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Multi-level factors of Chinese American family caregivers of individuals with dementia during COVID-19

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ABSTRACT

Chinese American caregivers face unique hurdles for family members with dementia. This study identified individual and contextual factors influencing family caregiving and ways in which caregivers managed pandemic-related challenges. A cross-sectional qualitative study was conducted in the Northwest region of the United States. Eligible Chinese American caregivers from a community-based organization were recruited. Semi-structured interviews were in participants' preferred languages. Thematic analysis and deductive coding were used. The analysis (N = 16) showed that individual factors contained family caregivers' perceptions, coping skills, knowledge, and empathy. Interpersonal factors included the dynamic of family support and dementia symptoms of care recipients, adversely affected by the pandemic. Community factors explored the resources provided by the partnering organization and adaptations to pandemic-related challenges. Societal factors encompassed participants' reliance on spiritual support groups, the influence of filial respect, perceived Asian xenophobia during the pandemic, and the impact of immigration history and policy on caregiving experiences.

Introduction

Family caregiving significantly affects caregivers' psychological, physical, and financial well-being.[1] While similar to other family caregivers, Chinese American caregivers, the largest subgroup of Asian Americans, encounter other conundrum.[2] They face stigma and misconceptions regarding mental disorders, cognitive disorders, and dementia.[3] They are less likely to seek help unless they perceive a dire need.[4] Moreover, filial respect, also known as filial piety, is a core value in parent-child relationships within Chinese and other Asian cultures. It emphasizes honoring, supporting, and showing devotion to parents and elders and plays a significant role in shaping family caregiving for individuals with dementia.[5] The aggregated data showed Asian American caregivers more commonly reported caring for their parents; however, higher reluctance to take on caregiving responsibilities was also reported compared to other race and ethnicity groups.[1] Little is known about how filial respect presents among generations of Chinese Americans in adapting this traditional value in family caregiving.

The Coronavirus Disease 2019 (COVID-19) pandemic exacerbated cognitive impairment in individuals with dementia, thereby increasing the burden on family caregivers worldwide.[6–8] Language barriers have further hindered Chinese and other Asian Americans' access to health services during this challenging time.[9] Additionally, Asian xenophobia in the U.S. becomes worsened following the pandemic's onset.[10] In such challenging times, Chinese Americans face even greater difficulties in coping with the unique challenges posed by the pandemic.

Research regarding racially minoritized dementia caregivers' well-being primarily focuses on African Americans and Hispanic Americans. The experiences of Asian Americans and American Indians are understudied.[11] Despite cultural and linguistic diversity among Asian Americans, the existing studies often homogenize Asian Americans into one group.[12] Such orientation and study design limit the potential to support Asian American families with culturally responsive solutions.[13]

To bridge the gap, this paper addresses the scarcity of information on the individual and contextual factors that influence dementia

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caregiving among Chinese American families. Notably, Asian Americans are often studied as an aggregate group. This approach consequentially masks significant cultural, socioeconomic, and immigration-related differences among diverse Asian groups. By concentrating on the largest Asian American group, this research endeavors to offer culturally responsive solutions and contribute to developing targeted support programs, ultimately enhancing the well-being of Chinese American family caregivers.

Material and methods

This cross-sectional, descriptive qualitative study was conducted in the Northwest region of the United States in 2022. It was part of a larger effort to assist a local community-based organization (CBO) in expanding its service to the Chinese community.

Sample and sampling

Purposive sampling was used.[14] The target population was the family caregivers of the recipients of the Program for All-Inclusive Care for the Elderly (PACE), a comprehensive care program funded by the U.S. Medicare and Medicaid. The inclusion criteria were: A family caregiver providing care to a PACE recipient who lived in their home in the Chinatown-International District and had a Rowland Universal Dementia Assessment Scale (RUDAS) score of 27 or lower,[15] which was considered at least mild cognitive impairment. Ranged from 0 to 30, RUDAS scores lower than 23 points are suggestive of dementia, 23 to 27 as a mild neurocognitive disorder, and higher than 27 as normal.[15] The cut-off score of 27 was chosen to encompass a broader definition of dementia, including a mild neurocognitive disorder. The PACE recipients' RUDAS scores ranged from 5 to 26 with a median of 20.5, indicating largely with dementia and a few with mild cognitive impairments. A total of 24 eligible caregivers were identified in the CBO's system.

Data collection

The semi-structured interview guide was developed following the Health Belief Model (HBM)[16] and the National Institute on Minority Health and Health Disparities framework.[17] The purpose was to capture individual, interpersonal, community, and societal factors that influence family caregivers' experience. Sociodemographic information on age, sex, primary language, occupation, whether leaving workforce for caregiving, relationship with the recipient, length of caregiving, and recipient's health conditions was obtained at the beginning of each interview.

The interview questions (see Appendix Table 1) were stated in English, Mandarin, and Cantonese. The questions were collaboratively authored by the first two authors, the CBO's program director, and an interpreter from the CBO. The Mandarin version was developed by the English-Mandarin bilingual first author and validated by the second author, an English-Mandarin bilingual and bicultural researcher with expertise in interpretative research. Minor corrections were made. The Cantonese version was verified by the interpreter to be comprehensible to Cantonese-speaking study participants younger than 60 years old. Participants were expected to have a certain degree of understanding of Mandarin, indicating no issues with using a mix of Cantonese and Mandarin when needed.

The interviews were conducted remotely through encrypted telephone calls, a communication approach the caregivers were most familiar and comfortable with than in-person interviews. The interviews were predominantly in Mandarin and Cantonese, except for one, as the participant preferred English. The lengths ranged from 13 min to 44 min, with an average of 24 min.

The IRB protocol for this study (STUDY00015663) was reviewed by the University of Washington's Human Subjects Division (HSD) and granted exempt status. With the CBO members' permission, the first author made phone calls to prospective participants to inform them about the study's purpose, interview outlines, length, and interviewees' rights to opt-out at any time. If agreed, the prospective participants provided verbal consent in the presence of both the first author and CBO member as witnesses. Interviews were scheduled after verbal informed consent was obtained. The study was independent of the CBO's regular services, in which caregivers were assured of non-interference from CBO staff and wouldn't affect their access to CBO services.

Data analysis

All interviews were administered from July 20 to 26, 2022. Braun and Clarke's Phases of Thematic Analysis were employed.[18] In conjunction with a computer-assisted qualitative data analysis software, Dedoose (version 9.0.46, 2023),[19] the first author became thoroughly familiar with the data by reading and re-reading all transcripts. The same first author coded the content of the 16 transcripts with words, terms, or statements reflective of individual, interpersonal, community, and societal factors. To ensure credibility,[20] another English-Mandarin bilingual coder independently coded the longest interview transcript. A 62 % intercoder consistency was determined by calculating the percentage of the codes consistently applied by both coders (numerator) over the total number of quotes coded by either coder (denominator). A preliminary codebook was developed after two coders reached a consensus.

The descriptive codes were organized, linked, and netted into a thematic map. The patterns and connections between the codes were examined and then grouped into potential themes during the mapping process. In consultation with other authors, the first author critically analyzed the myriad of themes and sub-themes that fell within the frameworks of individual, interpersonal, community, and societal factors regarding the lived experiences of the caregivers. Themes were defined. For example, the shared responsibility of caregiving provided by siblings, spouses, and other relatives was constantly mentioned. Those codes were grouped into "family support" as an interpersonal factor influencing caregiving experience. The same themes were repeatedly found in the interviews; thematic saturation was reached.[21]

Results

Sample description

Seventeen of the 24 eligible caregivers agreed to participate. One interview was removed from the analysis because the caregiver was an agency caregiver but misclassified in the CBO's system. The final sample size was 16.

Median age was 55 years (IQR=50–60.5), the majority (62.5 %) female. Primary languages included Cantonese, Toishanese, Mandarin, and English. Half of the caregivers resided with the recipient. One had no siblings, nine left their jobs (e.g., catering server and real estate renovator) to devote full-time to caregiving, and five balanced their regular job with caregiving duties. Two were housewives. Eight were daughters of the care recipients, two were daughters-in-law, and the remaining six were sons of the recipient. See Appendix Table 2 for the relevant demographics and interview information on study participants.

Individual factors

Individual factors were family caregiver characteristics, such as perceptions, feelings, attitudes, knowledge, and skills, that shaped the caregiving experience with family members with dementia. The factors encompassed family caregivers' perceived severity and susceptibility toward dementia, coping skills including self-awareness and self-efficacy, knowledge of dementia symptoms, and empathy towards care recipients.

Perceived severity and susceptibility toward dementia

Most participants demonstrated an understanding of the severity of dementia on the person with the condition, particularly their judgment, communication, and independence in daily activities. The participants had varying perceptions regarding the susceptibility of dementia. Some believed in the inheritable nature of dementia, expressing their concerns about the possibility of developing the condition themselves: "Since my mom having, most likely I'll get it" (P01, live-in daughter aged 60). Additionally, some participants dichotomized dementia and natural aging, such as natural versus unnatural or normal versus abnormal. On the other hand, some participants showed limited familiarity with the term "dementia," as P02 (daughter aged 57) stated: "I don't understand, not really sure what that [dementia] means."

Coping skills and feeling burnout

Feelings of exhaustion and burnout were consistently highlighted in the interviews. Coping skills were an essential factor in navigating the challenges of caregiving. The participants demonstrated self-awareness of their negative emotions and developed various coping strategies to manage them. For example, P07 (live-in daughter aged 50) expressed, "Adjust yourself! Go running, listening to music… it's all right, let me cry, then I'll be fine. I recover quickly. I always tell myself to only let unpleasant stuff last for 10 min." P06 (live-in son aged 62) managed his emotion with a different approach, "Sometimes (pause) I suppress myself for many things, let's say…ahh…sometimes I am so exhausted, want to take a trip back to China."

In addition to recognizing their own negative emotions, possessing self-efficacy in their ability to provide care can also assist caregivers in coping with stress. Most participants displayed a sense of self-efficacy in their caregiving role. For instance, P16, a live-in daughter aged 50, stated, "I am quite confident. Temporarily speaking, at least I am taking good care of her in daily life."

Despite their coping efforts, many participants had a sense of being forced into caregiving with limited choices, as illustrated, "I am forced to. I have no choice… Overall…I have no freedom, just like being stuck in a cage!" (P07, live-in daughter aged 50). While participants mentioned coping strategies such as running or listening to music, internalizing caregiving responsibilities independently without seeking external support from others or community resources was identified in the data.

Knowledge and empathy

The participants had different knowledge about the abilities and limitations of individuals with dementia. Their established knowledge about their care recipient influenced their caregiving decisions. Some held reservations about the capabilities of the care recipients with dementia-related symptoms, such as "poop on pants" from or to treatment sessions, "being very forgetful," and "suspect others when unable to find stuff."

There was less willingness to outsource the caregiving responsibility to others like adult day services (ADS). Some participants gave up encouraging their care recipients to participate in ADS out of empathy to avoid making them feel abandoned. As P05 (live-in son aged 48) expressed, "I don't want to constantly bring up the Day Center [to the care recipient]… I don't want to let her have the sense that her son wants to abandon her or get annoyed by her to give her away."

However, understanding dementia symptoms and empathizing with care recipients also positively influenced the participants' mindset towards caregiving. As P01 (live-in daughter aged 60) stated, "It's frustrating, but as long as you understand and you remind yourself, ok, that's the illness, it's not her, then it's ok."

Interpersonal factors

Interpersonal factors described the interactions between the caregiver and their family (spouse, children, siblings, and care recipient). There were two main themes: (1) sharing caregiving responsibilities among family members, which was disrupted during the pandemic, and (2) influence of dementia symptoms on the overall caregiving experiences.

Family support

Most participants had siblings, so caregiving responsibilities were often shared among family members. The burden of caregiving appeared to fall more on family members who were single or whose children had already grown up than those had other family obligations. Some families implemented a rotation family care plan for the responsibilities. This strategy involved sharing caregiving duties among family members, such as taking turns cooking for assigned days of the week. For healthcare needs, assistance from spouses or children was used to overcome language barriers and obtain knowledge support. For example, P12 (live-in son aged 62) talked about how family members proficient in English helped during medical appointments: "If I go to other hospitals, my wife goes with me to help me. My wife's English is not very good, sometimes if necessary I ask my children and bring them alone."

The dedication to caregiving sometimes came at the cost of neglecting their immediate families and relationships. Some participants shared that their devotion to caregiving resulted in less time spent with their spouses and children. This neglect was observed within the family. "[My wife and kid say] I stay with my mom all the time and ignore our home, "said P12 (live-in son aged 62).

However, the quarantine and isolation regulations at the start of the COVID-19 pandemic disrupted the shared caregiving plan. As P11 (daughter-in-law aged 50) explained, "Sometimes people got COVID, they were afraid of coming over. Or they had contact with people who got COVID, they could not come… constantly disrupt our care plan."

Dementia symptoms of care recipients

The care recipient's forgetfulness made the participants worried about them getting lost or not being able to find their way back home. Consequently, they limited their care recipient's outdoor activities to ensure care recipient's safety and reduce time spent on looking for them. Further, due to the nature of forgetfulness, the care recipients often failed to recognize the participant's efforts in their care to them. This lack of recognition led to feelings of being unappreciated and added to the emotional burden of caregiving. As illustrated by P13 (live-in daughter aged 68), "I put so much effort into taking care of her every day, and she would say things like that as if you don't exist."

Paranoia symptoms presented additional challenges for caregivers to manage. Some families faced disagreements and conflicts due to misunderstandings of these symptoms. Other families that had a better understanding of the progression of dementia developed coping strategies to handle the frustrating and repetitive behaviors associated with paranoia. P10's family (daughter-in-law aged 58) demonstrated a more supportive approach in response to the paranoia symptoms by letting go of arguments and reassuring the care recipient: "She always says that my daughter-in-law takes my passport... So, then I let it go, I cannot explain it clearly. I would just say 'yes, yes, I took them all.' "

Some participants had more positive experiences when their care recipients had less severe dementia symptoms, and their behaviors and social engagement were less affected by their symptoms. P16 (live-in daughter aged 50) described her mother's proactive approach to engaging in simple exercises (e.g., "moving around arms and legs," "tapping on legs"), which significantly improved her motivation and overall well-being.

The cognitive impairment experienced by the care recipients impacted their compliance with the pandemic regulations. The participants expressed concerns about their care recipient's reluctance to wear masks and cooperate with the safety measures outside the home. As P02 (daughter aged 57) shared, "For the elderly, she is not willing to wear masks, not willing to cooperate. So Since COVID-19 started, I seldom bring her out."

Community factors

Community factors described the resources and support of the partnering CBO. The resources included transportation, translation services, and referral functions. The study also identified how the partnering CBO coped with barriers caused by the pandemic and the effectiveness of their strategies.

The resources from the CBO

The resources from the partnering CBO had shown to be extremely helpful in facilitating caregiving for first-generation Chinese Americans with dementia. Many participants expressed their appreciation for the assistance provided by the CBO, particularly their transportation and translation/interpreter services. As P06 (live-in son aged 62) stated, "I am more relaxed now. They have transportation and medication delivery; basically, everything is on point."

Moreover, the partnering CBO connected the participants with existing governmental resources, provided valuable information, and helped them receive caregiver training to become a certified caregivers. As a result, the participants became eligible for financial assistance, which supplemented the income they lost due to caregiving. As P06 (live-in son aged 62) described, "[name of the CBO] told me how things worked... They said you needed take classes. So, I studied for 12 hours and started to work for a half month right after. Finally got the two-week pay."

The CBO's coping strategies during the pandemic

The partnering CBO's functions were disrupted during the pandemic, which affected the participants and their care recipients. One example was the pause of their on-site physical therapy. As P07 (live-in daughter aged 50) explained, "[physical therapy] was suspended due to the pandemic. She could not walk on her legs, would like to see a doctor but cannot see one due to the pandemic... We became depressed seeing her being depressed." To adapt to the pandemic, the CBO shifted to in-home physical therapy and offered mobile devices for health promotion among older adult clients. However, the participants found it challenging for their care recipient to do health promotion effectively when the interactions were in a virtual environment. For instance, P11 (daughter-in-law aged 50) mentioned, "There was a period of time we could apply iPad provided by the organization to learn Tai-Chi from home. However, she did not even persist over a month and wanted me to return the iPad... she was just not willing to."

Societal factors

Societal factors focused on the social norms and values within the Chinese American community and factors of the large U.S. context and systems. Factors identified included the participants' acceptance and reliance on spiritual support groups, the influence of filial respect, caregivers' perceived Asian xenophobia during the pandemic, and roles of immigration history and U.S. immigration policy.

Spiritual support

Spiritual groups or support groups played limited roles in the participants' lives. Active participation in religious or spiritual activities was uncommon. Even when some participants had religious beliefs, their engagement was limited. Like P03 (live-in daughter aged 67) shared, "We are all Buddhists, but not engaging in any [faith-based] activities. Just follow it in our mind, that's it."

Filial respect

The traditional value of filial respect strongly influenced how the caregivers perceived family caregiving. Most participants viewed caregiving as a duty they must fulfill without extreme positive or negative emotions. P05 (live-in son aged 48) shared, "From my point of view, taking care of parents is a calling. I don't think I have given up anything because of taking care of her."

While they were following the traditional expectations, the expectations of their children differed. Some participants planned to pass on the traditional value of filial respect by "setting a role model" for their children now and hoped they would treat them similarly in the future. Others expressed the willingness to take on their filial responsibilities for their parents but were reluctant to "burden" the next generation with caregiving expectations and responsibilities.

Asian xenophobia

The participants were aware of the Asian hate crimes that occurred in the local Chinatown during the pandemic and were fearful and concerned. Some even avoided going out to places like Chinatown due to safety concerns. However, when the interviewer directly asked about Asian xenophobia, most participants felt the environment was generally "okay." Notably, some participants and their care recipients did not go out much even before the pandemic. As P12 (lived-in son aged 62) shared, "Basically, these four years, I only go out when taking my mom to doctors, take care of my yard, trim the trees at my front door. I don't really go out, so I cannot sense [the societal] atmosphere change."

Immigration history and policy

The immigration history and policy shaped the participants' access to family support and resources. The participants who immigrated during China's cultural evolution in 1970−1980 were motivated to move due to their dissatisfaction with the political and historical background at that time. However, the economic opportunities and resources in the new country were limited for them. As P14 (son aged 52) described, "...Definitely people wanted to escape from China once you got a chance. I did. I got out, but I could not find any decent jobs, just working in the kitchen, doing remodeling, these types of jobs!"

Furthermore, immigration policies influenced their family support and resources available for caregiving. For instance, P08 (daughter aged 49) shared the challenges, “We have a younger brother who is in China right now.…the [visa screening] has been postponed… we have already applied for more than 10 years.”

Discussion

This study identified individual, interpersonal, community, and societal factors that shaped first-generation Chinese American family caregivers’ experiences when caring for an older family member with dementia during the pandemic. While the findings were presented in a linear way, these factors were interconnected in influencing the participants’ caregiving decisions, quality of life, and well-being.

Family support to foster social connection for Chinese American caregivers

Previous research has shown the association between caregiving and social isolation in caregivers of people living with dementia.[22] Our findings underscore a potentially prevalent issue of social isolation among Chinese American family caregivers. The pandemic is likely to intensify the burden of caregiving and exacerbate feelings of loneliness and social isolation among caregivers.[23] Lacking respite care during the pandemic was reported to impact family caregivers’ physical and mental health.[24]

Our study findings also revealed that caregiving had a significant impact on their relationships with their children and partners, and caregivers felt emotional fatigue and had limited time for social interactions. To address these challenges comprehensively, interventions must shift focus from individual caregivers to encompass entire families. While promising evidence-based programs for supporting family caregivers living with dementia individuals exist, their availability remains limited. Effective initiatives include phone-based assessments to identify unmet needs, home-based programs targeting environmental stressors, phone counseling services, and educational training enhancing caregivers’ knowledge, self-efficacy, and skillset.[25] The insights shed light on Chinese American family caregivers’ challenges and emphasize the need for family-oriented support measures to address their well-being and social connectedness.

The importance of tailored programs designed by CBOs

The role of CBOs in providing culturally appropriate services for dementia care for Asian American groups has been documented in the literature. Immigrant-serving CBOs often are the frontline whenever Asian immigrants seek help for cognitive impairment concerns. They can assist with early detection of dementia, provide services, and refer caregivers to other resources.[26] A qualitative study interviewing 26 Chinese American family caregivers in Texas and California highlighted deficiencies in transportation services, culturally tailored programs, and bilingual staff within some CBOs.[24] Our study findings support that CBOs can provide holistic family-centered care for Chinese American immigrants with dementia by providing transportation and translation/interpreter services.

Xenophobia impact on Chinese American caregivers during the pandemic

Studies focusing on Asian xenophobia during the pandemic[9,10] showed rising racism and xenophobia across the United States of America, especially targeting Chinese Americans in the Chinatown area. Lee and colleagues’ study during the pandemic showed that Chinese American family caregivers experienced discrimination, even verbal abuse, from facility staff.[24] Unexpectedly, despite the heightened awareness of Asian xenophobia during the pandemic, our participants reported experiencing lower levels of effects of Asian xenophobia on their lives than we had expected. Xenophobia-related safety concerns in Chinatown apparently changed some participants’ social behaviors and interactions outside their homes. However, their living situations as caregiver already limited their direct exposure to Asian xenophobia in their daily lives. The intensified isolation after the start of the pandemic may have led to lesser exposure to the xenophobic events happening outside their homes. As a result, they may not have sensed the changes in the societal atmosphere related to Asian xenophobia. In addition, the inconsistency may be associated with the samples as the studies discussed in Wang et al.[10] used national race-stratified mortality or state-reported hate crimes data, not specifically focusing on family caregivers engaged in heavy caregiving for individuals with dementia.

Filial respect on caregivers’ perception and expectations of children

Filial respect strongly influences the caregivers’ perceptions of caregiving. Caregiving was taken as an obligation, a vocation, an unavoidable duty to take on for the participants as what they must do instead of having extreme emotions. The influence of filial respect on Asian family caregiving is documented by the scholarly work done in East Asia Chinese cultural settings[27,28] and Western societies.[24,29] Our study shows how filial respect continues to shape the first-generation Chinese American caregivers’ perception towards caregiving and ways to fulfill their culturally expected roles. It is also important to note that the expectations around filial respect may be shifting among Chinese Americans, as suggested by some participants’ responses. A study investigating the aging expectation change in Canada[30] showed that almost all of their study participants (Chinese immigrants in Canada) reduced the filial expectations of their offspring. As the value and practice of filial respect evolves, future Chinese American family caregivers may have diminished perceived filial caregiving obligation. Hence, there could be an increasing need for community and governmental resources to support Chinese Americans in their caregiving responsibilities, especially for those caring for individuals with dementia.

Limitations

Several limitations should be acknowledged. First, the study was organization-based, focused on a specific program (PACE), and was conducted during the COVID-19 pandemic. These factors created a unique context for the participants’ experiences. The purposive sample does not fully represent the diversity and complexities of all Chinese American families that have a member with dementia and interface with different sociocultural and political climates towards the Asian population. The generalizability of the findings to other settings or contexts is limited. Second, a systematic review of family caregiver resilience by McKenna et al.[31] showed cohabitating spouses/partners are often the primary family caregivers for individuals with chronic neurological conditions (e.g., brain injuries, dementia), followed by children. This may be attributed to 80 % of their reviewed articles being from Europe and North America. It is essential to note that our study sample consisted solely of care recipients’ children and daughters-in-law. Third, all participants shared long-term caregiving experiences rather than insights from caring for individuals newly diagnosed with dementia. The experiences and perceptions of stigma, understanding of dementia, early care planning, and their management and support needs are not captured in this study’s findings.

Conclusions

The findings of this study have important practice and research implications for addressing the challenges faced by family caregivers in Chinese American communities. Ploeg and colleagues[32] promoted family-oriented care programs as essential for supporting individuals with dementia and their family caregivers, which is relevant to Chinese American families as Chinese culture places a high value on family fields. Healthcare providers should recognize both the caregiver and care recipient as “clients” and facilitate their access to health and community support services to meet the complex caregiving requirements faced by Chinese Americans. Additionally, support programs like All-Inclusive Care for the Elderly (PACE) that incorporate family-oriented care strategies, including caregiver training and reimbursement mechanisms, can be beneficial. In clinical practice, it is imperative to focus on increasing family caregivers’ knowledge and ease of access to local community resources. This involves not only disseminating information about available government assistance programs but also actively guiding caregivers toward these resources. This effort is significant when working with Chinese Americans born outside the United States of America. Cultural and ethnic factors may influence their caregiving experiences. Healthcare providers should recognize that the needs and perspectives of Chinese Americans may differ from those of caregivers from other backgrounds, be sensitive to these differences, and tailor their support accordingly.

Interventions targeted at Chinese family caregivers would be crucial in alleviating their care burden. Evidence from previous research supports the effectiveness of interventions focusing on cognitive empathy and affective empathy in reducing caregivers’ symptoms, as well as stress reduction interventions that show cognitive improvements in family caregivers.[33,34] However, these interventions have not been customized for Chinese American family caregivers, leaving a gap in culturally sensitive support. Social media-based intervention pilot studies were conducted with Chinese American dementia caregivers and showed promise in enhancing caregivers’ psychosocial health.[35]

Lastly, further research with more extensive and diverse Chinese American samples, such as Chinese American families experiencing newly diagnosed dementia, residing in geographic areas with different degrees of anti-Asian xenophobia, or living in communities with various culturally relevant resources, will provide additional insights into Chinese American family caregivers’ health and well-being and the interactions among the associated factors. By considering these implications, healthcare providers, policymakers, and researchers can develop targeted multi-level interventions and support systems to better assist Chinese American family caregivers on their caregiving journey. This effort ultimately will lead to better well-being of the caregivers and their families with dementia.

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Ethical Statement

The study (STUDY00015663) was qualified for exempt status by the University of Washington Human Subjects Division (HSD).

Declaration of competing interest

The authors declared no potential conflicts of interest regarding the research, authorship, and/or publication of this article.

CRediT authorship contribution statement

Erh-Chi Hsu: Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Data curation, Conceptualization. **Jenny Hsin-Chun Tsai:** Writing – review & editing, Supervision, Methodology. **Kannie Chim:** Supervision, Data curation. **Clarence Spigner:** Writing – review & editing, Methodology, Conceptualization.

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Appendix

Table 1
Interview questions examples.

No.	Questions
1.	What comes to mind when you think of aging, dementia, and what are the differences for you?
2.	How do you feel about taking care of family members with dementia?
3.	What is your ideal day as a caregiver like?
4.	What makes it easier for you to take care of family members with dementia during the pandemic?
5.	What are the difficulties of taking care of family members with dementia during the pandemic?
6.	What services do you expect the Adult Day Center to provide? How can those services help you?
7.	For taking care of (the care recipient), how would you describe your mental status and how do you cope with it?
8.	How does taking care of individuals with dementia affect your job or your own family life?
9.	Do you have any supports form the community for caregiving?
10.	What’s your expectation of aging, and how does your expectation differ from (the care recipient)?
11.	What’s your thought on filial respect?

Table 2
Sample characteristics and interview information (N = 16).

ID	Age	Sex	Language [a]	Occupation	Quit job for Caregiving	Relationship [b]	Length of Caregiving	Recipient’s Health Conditions [c]	Length of Interview
1	60	F	English	real estate agent	no	daughter	20 years	dementia, fall, gait abnormality	36 min
2	57	F	Cantonese, English	food service for patient	no	daughter	11 years	dementia, fall, gait abnormality	22 min
3	67	F	Cantonese, Mandarin	homecare	yes	daughter	unclear	asthma, dementia	19 min
4	54	F	Mandarin, Cantonese, English	housewife	no	daughter	1 year	lung cancer, COPD, dementia	21 min
5	48	M	Mandarin	restaurant server	no	son	1 year	dementia	28 min
6	62	M	Mandarin	cloth retail, fisherman, carpenter	yes	son	6 years	stroke, dementia	25 min
7	50	F	Mandarin, Cantonese	factory	yes	daughter	1 year	dementia, gait abnormality	44 min
8	49	F	Mandarin, Cantonese	restaurant server	yes	daughter	6 years	liver cancer, dementia	19 min
10	58	F	Mandarin, Cantonese	hotel server	yes	daughter-in law	unclear	dementia, pain	16 min
11	50	F	Mandarin	housewife	no	daughter-in law	unclear	dementia, fall	27 min

(*continued*)

Table 2 (*Continued*)

ID	Age	Sex	Language [a]	Occupation	Quit job for Caregiving	Relationship [b]	Length of Caregiving	Recipient's Health Conditions [c]	Length of Interview
12	62	M	Mandarin, Cantonese	real estate renovator	no	son	4 years	dementia, diabetes, glaucoma	29 min
13	68	M	Mandarin	unclear	yes	son	unclear	dementia, gait abnormality	18 min
14	52	M	Mandarin	part-time renovator	no	son	unclear	heart disease, dementia	33 min
15	56	F	Mandarin	restaurant server	yes	daughter	6 years	dementia, diabetes, hypertension, pain, fall	13 min
16	50	F	Mandarin, English	restaurant server	yes	daughter	10 years	dementia, fall	21 min
17	52	M	Mandarin	unclear	yes	son	5 years	dementia	20 min

[a] The language participants used for interview.

[b] The relationship between caregivers and care recipients.

[c] The health conditions of care recipients described by the caregiver. The care recipients receiving care from the study participants had a median RUDAS score of 20 (IQR=17–21), indicating possible dementia.[15] Based on the participants, many care recipients showed a decline in their physical and cognitive status after the passing of their spouse. Others experienced a significant deterioration in physical and cognitive function after events, such as surgery, falls, or strokes. In addition to dementia, most care recipients had comorbidities, including gait abnormalities and activities of daily living (ADL) dependence, as reported by their caregivers.

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