregivers' perspectives on key domains related to their caregiving experiences: a) recollection of the first time their family member received an official diagnosis of AD, b) knowledge about AD and its manifestations; c) perceived barriers in accessing information about AD and resources for caregiving needs; d) caregiving stress and burden and strategies for managing these challenges. All interviews were face-to-face and took place mostly at the participants' homes. Each interview took approximately an hour and was audio-recorded.

Data Analyses

Interviews were transcribed verbatim in the language in which the interview was conducted. Vietnamese transcripts were then translated into English by bilingual transcribers. One of the authors listened to all audio-recordings and verified translated transcripts for accuracy. We analyzed the interview transcripts using thematic analysis (Braun & Clarke, 2006). The first and last authors developed the coding tree, using the interview guide to inform the initial themes. At the initial stage of coding, three transcripts were read multiple times and coded independently by two coders in Dedoose, a qualitative and mixed data analysis tool (Dedoose, 2018). After each of the three transcripts was co-coded, raters met with a third coder, a qualitative expert researcher (H.N.) to review and refine the initial codes. The team

compared similarities and differences among the raters' preliminary codes, and with the third coder's input, the codes within the coding tree were finalized. Once the coding tree was finalized, coders one and two went back to co-code all the transcripts; approximately three to four transcripts were co-coded per week. Each week, coders one, two, and three met to review the coding and assess for areas of agreement and disagreements. In cases of disagreement, coder three (H.N.) facilitated the discussion until the team reached a consensus.

Results

Characteristics of family caregiver participants

A total of 20 Vietnamese-American family caregivers participated in the interviews. The characteristics of participants were presented in Table 1. Caregivers' mean age was 61.5 years, ranging from 43 to 82. Half of the participants (10 of 20) were adult children (nine daughters and one son). More than half of the participants reported they believed in Buddhism, and about 40 percent (8 of 20) were Christian (Catholic or Protestant). More than half of the participants (11 of 20) reported they completed a college education. Participants had lived in the U.S. on average more than 26 years, but rated their English proficiency as not very good ($n=5$ of 18 who responded, 28%). Most caregivers ($n=14$ of 20, 70%) lived at home with family members with AD while others lived close by.

Several salient themes emerged in the caregivers' understanding of AD: (a) *"Now I know:" the disruptions, shocks and surprises leading up to the initial diagnosis;* (b) *The frustrations of managing family members' cognitive impairments;* (c) *"Going with the flow:" challenges in managing personality and behavioral changes;* (d) *The exhaustion of around-the-clock caregiving;* and (e) *"Taking it day by day" in the face of progressively worsening symptoms.* Caregivers' understanding of AD ranged from some to extensive, depending on the duration of the family members' illness and the caregivers' access to information about AD from social service agencies, family and friends, and the media. Personal accounts of the first time a family member was officially diagnosed by a family doctor revealed the caregivers' lack of knowledge about dementia more broadly, and AD more specifically, thus making it difficult for them to recognize and seek appropriate help early on. Over the course of caregiving and increasing access to information and resources for dementia, the caregivers began to grasp the symptoms as observed in their family members and ways to respond to these symptoms. Underlining the participants' descriptions of AD was a shared understanding of the progressively worsening, complex and unpredictable nature of the disease that made it challenging for the family caregivers on a daily basis. Caregivers' access to culturally- and linguistically-appropriate information and resources (e.g., written materials in the Vietnamese language, available support from Vietnamese-speaking social workers and case managers) helped to improve their awareness and knowledge about dementia and AD, thereby easing the burden of caregiving that they have had to endure alone prior to interfacing with the healthcare and social service systems.

"Now I know:" the disruption, shock and surprise leading up to the initial diagnosis—Caregivers reflected on the first time their family member was diagnosed with

AD at the primary care doctor's office, following a series of "disruptive" or "unusual" behaviors that interfered with the care recipient's daily life and interpersonal relationships. The caregivers expressed shock and surprise while recounting their loved one's first diagnosis, asserting that they had not associated "the signs" with a disease. Many recalled thinking that the family members' "disruptive" or "unusual" behaviors were a "normal part of aging" or "part of their habit," until the disease progressively worsened and became disruptive. At that point the family member was brought in to see the family physician and received a diagnosis of AD.

Weaved throughout every caregiver's account were the moments when their family member "began to forget things" that happened most recently, "kept asking the same questions over and over again," "complained of losing stuff, which was not real," or "wandered and got lost." These moments became repeated occurrences that eventually alarmed the family to seek help from the primary care physician. One caregiver shared, "At the beginning, we saw how she kept asking the same question again and again, and we knew something was wrong with her. I answered them, and she would ask the same question again after 5-10 minutes." Other caregivers similarly described the unusual changes in the family member's behaviors.

The first time it happened was when he had a lunch gathering with friends to a commonly frequented place. He left and called his friends and relatives to say that he didn't know where it was. I took him to the doctor. The physician tested his memory... He got diagnosed, and I was very surprised and shocked... I guess I associated this and other symptoms with his habits, because my husband has always worried about money. So, when he kept asking me and the children where we hid his money, I thought it was part of his old habit. Looking back, my husband had exhibited signs...like putting a toothbrush where you normally would put a knife or saying one thing in the morning but another in the afternoon. And if you pay attention you would know something was not normal. But the thing is, my husband got this illness when he was much older, and I didn't have the knowledge then to differentiate between memory decline associated with Alzheimer's disease versus that of normal aging. But now I know. (Participant 17, wife)

Some caregivers further described the onset of AD as a manifestation of multiple symptoms to include increasing agitation and aggression toward other family members. One daughter shared her family's experience,

At the beginning my mom had become forgetful and talked about unreal things. She was screaming and agitated with everything. People around her felt uncomfortable, but I am her daughter and I love her. In addition, I knew the disease was controlling her, so I tried my best to take care of her. I never argued with her and let her talk about whatever she wanted, or thought was right. She also often hid her cash and then forgot about it. After that she would tell me her cash was lost and ask me to help her to find the money. (Participant 11, daughter)

The early symptoms not only disrupted the home life but further impacted the care recipient's social life and employment, namely the inability to carry out mundane tasks. One participant's story about her husband shed light on this experience:

At the time, he did a lot of paperwork for a volunteer job, but his memory problem would affect the job. I drove him to the doctor's office. The doctor diagnosed my husband with Alzheimer's. Finally, he decided to quit volunteering. At that time, I had a dry cleaner shop, so he came to help me. Sometimes he put on the wrong name and gave customers the wrong clothes... but he did not accept his mistakes... he argued with customers and told them he did not want to serve them after he made mistakes. It kept happening more frequently. (Participant 14, wife)

The frustrations of managing family members' cognitive impairments—

Cognitive impairments emerged as a common cluster of symptoms throughout the participants' understanding of their family members' AD, encompassing several key dimensions: (a) short-term memory loss, (b) impaired judgment and reasoning, (c) disorientation, and (d) suspicion, delusions and hallucinations.

The caregivers described short-term memory loss as their family members' inability to remember most recent events despite being able to recall past events from many years ago. As one participant put it, her father could "remember the things that happened in the past" but would lose all the "recent memory." Another similarly echoed, "She (mom) would quickly forget the content of a book we just read" but nonetheless would "remember everything about her life before she got married. We were really surprised at that." Short-term memory decline put a tremendous demand the caregivers to continually remind and respond to the family member's repetitive questions and requests. One spouse exclaimed, "For example, I would remind him again and again every day to help him remember, but that did no good because he would forget it a few minutes after." One daughter similarly detailed the concerning extent to which her mother had forgotten the things she said or did just moments ago:

My mom forgets everything that is current. For example, when her children and grandkids came over and left, she asked how come no one ever comes to visit, and we had to show proof of pictures that they just did. Another instance was when we just had dinner, and she finished ahead of me. She saw me chewing my food and asked how come we didn't feed her. There was one time, after I gave her medication, a while later she repeatedly asked whether she took the medication or not. Often, she would ask twenty times within one night, and it was tiring to repeat my answers. (Participant 6, daughter)

In many instances the caregivers gave examples of the family members' disorientation, described as being out of touch with their environment, not knowing how to "navigate the surroundings," or "not recognizing familiar people and situations." Some caregivers shared that the care recipients "could be taken to the garden in the backyard," where they previously enjoyed gardening, but now would just wander around mindlessly. Others gave the example of the family members "having no concept of the date and time." One spouse sadly shared her experience with her husband's disorientation, "Sometimes he knows who I am, but sometimes he doesn't. And sometimes he doesn't want to talk to me. He acts like a stranger." The excerpts below elaborated on the challenges of having to keep a close watch, remind, and direct family members when they are constantly in a state of confusion:

I would tell him don't do certain things, and after one minute, he would do it again. The thing is whatever I tell him, he does not remember despite me repeating and reminding him... Like at the shopping center... I would stand outside the restroom and show him which way to go, and he still could not find his way to the restroom. One time, I went to Store A and asked him to sit on the front bench, and he would wander to Store B. I had to ask security to find him. Since then, I would not dare to leave him alone. (Participant 17, wife)

A month ago, she had to go to the hospital for a pleural effusion. We told her about the situation, but she kept forgetting and asking why she was there, whose house does this belong to. The nurses came in and out of the room, which caused her to be anxious and nervous. Every time they came in to take blood samples and tests, she was so scared and didn't comprehend what they were doing to her and why. She kept herself awake and watched out for healthcare workers because she was scared of what they were doing to her. When the paramedics came to transfer her to the ambulance... she said: "what did you do to get arrested by the police?" (Participant 7, daughter)

In some cases, the caregivers described symptoms of suspicion, delusions and hallucinations that were difficult to manage and impossible to challenge. A common observation was the prevalence of their loved ones' belief that someone in the family had "taken and hidden" something from them, or "the suspicion" of others' "intent to harm" them. Despite the caregivers' assurances, family members continued to hold these beliefs, to which the caregivers must provide proof to ease the suspicion. In a few instances, the caregivers reported seeing the care recipients "talking to themselves" or "to invisible people" around them. Other caregivers' stories similarly shed light on this struggle:

He often talks about things that didn't happen. For example, a couple of nights ago, he wanted to open the garage. I asked why, and he said that someone was trying to steal our car. I took him to see our car and assured him that no one was trying to steal it. We have to go with the flow and listen to them, even if it is at midnight. These experiences teach us lessons: Don't try to argue or go against their accusations. It will not work. (Participant 20, wife)

I don't know how other patients behave, but my sister gets angry and agitated very easily. When she talks to me, she never makes eye contact with me. She is usually yelling at me. Sometimes she talks to someone invisible and thinks I talk badly about her. (Participant 10, sister)

"Going with the Flow:" Challenges in Managing Personality and Behavioral Changes—With a few exceptions of care recipients being described as generally more "calm" and "easy" to deal with after the diagnosis of AD, many caregivers observed an increasingly "irritable," "difficult," and "rigid" personality in their loved ones over the course of the disease. Participants elaborated about the times when the care recipients would become upset because things were not done according to their liking, or when the caregivers attempted to reason with them about why things have to be done a certain way. Regardless of the caregivers' helpful intent, the family members could not take perspective, and instead,

would respond with irritation and aggression. One caregiver spoke with sadness about the changes in her husband's personality, alluding to her grieving as she lost a part of him that she knew for so long:

His disease is unique because it does not get better by treatment. His memory gets worse day by day. I was scared to see his disease worsening and his personality changing. Before, he was a happy, humorous person; everyone enjoyed listening to him. But after having disease, he is very angry. He gets angry with everything I do. (Participant 14, wife)

A common complaint throughout the caregivers' narratives about the care recipients' increasingly "inflexible" and "difficult" personality was their preferences for things to be done in a particular way, to which the caregivers would try to accommodate rather than change. For example, one care recipient would "watch TV on loud volume all day" or would "turn on the light and ceiling fans all day even though it was winter, not allowing anyone to turn it off." Others would have preferences for "daily fresh meals" rather than leftovers or canned and frozen food, thus requiring a lot of time and effort from caregivers and could take "all day" for meal prep.

Caregivers asserted that the family members' impaired judgment and reasoning, combined with delusional tendencies and inflexible thinking, can make it impossible to reason with or convince the family members that certain routines needed to be carried out for their safety and well-being. Participants generally struggled with responding to the care recipient's rigid mindset and deeply held beliefs and preferences (e.g., "not wanting to take baths" or "not wanting to wear diapers"). Efforts to reason with, convince, or challenge the family members would result in irritable and defensive reactions. One caregiver eloquently captured this struggle:

Caring requires patience. We cannot apply logic and explain things to them. If they say 1, then we agree that's 1; then they will be happy. We don't go against their will. We know their perspectives are absurd, and it can be frustrating, but we have to calm down as it can affect us and make us exhausted. They can misplace something and blame and accuse us of hiding it from them. In the past, I would argue with him (husband). Now, from experience and through time, I just go with the flow. (Participant 20, wife)

In addition to the care recipients' changes in personality, the caregivers described - with sadness and confusion - other behavioral changes that can be disruptive and stressful for the family. Some participants alluded to the "self-destructiveness" of the family members' "aggressive" behaviors toward them, usually sparked by suspicions of the caregivers' intent or assertions for how things should be. These behavioral and personality changes could lead to resentment and frustration in the caregivers. One daughter spoke about her exhaustion:

Oh, the self-destructive behavior: hiding stuff, yelling...I want to help her, but every time I try to, she does not want me to help. She would yell, say bad words and even hit me. Every time I change her and take her clothes for a wash, she would yell at me. She is afraid that I would steal it and would wash the clothes herself... so she takes a pot of water and pour bleach on the clothes, and then puts

them inside the drying machine. After all that is done, I then need to clean the dryer. It's a lot of work to take care of her. (Participant 15, daughter)

Other behavioral changes included the family members' constant "complaints of losing things," when in fact they had misplaced the items while repeatedly "moving" or "reorganizing" things around the house. Some caregivers would take note of family members' tendencies to "take and store away things," upon which the family members would then question caregivers and other family members about the misplaced items, at times accusing them of having taken these items. One daughter shared her mother's experience:

Every symptom has a phase. Each symptom happens for a few months, and then it will change to another. The most difficult thing is that she likes to hide stuff. She really likes kitchen utensils. When I took her to a restaurant, she put a spoon, fork, and chopstick into her pocket. One time, before we left the restaurant, I asked her to give it back. She disagreed and yelled very loudly and screamed bad words. (Participant 15, daughter)

One common behavior that most caregivers must keep a vigilant watch over was their family members "wandering" away from home and "getting lost." While some care recipients stayed put inside the home, others had the tendency to leave the house but could not find their way around. One participant shared:

He would easily forget, and when he goes outside, he would get lost. Then I have to look for him. There was one time he wandered off from 3pm-9pm so we had to call police for help. Now I have to take him everywhere I go. The physician's office is just in front of the house, but he would walk off so far away when we have our visits. It has happened 3 times already. (Participant 18, wife)

Some caregivers also described disruptive sleep patterns among their family members since the diagnosis, typically sleeping very little and waking up at odd hours during the night and disrupting the caregivers' sleep. One caregiver lamented her husband's poor sleep patterns, his irritability, and their impact on her.

He would wake me up at 1 or 2 am every day and not let me go back to sleep, telling me it is already morning time. Last night, I couldn't sleep. I was tired earlier so I wanted to take a nap, but I was afraid that I would oversleep and miss your interview, so I stayed up and waited until now. He makes me feel tired very often. Sometimes, he would become upset and tell me to get out of his sight. (Participant 18, wife)

The Exhaustion of Around-the-Clock Caregiving

Throughout the participants' narratives, another salient theme emerged around the care recipients' decline in their ability to carry out activities of daily living. Most concerning and demanding were the time and effort required to assist care recipients with feeding, toileting, and bathing. Many caregivers discussed the distress of caring for family members with personal care needs - in one or more areas of care - because they had somehow forgotten and seemed disoriented with the routine they once carried out independently. The caregivers'

stories were similarly overshadowed with fatigue and despair in light of the poor prospects of the situation:

If I let her take a bath by herself, she never completes it. She just comes in and washes her face, then comes out and tells me that she is done. I need to help her bathe now because she can't do it by herself. She doesn't even know how to squeeze the toothpaste, so I need to help her with everything. This disease is about the dead cells not being replaced by the new ones. So, it is reducing and dying through time. I know that medication only helps to reduce the progression of the disease but not cure the disease. (Participant 16, husband)

I had a lot of difficulties because I had no experience with taking care of someone with Alzheimer's before him. Sometimes he remembers, and sometimes he does not. For example, sometimes he eats and then goes to sleep, but after waking up, he says I did not feed him. He is disoriented to time. He doesn't want to take a shower and doesn't listen to me. He just does whatever he wants. He doesn't know what he needs to do. The disease is like that. (Participant 13, daughter)

Caregivers spoke about having to manage a multitude of personal care challenges that continued to change daily and worsen over time, including incontinences. While the caregivers understood that incontinence and the inability to carry out activities of daily living were due to the declining state of AD, they did not anticipate the exhaustive extent of having to look after, clean up, and dress the care recipients throughout the day. Reports of leakages and uncontrollable bowel movements were commonplace. The caregivers kept a constant watch to avoid "messy accidents" or leaving the family member in "spoiled diapers." Among a few families, the care recipients' inability to control their bowel movements and other behaviors made it difficult to leave them alone or to send them to an adult day healthcare facility. One daughter expressed her exhaustion in navigating these challenges:

Mom can't go to daycare because she is yelling all the time. The other difficult thing is her toilet habit... now her anal muscle is getting weaker. Every time she has the urge to have a bowel movement, but the feces doesn't come out, she puts her fingers into the anus to grab the feces. It is becoming her habit. So, I adjust by predicting the day that she will have bowel movement and make her wear gloves on that day, just in case she puts her fingers in. Because of Alzheimer's, every time she grabs the feces, she throws it on the carpet. I can't have floor tiles because I am worried that she will slip and fall, so I put in carpet, but that then makes it very difficult to clean after the fact. (Participant 15, daughter)

A few participants voiced that their family members seemed aware of the impact of their actions (e.g., urinating or getting angry) despite having little to no control over them. Caregivers could tell the care recipient felt embarrassed about "the accidents," to which they would respond with anger toward themselves because they could not control it. One spouse shared, "Every time he gets angry or pees and poops on the floor, he gets very scared because he understands that it is wrong. I would assure him everything will be ok, I will take care of it." Another expressed her frustration and struggle when trying to come to terms with her husband's condition because she saw how badly he felt about it:

It's to the point where he doesn't remember that he screams and yells, and he would say 'I didn't do anything. I didn't scream' when in fact he just did. It makes me sad, very sad. In his mind, he doesn't believe that he would ever say such things to make me sad. So how can I blame him when he would sometimes say this to me, 'I am so sorry... this is all because my mind does not know what is going on. So, if I scream and yell at you, I am sorry, my love.'" (Participant 18, wife)

"Taking it day by day" in the face of progressively worsening symptoms

The unpredictable and progressively worsening nature of the illness is a reality that all caregivers face daily. In one rare instance, the caregiver described her mother's AD as mild and manageable, elaborating that the family member could still carry out personal care tasks (such as eating and toileting) and socialize despite being forgetful. Nonetheless, the majority of caregivers described their family members' AD as increasingly severe and challenging: characterized by a multitude of symptoms and exacerbated by physical and mental health problems that have slowly taken away their daily functioning. As one caregiver eloquently summed up, the family members were "no longer who they used to be," and the only thing caregivers could do in the face of the progressively worsening disease was to take it day-by-day. The following excerpts exemplified a deep sense of helplessness, sacrifice and resiliency among caregivers as they tackled each new day of caregiving:

He is just like a child. I mean he doesn't know what he should and shouldn't do. If he wants to go on a walk, he opens the door and leaves. But he doesn't know where to go and how to get home. In the past, he used the internet or watched TV for entertainment or hung out. Now, he can't do these things. He wants to talk to friends, but he is deaf, and his vision and legs are very weak. He went out by himself a couple times, but he fell. People on the street called 911, and the ambulance took him home. He enjoys walking but he doesn't understand that he can't walk too long... I always put my eyes on him. Every time he walks out, I follow him and let he walks until tired, then I come and drive him home.
(Participant 13, daughter)

My mom is in the severe stage of Alzheimer's now. She can't walk. When she began the severe stage, I went to work and left the medication for her at home. The medication was for her high blood pressure, and maybe she forgot to take it, and then she got a stroke. Now she is paralyzed in half of her body. I feel bad and regret not giving her better care. It was about 5 years after she was diagnosed with Alzheimer's. (Participant 11, daughter)

Back then when we talked about Alzheimer's, I thought the symptom is simply about memory, but now I understand that Alzheimer's is a terrible disease. It is not about memory loss. It gets worse with time. At first, he was able to drive, but after that he got into accidents 3 times per year. I was scared because he could not remember the street names and did not remember where he should turn right or left, or when he needed to stop. He drove straight when the red light was on and got into an accident... I did everything, but the disease still got worse gradually. I feel like it exceeded my endurance limit. The disease finally made him forget everything. He

does not even know how to turn on the TV, get food, or do anything. I do everything, 100%. (Participant 14, wife)

Discussion

A growing body of research has documented persisting gaps in knowledge about dementia and the dire need for culturally-appropriate interventions to reduce the burden of dementia caregiving in Vietnamese American communities (Hinton et al. 2005; Meyer et al., 2015; Ta Park et al., 2018; Ta Park et al., 2018; Yeo, Tran, Hikoyeda, & Hinton, 2002). In our study, we specifically examined Vietnamese American caregivers' understanding of and response to AD, informed by their experiences of day-to-day caregiving to a family member living with the disease. Drawing upon the knowledge gained from support groups, family and friends, and resources and media outlets in the community, caregivers' descriptions revealed the complex, unpredictable and challenging nature of AD. The caregivers' explanations highlighted cognitive and functional impairments in the care recipients that have similarly been documented in other studies on the public's and family caregivers' knowledge of dementia and/or Alzheimer's disease – conducted with diverse samples from multiple countries (Cahill, Pierce, Werner, Darley, & Bobersky, 2015; Eshbaugh & Stratton, 2016; Sanders & Power, 2000).

Despite caregivers' informed discussions of AD at the time of the interviews, their recollection of the first time their loved ones were diagnosed with AD revealed that the diagnosis came as a surprise. A common thread that weaved through the accounts was matter-of-fact acknowledgements of - and to some extent an unuttered self-blame for - the caregivers' lack of knowledge about the disease. They simply did not have the knowledge to detect the early signs until the symptoms worsened and disrupted the lives of the care recipients and family members. This finding was not surprising, as the lack of awareness about AD would make it difficult for caregivers to recognize the early symptoms, and in many cases the family would discount or misattribute the signs and symptoms (Hinton, Franz, Yeo, & Levkoff, 2005). Some caregivers in this study attributed the care recipients' behaviors to aging or a habit that has gotten worse with old age, commonly held beliefs that may hinder the early detection and recognition of dementia (Glueckauf et al., 2005; Lee, Lee, & Diwan, 2010; Liu, Hinton, Tran, & Barker, 2008). These findings are particularly telling and concerning: the lack of awareness about AD in the Vietnamese American community poses a barrier to early detection, service access and utilization among many families who unknowingly provide care to a member living with AD. Consequently, the prolonging of caregiving without an adequate understanding of the disease and effective caregiving strategies could exacerbate the burden of caregiving for the entire family for months or years, until the severity and disruptiveness of the symptoms necessitate a visit to the primary care doctor's office.

While the family caregivers in this study did not overwhelmingly attribute cultural factors to the delay in assessment and diagnosis of their loved one's Alzheimer's disease, it is noteworthy to situate the above findings within the Vietnamese American cultural context of illness and caregiving. The loss of face – immense shame, guilt, and embarrassment experienced by individuals with AD and their family members – could likely deter families'

disclosure of their loved one's AD-related symptoms, particularly severe ones, to outsiders and professionals (Ta Park et al., 2018). Further exacerbating the family's fear of losing face is the attribution of Alzheimer's disease to moral failing within the individual and the family or to karma – the idea that the illness is a consequence of the individual's actions in the previous life and should be dealt with through acceptance of one's fate. It is not surprising that some Vietnamese families may be hesitant to speak about and reach out for support despite seeing unusual changes in their loved one's behaviors.

Gaps in knowledge among family caregivers about dementia, and AD more specifically, has implications for the caregiving process: caregivers' ability to detect, understand, and provide appropriate care to the recipient (Meyer, Ayalon & Areal, 2004; Wang, 2012). Recognizing this need, healthcare workers can better support caregivers and alleviate the burden of long-term caregiving through community outreach and education that aim to increase awareness and knowledge about the disease, ways to effectively manage it, and knowledge about available resources to facilitate the caregiving process. Following the care recipients' medical diagnosis of AD, the caregivers in this study eventually accessed linguistically- and culturally-tailored information from local social service agencies to manage the illness as it manifested and progressively worsened. Over the course of caregiving, participants reported benefiting from the usefulness of information they received, as reflected in an increase in their knowledge about dementia and AD, how to manage the symptoms, and how to access supportive services.

Findings provide insight into practical implications for healthcare and social service workers to broaden their scope of outreach to Vietnamese American families impacted by AD or other dementias but have yet received help. The study participants all shared the constraints of having to remain at home to provide around-the-clock care, thus making it challenging for them to access resources that would require leaving home. Recognizing this constraint, feasible and effective avenues for outreach and education are the Vietnamese-language television and radio programs that reach Vietnamese Americans nationally. Broadly, the utility of media - including radio stations, TV shows, and YouTube - appear to be promising venues to address dementia knowledge in ethnic minority communities, as several studies with Chinese American caregivers have found (Woo, 2012, Zheng et al., 2016; Zheng & Woo, 2017). Among the few outlets that home-bound Vietnamese Americans have access to are Vietnamese-language radio and television stations that broadcast nationally. These media outlets are influential sources of information and connectedness for the Vietnamese American community and have been effectively utilized in mental illness stigma reduction (Han, Cao, & Anton, 2015). Interdisciplinary efforts among healthcare and social service providers to promote materials through ethnic media - primarily television and radio - would maximize the impact of outreach, thus making the information available and accessible to the caregivers who are homebound.

Education materials on topics such as the developmental process of aging, the type and course of illness, illness management, stress management, and where to go to seek help would be beneficial to the caregivers and family members (Meyer, 2015; NICE, 2007; Ta Park et al., 2018). Many caregivers in this study expressed distress as the care recipients' AD symptoms manifested and progressively worsened. They did what they could, while at times

not knowing what the most effective approach would be, to manage the cognitive and behavioral changes and personal care needs of the family members. Social workers and clinicians hold a key role in providing psychoeducation, skills training, and in-home and out-of-home placement and financial resources to Vietnamese American families to improve the quality of caregiving and alleviate the stress of family caregivers (Ta Park et al., 2018).

There are a few limitations in this study. First, the majority of participants were recruited from either support groups designed for caregivers of family members with AD or ethnic-specific community agencies that provide resources for Vietnamese Americans. As such, the caregivers in this study already have access to information and are more knowledgeable about the disease compared to caregivers who have yet accessed the support group and social services. Second, 19 of our 20 participants were female caregivers. The findings may be reflective of the experiences of female caregivers and shed limited understanding of the perspectives of male caregivers. Moreover, participants were split between older spouses and children caregivers who are younger in age and more acculturated, all factors that could possibly impact their knowledge and understanding. Our study also did not differentiate among the stages of AD among participants, which could manifest differently in symptoms and severity. Future research could tease out these elements to examine the nuances of AD knowledge and caregiving and inform a more tailored outreach and education curriculum that meet the diverse needs of Vietnamese American families impacted by AD.

Conclusions

Caregiving for a loved one with AD requires taking on new demands, unfamiliar tasks, and changes in cognitive and functional declines. Given the limited knowledge about dementia caregiving in the Asian American community, this study aimed to shed light on how Vietnamese American caregivers understand and provide care to a family member with AD - yielding implications for healthcare and social service providers. Findings highlighted the persisting gap in knowledge for the early detection of AD in this community, until the symptoms become severe and disruptive. This study provides support for the development of culturally- and linguistically-relevant interventions, drawing on the widespread availability and influence of ethnic media network, to increase dementia awareness and knowledge in this community. Healthcare and social workers - who are likely the first point of contact for families of individuals living with dementia - must initiate collaborative, targeted efforts to address the disparities in care for Vietnamese American families impacted by AD. A deepened understanding of dementia, and AD more specifically, could help the family caregivers detect and effectively respond to the cognitive and functional changes early on, thereby easing the burden of caregiving.

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Table 1.

Characteristics of Study Participants

	Vietnamese American Family Caregivers (N=20) Frequency (percent)
Gender (female)	19 (95.0%)
Age (year)	Mean = 61.5 ± 11.4 Median = 61 (Range, 43-82)
60	9 (45.0%)
61-70	6 (30.0%)
71	5 (25.5%)
Caregiver relationship with the patient	
Spouse	9 (45.0%) – 8 wives
Adult child	9 (45.0%) – 9 daughters
Sibling	2 (10.0%) – 2 sisters
Marital status	
- Married	15 (75.0%)
- Widowed/divorced	2 (10.0%)
- Single	3 (15.0%)
Religion	
- Buddhism	11 (55.0%)
- Catholicism/Protestant	8 (40.0%)
- No religion	2 (10.0%)
Years of Living in the United States	Mean = 27.15 ± 12.26 Median = 30 (Range, 1- 42)
English Proficiency, * mean (SD):	2.8 (±1.1)
Having a health insurance (Yes)	20 (100%)
Education	
- College or above	11 (55.0%)
- High School	5 (25.0%)
- Middle School	2 (10.0%)
- Elementary School	2 (10.0%)
Currently employed	13 (65.0%)
Recruitment methods	
- Vietnamese community centers	5 (25.0%)
- Caregiver support groups	10 (50.0%)
- Snowballing	5 (25.0%)
Stage of Alzheimer’s disease of the patient (reported by the family caregiver)	
- Mild stage	1 (5.0%)
- Moderate stage	11 (55.0%)
- Severe stage	5 (25.0%)
- Do not know	3 (15.0%)

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* English proficiency measured with 5-likert scale (5=Excellent, 1=Cannot speak English at all): One participant whose primary language is English was excluded in the mean calculation.

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