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Impact of War and Resettlement on Vietnamese Families Facing Dementia: A Qualitative Study

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Abstract

Objectives: Most Vietnamese immigrants in the U.S. today arrived as political refugees due to the Vietnam War in the late 20th century. Refugees are disproportionally affected by health and mental health disparities as a result of experiencing distress and potentially traumatic experiences before, during, and after their migration processes. This study involved Vietnamese families facing dementia and used a qualitative approach to investigate participants' experiences before, during, and right after their resettlement in the U.S.

Methods: In-person interviews were conducted with 11 Vietnamese adults who cared for their family member with dementia. A descriptive analysis approach was used.

Results: Five major themes emerged from the interviews:1) immigrating separately from family members, 2) difficult and unsafe journeys, 3) experiences of loss, 4) lack of support systems in the U.S., and 5) feelings of unhappiness, sadness, or signs of depression.

Conclusions: This study provides a close examination of Vietnamese refugees' unique backgrounds and how individuals with dementia and their caregivers from this population may be disproportionally impacted by stress.

Clinical Implications: To reduce health disparities, we recommend that providers and policymakers allocate more resources for culturally appropriate routine assessment, treatment, and referrals of those with dementia and their caregivers.

Keywords

dementia; caregiving; qualitative analysis; trauma; Asian; refugee issues

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Ethical Statement

Written consent was obtained in-person from all participants. This study was approved by the Institutional Review Board of the University of California, Davis (#441522-4).

Asian Americans are the fastest growing ethnic minority group in the U.S. (Pew Research Center, 2012); as this population grows and ages, the number of individuals with dementia and their family caregivers will also increase (Family Caregiver Alliance, 2012). In the U.S., Vietnamese are the fourth largest Asian subgroup, and the growth of the older Vietnamese population has been rapid: from 2000 to 2019, the percent change of Vietnamese above 55 years of age was 12.4%, while this number was only 7.9% for all Asian subgroups combined and 8.3% for all racial groups combined (U.S. Census Bureau; 2000, 2019). The majority of Vietnamese arrived in the U.S. after the Vietnam War in 1975 as political refugees. Despite the unique immigration background and fast-growing older population, there is little literature on the effect of the war and immigration on older Vietnamese' health and mental health, especially in families facing dementia, who are already vulnerable to stress and health disparities (Chan, 2010).

Many Southeast Asian refugees faced stressors related to pre-immigration, the actual immigration process, and post-immigration. Previous studies conducted on Southeast Asian populations have shown that the immigration experience as well as related trauma have negative impacts on refugees' cognitive and psychological health (Nicholson, 1997). While the resettlement process affects refugees in multiple aspects, individuals with dementia and their family caregivers may be impacted even more. Studies have shown that previous exposure to psychological trauma and having a diagnosis of post-traumatic stress disorder (PTSD) increase the risk of developing dementia later in life, in both Veteran and civilian populations (Desmarais et al., 2020; Günak et al., 2020; Qureshi et al., 2010; Yaffe et al., 2010). Positive relationships between childhood psychological trauma and dementia have also been discussed (Radford et al., 2017; Tani et al., 2019; Wang et al., 2019); Günak and colleagues suggest that exposure to psychological trauma may be associated with other neurological, cognitive, and psychological factors (e.g., threat- and stress-related neurobiological pathways, social isolation, depression) that later contribute to developing dementia. Additionally, Vietnamese who take care of their family members with dementia may also be impacted by their immigration background. Having lived through the trauma of the war could cause stress and depression (Leggett et al., 2013), which can consequently affect caregiving abilities. Research has shown that experiencing repeated stress can contribute to allostatic load, or the 'wear and tear on the body' when individuals experience chronic or repeated stressful events (McEwen and Stellar, 1993). Experiencing war, having to leave Vietnam, and then later providing care to family members with dementia can be cumulatively stressful, and thus allostatic load is especially relevant for Vietnamese families facing dementia (Dich et al., 2015; Roepke et al., 2011).

The Present Study

Previously, we conducted in-person interviews with Vietnamese[a] caregivers to investigate their experience of taking care of their family members with dementia[b]; perceptions of dementia, sources of stress and support, as well as caregivers' needs were explored in

[a]Vietnamese in this article refers to Vietnamese immigrants in the U.S. While some may self-identify as Vietnamese American (not measured), this article uses Vietnamese for brevity.
[b]Specific type of dementia was not examined. The diagnosis of dementia was reported by caregivers.

these interviews and published elsewhere (Meyer et al., 2015). From these interviews, it was clear that all caregivers had shared experiences of harsh migration journeys and associated stressful experiences. Due to this common experience shared by all families, the current study was developed to analyze these sections of the interviews in greater detail to better understand the experience of immigration and potentially traumatic experiences for Vietnamese families facing dementia. That is, the commonality in caregivers' immigration experiences, as with much of inductive research, prompted our subsequent focus (Williams & Moser, 2019). This study enriches the literature by describing Vietnamese refugees' immigration and resettlement process and exploring the potential impact on their health, mental health, dementia, and caregiving abilities. Towards that end, we analyzed semi-structured qualitative interviews with 11 Vietnamese dementia caregivers living in Northern California.

Methods

Sample

Participants were Vietnamese dementia caregivers who were recruited through the local Alzheimer's Association chapter, community partners (two Asian-specific organizations in the local area), and word-of-mouth. Inclusion criteria were the following: 1) currently caring for a family member with dementia, 2) self-identified as Vietnamese, 3) at least 18 years old, and 4) spoke either English or Vietnamese. Following written informed consent, caregivers completed a demographic questionnaire and participated in an individual interview either in their home or at a public space (e.g., library). A total of 11 caregivers enrolled in the study and completed the individual interviews. At the end of the interview, all caregivers received a $50 gift card.

Procedure

All but one in-person interview were conducted in 2013, with the last one in 2015. All interviews were co-conducted in Vietnamese by the principal investigator (O. Meyer) and a trained research assistant. As shown in Table 1, interviewers queried caregivers on their and their care recipients' immigration experience from Vietnam to the U.S. Most of the individual interviews ranged from 45 to 90 minutes.

Data Analysis

Vietnamese interviews were audio-recorded, transcribed verbatim, and then translated into English for coding and analysis by trained research assistants. A descriptive approach to coding was used (Creswell, 2015). The research team, the majority of whom were bilingual and bicultural, underwent an open-coding process that involved independently reading the transcripts and highlighting/labeling key phrases and sentences for the first few transcripts. Similar labels and phrases were then grouped together into codes (Creswell, 2015). Research assistants first generated their own codes and then met as a group to discuss. A codebook of overlapping codes and themes was developed after two rounds of independent coding and team discussions. During these team meetings, independent coders met to compare their work and discussed any disagreement in codes until consensus was reached.

For subsequent transcripts, two team members coded each interview based on the initial codebook. The next step involved axial coding where the themes developed from the codes in the first round were condensed and/or combined into larger categories to reflect the major themes. This resulted in fewer major themes, condensed from originally eight themes to five themes, and wherein certain related themes were combined. Previous transcripts were then re-coded if new themes emerged in subsequent transcripts until data saturation was reached, when no additional new themes were proposed. The principal investigator independently reviewed all transcripts when all data had been coded to finalize the organization of themes and recommendations (Morse, 2015). All interviews were prepared for analysis using Dedoose, which is a web-based qualitative analysis software program that allows for collaborative coding based on selected text and quotes (SocioCultural Research Consultants, 2015). Themes and sub-themes are color-coded and simple analyses such as descriptive frequencies can be generated via Dedoose.

Results

The sample in this study consisted of eight self-identified female and three self-identified male family dementia caregivers. Detailed demographic data is reported in Table 2. Several themes emerged from the interviews: 1) immigrating to the U.S. separately from family members, 2) difficult and unsafe journey, 3) experiences of loss, 4) lack of family or community support systems in the U.S., and 5) feelings of unhappiness, sadness, or signs of depression. Of note, participants primarily shared about their own experiences, and some shared their care recipients' experiences. Below, we describe each theme in detail; quotes and statements represent caregivers' own experience unless otherwise indicated. See Table 3 for endorsement frequencies.

Immigrating to the U.S. Separately from Family Members

Eight of the 11 caregivers fled Vietnam after the Vietnam War as refugees between late 1970s and early 1980s, and the other three came to the U.S. in the 1990s to reunite with their families who had resettled earlier. When the participants reflected on their immigration experience, seven stated that their family members did not come to the U.S. at the same time as them. It was common that family members would not be reunited until many years later.

Those who could not leave with their family members, however, had to wait in Vietnam or stay at refugee camps. In addition to facing the stressful political climate in Vietnam or suffering the sometimes-harsh conditions in the refugee camps, participants described the worry and anxiety from their family members.

> The hard part was that my father knew what the experiences on the boat could be like, and then sending his daughter to a place no one knows what was going to happen. (*Female, 55*)

For those who were able to receive sponsorships and leave Vietnam first, they expressed feeling lonely and having the pressure of bringing the rest of their families to the U.S. The inability to migrate with all family members at the same time was stressful for both those stayed behind and those who had left first.

Difficult and Unsafe Journey

Six of the 11 participants fled Vietnam via boat and traveled for three to four days to refugee camps in nearby countries such as Thailand, the Philippines, and Malaysia. Participants described their boat journey as difficult and unsafe due to the threat of or actual encounters with pirates, robbery, rape, and physical injury. One participant recalled,

> I do remember some of it myself, like being at sea and how our boat ran out of gas, and that we were stranded… Paying pirates and hiring pirates to take us closer to the shore. But they just left us in the middle of the ocean. (*Female, 41*)

In addition to encountering pirates, another participant described their other challenges in the ocean:

> It was cold – very cold. And – the waves – it was extremely strong waves. So, it was scary. You know that you could die the next minute. (*Female, 55*)

The boat journey was described by most as dangerous and life-threatening. However, while multiple participants described their boat experience as dangerous, one participant who was seven years old at the time shared that she mainly thought the journey was ‘fun’ and ‘exciting.’ For this participant, she did not reflect on her immigration experience as negatively as others, although she was able to perceive her parents’ anxiety and fear. Through the eyes of this younger participant, challenges were interpreted quite differently.

Experiences of Loss

About half of the caregivers or their care recipients (as detailed by caregivers) had experienced loss in various forms, including losing family members, good health, possessions, and high-status occupations.

Loss of family members—Many refugees lost their family members prior to, during, or after their migration. One participant described that his father was a South Vietnamese government official prior to the end of the Vietnam War and thus was imprisoned. This caregiver’s mother developed dementia years after, and the participant suspected the trauma from his father’s death and the war could have had contributed to the development of his mother’s dementia.

Loss of good health—During the difficult and unsafe migration journey, in addition to psychological trauma, many also had physical injuries along the way. For example, one care recipient suffered a blow to the head when he fell on the boat. Their boat was escaping from the police, and his caregiver suspected that his head injury was one of the reasons he had dementia. They also did not have access to first-aid tools for medical emergencies. For many participants, the escape from Vietnam was a harrowing experience and put refugees’ mental and physical health in a vulnerable condition.

Loss of possessions—Many also experienced loss of possessions after the war. More than half of the participants escaped right before or right after the war, and so they were unprepared to travel and could only bring limited belongings with them. Moreover, many participants’ possessions were taken away by the new government.

Loss of high-status occupations—Several caregivers described the experiences of their care recipients losing their high-status or prestigious occupations. Care recipients who previously held high ranks in the military or worked in well-respected positions suddenly lost their careers. Some of them were forced to leave their jobs, and others lost their positions due to having to leave Vietnam. After these care recipients resettled in the U.S., many could not obtain the same level of occupation they had in Vietnam and often worked in lower-status and much less lucrative jobs.

Loss in these different forms were mentioned repeatedly by participants and were often described in correlation to the care recipients' development of dementia.

Lack of Family or Community Support Systems in the U.S.

Another theme that emerged was the lack of support systems when first settling in the U.S. Taking months to adjust to their new lives in the U.S., participants shared that having to overcome difficulties such as language barriers and learning a new culture without their family was challenging. Many also described feeling exhausted due to their family responsibilities. Moreover, not only was there no family support when they first arrived in the U.S., but they also had very little community support. Many Vietnamese first arrived on the East Coast where few Asian Americans and Vietnamese were present. Without having someone who could relate to their culture in the community, participants recalled feeling extremely lonely. For example, one participant shared, 'I did not enjoy it because when I came, there was no Vietnamese in the high school I went to. I was the only one… So, I felt very lonely. I cried a lot.' (*Female, 55*)

Feelings of Unhappiness, Sadness, or Signs of Depression

Negative emotions, such as feelings of unhappiness or sadness, and signs of depression, were common among caregivers and care recipients prior to migration and after arriving in the U.S. Many caregivers commented on their care recipients' previous emotional disturbances during and after the Vietnam War. Then after arriving in the U.S., many had to take on new and demanding jobs while adjusting to the new environment and simultaneously, looking after their families.

One caregiver discussed her mother's demanding workload when first resettling in the U.S.:

> [My mother] worked a night shift at a chemical factory, which I think also plays into some of her health. I think she was struggling with depression. She was in an arranged marriage. She had to raise four kids pretty much on her own. I saw my mom as a very overwhelmed, exhausted woman all the time. (*Female, 37*)

One participant also reported feeling depressed during the first few months because it was difficult for her to adjust to the new environment and culture:

> It was really life-changing for me. It was totally different, everything was different - the culture, the weather, the environment, and the social life. Everything was different, so I really had a hard time adapting to the new environment. At first, I was really depressed. I thought that I hadn't made a good choice by coming [to the

> U.S.]. So, for the first few months, I didn't work. I didn't do anything. I didn't go to school, and just stayed home and helped with housework. (*Female*, 53)

In short, the hardships from the war, the resettlement process, and adapting to a new environment contributed to participants' feelings of sadness and depression.

Discussion

This study provides insights regarding the impact of the Vietnam War and resettlement experience in Vietnamese families facing dementia. More than half of the participants in this study were refugees who had resided in the U.S. for more than 20 years. Through our qualitative interviews, five themes emerged, and many of our findings are consistent with the existing literature in other refugee groups (e.g., Gold, 1992; Hauff & Vaglum 1995). To our knowledge, our paper is the first to focus on war and resettlement experiences in Vietnamese dementia caregivers and their care recipients.

Our first theme was that all families traveled to the U.S. from Vietnam at separate times, similarly to the findings by Nguyen (2019) that many families who came to the U.S. by boat were separated. Negative impact of family separation in refugees was evident in our findings and supported by the literature. Mental health concerns, such as depression, anxiety, PTSD symptoms, poor quality of life, or high emotional distress, are related to family separation (Bogic et al., 2012; Miller et al., 2018; Rousseau et al., 2001). Furthermore, the mental health of Vietnamese dementia caregivers may be affected even more than their non-caregiver counterparts because caring for older adults with dementia is physically and psychologically draining (Sörensen et al., 2006). Ta Park and colleagues found that trauma as a result of the Vietnam War, harsh experiences as refugees, and other factors such as low SES affected the mental health of Vietnamese caregivers in the U.S. (Ta Park et al., 2018).

For our participants who immigrated by boat, the theme of harsh and unsafe journeys was described. Caregivers and care recipients were victimized by different types of threats – perceived and actual harms to their safety. Unfortunately, the current study did not explore participants' perceptions of how their immigration journey may have directly affected their health and mental health; however, this should be explored in the future to understand long-term effects of harsh resettlement processes in Vietnamese and other refugee populations.

Many participants also shared experiencing loss in various forms, including losing family members, good health, possessions, and high-status occupations. Other forms of loss in refugees have been described in the literature, such as loss of feelings of stability and security, loss of interpersonal connections, loss of identity, loss of dignity (Taylor et al., 2020), and loss of culture (Betancourt et al., 2015). Caregivers shared that the multiple forms of loss their care recipients experienced may have had contributed to the development of their dementia. This was indirectly supported by the current literature that psychological stress and trauma are significant risk factors for developing dementia (e.g., Wang et al., 2016, Yu et al., 2020). These multiple forms of losses can cause chronic mental health problems (Kartal et al., 2018), which may affect the ability of caregivers to provide optimal care to their care recipients years later. In addition, research has shown these losses can be carried through into the next generation (Boehnlein, 1987; as cited in McLellan, 2015).

Thus, Vietnamese caregivers who are already at risk for health and mental health disparities may have impaired physical ability to provide care.

Another prominent theme, lack of social support, is consistent with previous literature describing when refugees first arrive in the resettlement country (e.g., Hynie, 2018; Stewart, 2014). Having few or no relatives, friends, or people from one's own cultural background can lead to various negative mental health issues, such as anxiety and depressive symptoms (Pernice & Brook, 1996). Furthermore, Beutel and colleagues (2017) found in their study that loneliness was related to depression, general anxiety, and suicidal ideation. Feeling lonely was also related to greater cognitive decline (Luchetti et al., 2020).

The last theme, feeling sad and depressed, is not surprising given all the stressors and experiences Vietnamese families underwent prior to and after immigrating to the U.S. Undergoing multiple stressors, the risk for depression and psychiatric morbidity is high (Hauff & Vaglum, 1995). Refugees often experience high psychological stress, and identified mental disorders usually include PTSD, mood disorders, and anxiety disorders (Fazel et al., 2005; Hynie, 2018; Murray et al., 2010) Furthermore, research shows that these feelings often persist and do not diminish after two to three years (Lin et al., 1979). Evidence has shown that not only psychological trauma but also depression and stress have an impact on increasing the likelihood of developing dementia (Rafferty et al., 2018; Ritchie et al., 2021; Yu et al., 2020). In addition, previous trauma and mental health symptoms such as depression may contribute to poorer caregiving abilities in dementia caregivers.

As mentioned earlier, Vietnamese dementia caregivers are at risk for poor mental health given the accumulated stress and allostatic load evidenced in many refugees (Henkelmann, 2020). A recent meta-analytic review suggested that refugees' migration experiences contribute to allostatic load due to factors such as uncertainty about the future, unemployment, unstable access to healthcare, and food insecurity (Henkelmann, 2020). Nguyen and Goel (2015) further stressed that these social determinants of mental health significantly impact older Vietnamese Americans due to their refugee status and likelihood of having low socioeconomic status. The multiple forms of loss discussed also contribute to overwhelming stress – loss of jobs and social support (Dich et al., 2015). Our findings showed that caregivers in this study experienced multiple types of stressors. Thus, these cumulative stressors and the social determinants of health can further exacerbate Vietnamese caregivers' stress.

This study was not without limitations, including the small number of participants in just one region of the U.S., limiting the generalizability of findings to non-Vietnamese dementia caregivers outside of California. Although this study described participants' immigration experiences and the potential impact on their health, mental health, caregiving, and their care recipients' dementia, many of these relationships were not explicitly shared by caregivers. Future research should directly investigate the impact of the immigration experience and trauma on caregiving outcomes using more specific queries or longitudinal data. Another limitation is that we did not interview care recipients directly about their own experiences due to their level of cognitive impairment. However, we believe the focus on general trauma

and dementia (regardless of first-person experience, inter- or intra-generational trauma) is an important area of focus.

In spite of the limitations of the study, the salient themes are meaningful in both research and practice. In-depth analysis of participants' experiences enriched our understanding of Vietnamese dementia caregivers' and care recipients' unique struggles. Furthermore, it provides future research directions to investigate the impact of war and resettlement process on dementia and caregiving in other refugee and immigrant populations.

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Clinical Implications

- We recommend providers become more informed about refugees' unique history and experiences to better detect comorbid health and mental health disorders for early treatment. Specific cultural and awareness training for providers who see a large number of refugees could be implemented in clinical settings.
- We recommend providing routine psychological and cognitive screening for older adults who have a refugee background. In addition, culturally and linguistically appropriate assessments are particularly important in this process.
- Clinicians and providers treating someone with dementia should have referrals to culturally and linguistically appropriate resources on hand, such as local ethnic-specific support groups, in-language social and mental health services, and culturally competent ethnic providers.

Table 1.

Interview questions.

1. *Can you tell me a bit about you and your family?*
Probing: number of siblings, parents, and other family members; and where they all currently live; where caregiver and care recipient live; currently whom do caregiver and care recipient live with.
2. *Tell me about your (or your care recipient's) immigration to the U.S. (and to California).*
Probing: year, mode of transportation, how long the journey took, any delays, who they traveled with, immediate or gradual decision.
3. *How was the [immigration] experience for you?*
Probing: specific emotions such as scared, excited, sad, etc.; reasons for their emotions (pay attention to any potential trauma).
4. *What, if any, aspects of your background or identity influence how you approach taking care of your care recipient? By background or identity, I mean, for example, where you or your family are from, your race or ethnic background, or your faith or religion.*
Probing: issues surrounding filial piety or sense of obligation to care for care recipient; *'Please give me some examples of how your background or identity comes into how you care for your care recipient.'*

Table 2.

Sample demographics ($N = 11$).

Variable	*n*
Caregiver	
Gender	
Female	8
Male	3
Age (in years)	
37 - 50	3
51 - 60	3
61 - 70	4
71 - 86	1
Age at immigration (in years)	
3 - 10	2
11 - 20	1
21 - 30	4
31 - 40	2
41 - 66	1
Employment	
Employed	7
Unemployed	1
Retired	1
Relationship to care recipient	
Daughter/son	6
Spouse	3
Grandson	1
Sister-in law	1
Care Recipients	
Gender	
Female	6
Male	5
Age (in years)	
65 - 70	4
71 - 80	2
81 - 91	5
Age at immigration (in years)	
32 - 40	2
41 - 50	2
51 - 60	2
61 - 67	2

Note: Numbers do not add up to the entire sample of participants because of missing values.

Table 3.

Theme frequencies.

Theme	*Number of caregivers endorsed*
1) Immigrating to the U.S. separately from family members	7
2) Difficult and unsafe journey	5
3) Experiences of loss	5
4) Lack of family or community support systems in the U.S.	5
5) Feelings of unhappiness, sadness, or signs of depression	4

Note: Themes could have been discussed multiple times in each caregiver interview, but is only represented one time in the above table.