

# Perceptions and Experiences of Family Caregivers of Older First-Generation Chinese Americans With Dementia

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## Background

### Family Caregiving

Mental, physical, and financial challenges:

- Psychological symptoms
- Lower self-rated physical health
- Higher rates of chronic diseases or frailty
- Financial strain due to the time consumed and deprivation of working hours

### Chinese Americans

- The largest subgroup of Asian Americans
- Stigma toward cognitive impairment, less likely to seek help
- Filial obligation perpetuated in Asian culture
- Language and cultural barriers
- Xenophobia impacting mental well-being



### COVID-19 Pandemic Impact

- Social isolation increased impairment of care recipients
- Language barriers hindered access to health services
- Asian xenophobia worsened due to blaming on the origin of the virus

Chinese and other Asian American family caregiver experience is understudied

## Purpose

To identify individual and contextual factors influencing the experience of family caregivers of first-generation older Chinese Americans with dementia

## Research Design and Method

### Design

- Cross-sectional qualitative study conducted in July 2022 in Washington, USA

### Sampling

- 24 Chinese American caregivers recruited
- Inclusion criteria:
  - A family caregiver providing care to a Chinese American enrolled in the Program of All-Inclusive Care for the Elderly (PACE) offered at a community-based organization
  - Care recipient living in their home in the Chinatown-International District, Seattle.
  - Care recipient with dementia, defined by Rowland Universal Dementia Assessment Scale scores  $\leq 27$  (Forté et al., 2021)

### Data Collection

- Semi-structured interviews using participant's preferred language
  - Cantonese + Mandarin (n=7)
  - Mandarin (n=8)
  - English (n=1)
- Questions guided by the Health Belief Model (HBM) (Janz & Becker, 1984) and the National Institute on Minority Health and Health Disparities (NIMHD) framework (NIMHD, 2017).

### Data Analysis

- Thematic analysis (Clarke et al., 2015) and deductive coding

## Results

### Sample (N=16)

		n (%)	Median (IQR)
Age (years)			55 (50-60.5)
Sex	Male	6 (37.5)	
	Female	10 (62.5)	
Living status	Living together	8 (50.0)	
	Living apart	8 (50.0)	
Having siblings	Yes	15 (93.8)	
	No	1 (6.3)	
Quit job for caregiving	Yes	9 (56.3)	
	No	5 (31.3)	
	N/A*	2 (0.13)	
Relation with care recipient	Son	6 (37.5)	
	Daughter	8 (50.0)	
	Daughter-in-law	2 (12.5)	

Note. \*Two participants were housewives without paid job.

### Individual Factors

**Definition:** Family caregiver's characteristics, such as perceptions, feelings, attitudes, knowledge, and skills, that shape caregiving experiences with family members with dementia

Perceived severity & susceptibility	<i>"I don't understand, <b>not really sure what that [dementia] means</b>" - P02, daughter aged 57</i>
Coping skills	<i><b>"Adjust yourself! Go running, listening to music..."</b> I always tell myself to only let unpleasant stuff last for 10 minutes." - P07, live-in daughter aged 50</i>
Knowledge & empathy towards care recipients	<i>"Since 2019 to now, we ask her whether she wants to go to Day Center... What I worry the most is that <b>she is very forgetful. If she forgets anything, how we are going to find it?</b> She will suspect others when she cannot find her stuff." - P02, daughter aged 57</i>

### Interpersonal Factors

**Definition:** Interactions between the caregiver and their family (spouse, children, siblings, and care recipient)

Family support	<i>"If I go to other hospitals, my wife goes with me to help me. My wife's English is not very good, sometimes I ask my children and bring them alone. I don't understand English. So <b>they help me if we have any language barriers.</b>" - P12, live-in son aged 62</i>  <i><b>"We take turns..."</b> who cooks for what days of the week, our family share the responsibility. Well... <b>COVID... constantly disrupt our care plan.</b>" - P11, daughter-in-law aged 50</i>
Dementia symptoms of care recipients	<i>"No, <b>I don't let him go anymore. What if he doesn't remember how to get back?</b> Who has the time to find him? I don't let him go, and then he doesn't want to go outdoors anymore." - P14, son aged 52</i>  <i>"For the elderly, she is not willing to wear masks, <b>not willing to cooperate. So, since COVID-19 started, I seldom bring her out.</b>" - P02, daughter aged 57</i>

### Community Factors

**Definition:** The resources and support provided by the partnering community-based organization (CBO)

Resources from the CBO	<i>"[Her wheelchair] did not fit in my car. Sometimes we drove 5 or 6 hours out there... It was like this for several years. Until we met the [CBO] and in the PACE program. <b>They have transportation, medication delivery; basically, everything is on point.</b> ...I had no job for a half year in order to take care of her. I didn't know anything then. <b>[CBO] told me how things worked...</b>" P06, live-in son aged 62</i>
CBO's coping strategies during pandemic	<i><b>"She originally did physical therapy... it was suspended due to the pandemic.</b> She could not walk on her legs, would like to see a doctor but cannot see one due to the pandemic... (blurry)...This caused us a lot of affliction. We became depressed seeing her being depressed... now it's finally getting better." – P07, live-in daughter aged 50</i>  <i>"There was a period of time <b>we could apply for an iPad from the organization to learn Tai-Chi from home..</b>" - P11, daughter-in-law aged 50</i>

### Societal Factors

**Definition:** Societal factors focusing on the social norms and values within the Chinese American community and factors of the large U.S. context and systems

Spiritual support	<i><b>"We are all Buddhists, but not engaging in any [faith-based] activities.</b> Just follow it in our mind, that's it." - P03, live-in daughter aged 67</i>
Filial respect	<i><b>"I guess it's what a son should be. It's annoying, but so be it!</b> Just for however long she can live. I feel better after I think through. I also <b>hope my children can treat me the same.</b> I am setting a role model for them." - P12, live-in son aged 62</i>  <i><b>"I want to take care of my mom, my in-law, but I don't want my kid take care me."</b> - P01, live-in daughter aged 60</i>
Asian xenophobia	<i>"People were smashing stores in Chinatown, things were broken, right?... Not dare to go for a long time. I <b>did not dare to do grocery shopping in Chinatown during that pandemic period.</b>" - P11, daughter-in-law aged 50</i>  <i><b>"I couldn't feel it [Asian xenophobia] because I don't even step out of the door."</b> - P12, lived-in son aged 62</i>
Immigration history & policy	<i>"The [visa screening] has been postponed right now. No idea when he can come. <b>We have already applied for more than 10 years.</b>" - P08, daughter aged 49</i>

## Implications

- Our findings showed the common and unique challenges faced by Chinese American family caregivers, some of which were influenced by the COVID pandemic.
- Prioritizing family-oriented interventions, acknowledging social isolation and xenophobia experiences, and expanding community and governmental resources are necessary to assist Chinese American family caregivers.

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