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

Erh-Chi Hsu

A thesis

submitted in partial fulfillment of the

requirements for the degree of

Master of Public Health

University of Washington

2023

Committee:

Clarence Spigner

Jenny Hsin-Chun Tsai

Program Authorized to Offer Degree:

Department of Health Systems and Population Health

University of Washington

Abstract

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

Erh-Chi Hsu

Chair of the Supervisory Committee:
Clarence Spigner
Department of Health Systems and Population Health

Objective: This qualitative study aimed to explore the experiences and perceptions of Chinese American family caregivers of individuals with dementia during the COVID-19 pandemic. **Methods:** The study utilized the Health Belief Model and the National Institute on Minority Health and Health Disparities framework to develop a semi-structured interview guide. Purposive sampling and phone recruitment were used with the assistance of the collaborating agency. One-on-one in-depth interviews were conducted in Chinese, Cantonese, and English. Intercoder reliability between two coders was assessed before the primary coder completed the thematic analysis of the interviews. The Chinese-English bilingual committee expert reviewed the identified themes and the translation. **Results:** The study included 16 Chinese American caregivers sponsored by the Medicare and Medicaid funded Program for All-Inclusive Care for the Elderly (PACE). Caregivers understood the severity of dementia and showed self-efficacy in caregiving; however, most of them could not distinguish between natural aging and dementia. At the individual level, coping skills and self-efficacy played a

crucial role in facilitating positive caregiving experiences. At the interpersonal level, care recipients' self-motivation, social engagement, and familial support were identified as facilitators. Community-level facilitators included transportation, interpretation services, community events, and the presence of community-based organizations. At the societal level, filial respect influenced caregivers' attitudes toward dementia care. Various barriers were also identified. At the individual level, a lack of achievement hindered caregivers' motivation to provide persistent care. Dementia symptoms and functional declines in care recipients posed challenges as an interpersonal level barrier. At the community level, spiritual or support groups played limited roles in caregiver's life. At the societal level, the COVID-19 pandemic disrupted community activities and family's care plans, while Asian xenophobia heightened caregivers' burden. Additionally, the cultural and political circumstances of caregivers' home countries, along with restrictive US immigration policies, limited the available human and social resources for these caregivers. **Implications:** Implications for practice include the development of tailored educational materials, support from community organizations, and governmental assistance through initiatives like PACE. More research is needed to understand the effects of PACE on care burden and health outcomes of caregivers, particularly in Chinese Americans and other marginalized populations, across sites and states to inform program enhancements.

Table of Contents

List of Acronyms

AARP: American Association of Retired Persons
CBO: Community-based organization
CID: Chinatown-International District
CMS: Centers for Medicare & Medicare Services
HBM: Health Belief Model
HCA: Home Care Aide
HRS: Health and Retirement Study
ICHS: International Community Health Services
IP: Individual Provider
I-5: Interstate-5
MPH: Master of Public Health
MMSE: Mini-Mental State Examination
NHATS: National Health and Aging Trends Study
NIH: National Institutes of Health
NIMHD: National Institute on Minority Health and Health Disparities
PI: Principal Investigator
PACE: Program for All-Inclusive Care for the Elderly
RUDAS: Rowland Universal Dementia Assessment Scale
UW: University of Washington
ZBI: Zarit Burden Interview

1. Introduction

The world is experiencing a demographic shift towards an aging society, with rapid growth observed in the Asian American population. Despite this, research on Asian Americans and their subgroups remains limited. Historically, Asian Americans have been marginalized and inappropriately aggregated with Pacific Islanders, overlooking the unique diversities among subgroups. Although there is growing awareness of the need to disaggregate Asian Americans and Pacific Islanders, the tendency to homogenize Asian Americans into a single category persists. In reality, the Asian American population comprises over 20 distinct ethnic groups, with more than 50 languages spoken, each with its own culture, history, and immigration experiences.[1] Given this heterogeneity, it is important to conduct research to understand the unique experiences and needs of different Asian American groups and to develop tailored health programs that cater to their characteristics. This study aimed to focus on the care of first-generation Chinese American older adults, who constitute the largest aging Asian American subgroup,[2] in order to contribute to a better understanding of the health needs of this population.

1.1. Demographics of Asian Americans

The Asian American population is rapidly growing and aging. Thirteen percent of Asian Americans are aged 65 and over, the highest among all racial and ethnic groups other than White Americans in the United States.[3] The Asian American old adult population aged

65 and over is projected to increase by 93% from 2020 to 2040, making it the fastest-growing non-Hispanic aging population.[3]

When examining the demographics of Asian Americans at a state level, Washington State has seen a significant increase of 55.5% in its Asian population over the past decade.[4] In King County, where Chinatown-International District is located, the Asian population has increased by 61.9%, surpassing the national average from 2010 to 2020.[4] As the Asian American population continues to rapidly grow and age in the United States, understanding the unique needs and challenges they face, particularly in relation to aging and healthcare, is becoming increasingly important.

1.2. Demographics of Chinese Americans and the Chinatown-International District

Based on the 2021 American Community Survey 1-Year Estimates, Chinese Americans comprise the largest subgroup (27.5%) of all Asian Americans aged 65 and over.[2] The Chinatown-International District (CID) in Seattle is an ethnic enclave where many Chinese immigrants live, work, socialize, and age. According to the 2017-2021 American Community Survey, Chinese Americans make up 13.2% of the population in CID (zipcode 98104), which is second only to the White population (50%).[5] The foreign-born population constitutes almost one-third (29.6%) of the population in CID, with more than half (54.2%) lacking US citizenship.[6] Over two-thirds (69.1%) of the foreign-born population is from Asia and two-thirds (65.7%) of those who speak Asian languages at home in CID lack proficiency

in English.[6] Furthermore, 12.1% of households in CID earn less than $10,000 annually, which is three times higher than the Washington State average (4.2%).[7] Given these dwelling patterns and the barriers associated with immigration status, English proficiency, and poverty, this qualitative research specifically focused on Chinese-origin Asian Americans.

1.3. Health inequities among Asian and Chinese Americans

The myth of "model minority" for Asian Americans perpetuates for decades and shapes the image of Asian Americans into a diligent and problem-free cohort. This myth, which originated in 1966 in a New York Times article as a means to describe a successful story of Asian American immigrants, masks health disparities experienced among the diverse Asian American group.[8] Opposing this myth, Asian Americans do experience health inequity in multiple aspects. For instance, a cross-sectional study conducted in California revealed that Chinese Americans had the lowest health literacy score compared to other Asian subgroups, which was positively correlated with their health outcomes.[9] Moreover, a national cross-sectional survey found that Asian Americans experience discrimination when accessing healthcare compared to White individuals.[10] Similarly, a systematic review found that racism has a more pronounced negative impact on the mental health of Asian Americans than African Americans.[11]

Furthermore, research has highlighted that Chinese Americans, in particular, are less likely to report or seek help for mental health conditions and dementia among older adults,

due to stigma and misperceptions.[12,13] Recent cross-sectional studies conducted between 2015-2018 have shown that Chinese Americans were 60% less likely to seek mental health help compared to Whites, unless they perceived a high need to do so.[14] The experience of health inequity in life and being less likely to seek help can create a vicious cycle for Asian Americans in accessing resources and opportunities to maintain their health.

The current state of health research for the Asian American population is characterized by underfunding and a failure to fully capture the rich diversity present in this heterogeneous group, which is composed of various ethnic groups and language branches.[13] The current system lacks adequate resources to develop appropriate instruments and hire specialists necessary to compile comprehensive health data that accurately represents the diversity of the Asian American population. Funding for Asian American health research has been historically low, with only 0.17% of the National Institutes of Health (NIH) budget allocated to the aggregated Asian American, Native Hawaiian, and Pacific Islander individuals from 1992 to 2018.[15] An even smaller proportion is dedicated to Chinese Americans, though the exact percentage is unknown. This unequal distribution of funding has contributed to scarce knowledge generation to support Chinese American older adults who represent a significant aging population in the United States.

1.4. The Impact of Dementia Caregiving during the COVID-19 Pandemic

In the context of the SARS-CoV-2 pandemic, cross-sectional studies conducted in Japan, Southern Europe, India, and Canada have reported an exacerbation of cognitive impairment in dementia patients, leading to an increased care burden for their caregivers.[16-20] Furthermore, a retrospective cohort study in China revealed that the care burden and prevalence of mental health problems in caregivers persisted even after lifting quarantine regulations, highlighting the longer-term impact of the pandemic on caregivers.[21] Overall, the pandemic has intensified the burden on individuals with dementia and their caregivers. The language barrier has further complicated matters for some Asian Americans, hindering their ability to access accurate health information and engage in social activities.[22] Additionally, the heightened stress associated with discrimination and xenophobia towards Asian Americans has widened health disparities during the pandemic.[23] Research on care burden in the Chinese American cohort in the context of the pandemic is notably lacking.

1.5. Informal Caregiving of Older Chinese Americans

The role of informal caregiving for older Chinese Americans plays a crucial but overlooked part in providing support and assistance to this aging population. In the National Alliance for Caregiving and American Association of Retired Persons (AARP) 2020 report, Asian Americans were found to be more likely to report taking care of their parents (52%)

compared to Whites (43%) and African Americans (33%).[24] However, the percentage of Asian Americans who felt they had no choice but to take on caregiving responsibilities increased from 46% in 2015 to 61% in 2020.[24] Their self-rated health declined substantially from 60% as good health to 41% in the past five years, with 27% stating that caregiving had negatively impacted their health.[24] While this report provided important insights into the caregiving experiences of Asian Americans, they did not collect and analyze disaggregated data to draw conclusions about the Chinese American subgroup.

Cross-sectional studies conducted in China and Singapore revealed that Chinese individuals tend to value informal sources of information and support, such as friends and family, over formal medical assistance for mental disorders.[25,26] Another study in England and Wales assessed the social support networking types of older migrants, including Chinese, Black African, and others.[27] The study pointed out that Chinese immigrants had a higher proportion of non-kin and friend networks compared to most other ethnic groups. Based on these previous studies, Chinese individuals place a high value on the opinions of their families and friends, which influences their care practices.

These studies were conducted in China, Singapore, and UK. Their findings may not fully reflect the experiences of Chinese American caregivers. Studies on informal caregiving experiences among Chinese have mainly been cross-sectional quantitative studies, with limited qualitative research exploring the ethnic-specific mechanisms of facilitators and

barriers to dementia care. A decade ago a qualitative descriptive study was conducted in Seattle, Washington, to examine the impact of the caregiver role on the lives of informal caregivers of elderly Chinese immigrants.[28] Qualitative and quantitative data were collected from informal caregivers of older Chinese immigrants. Although their Zarit Burden Interview (ZBI) scores reflected care burden, the study revealed that fulfilling filial respect brought about a positive experience and satisfaction for the caregivers. With changes in contexts and time, the present study sought to update our understanding of how Chinese American caregivers perceived dementia and how the pandemic affected their experiences, providing much-needed qualitative insights into the unique challenges and opportunities facing this population.

2. Purpose

To understand the caring experience of family caregivers of individuals with dementia and the perceptions of aging for the Chinese American population in the COVID-19 era.

3. Research Question

3.1. How do Chinese Americans perceive aging and dementia?

3.2. What are the facilitators of taking care of family members with dementia for the Chinese American population during the pandemic?

3.3. What are the barriers of taking care of family members with dementia for the Chinese American population during the pandemic?

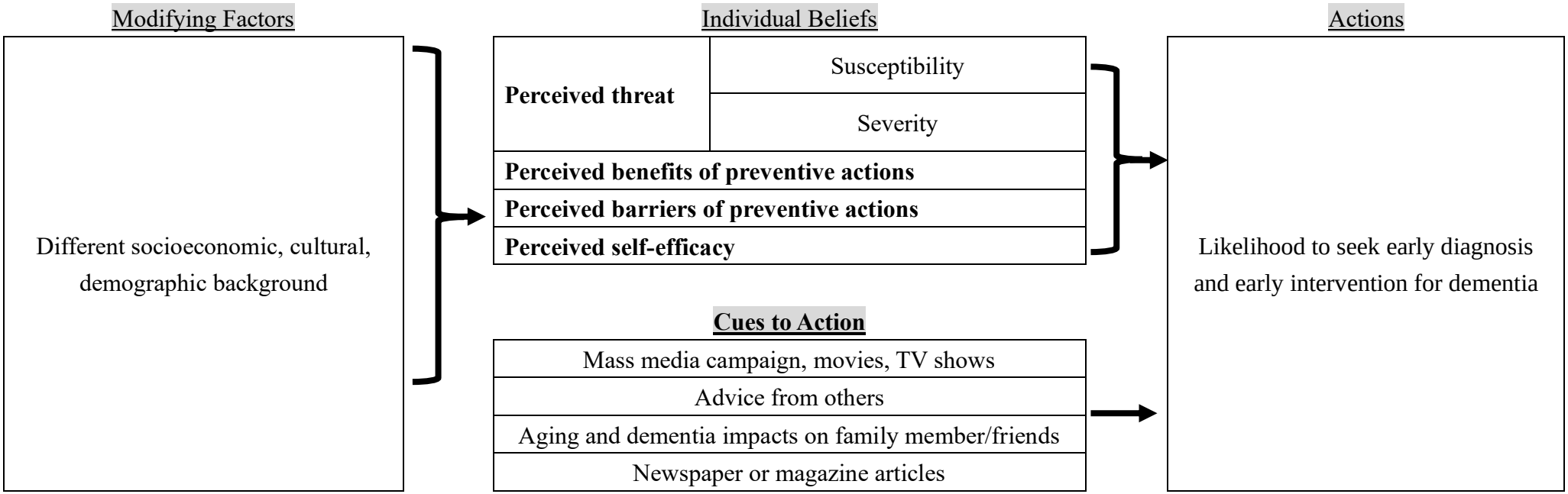
4. Conceptual Framework

This research study utilized the Health Belief Model (HBM) to explain the influence of individuals' perceptions and cues in their lives on their help-seeking behaviors for dementia.[29] The HBM focuses on individual-level and interpersonal-level factors that affect health behaviors, including perceived susceptibility, severity, benefits, and barriers. However, the model does not account for broader societal and environmental factors, such as social norms and cultural values, that may also impact health behaviors. Therefore, the study adopted the National Institute on Minority Health and Health Disparities (NIMHD) framework, which encompasses various determinants of health at individual, interpersonal, community, and societal levels of impact, to guide the interview questions and explore the facilitators and barriers of dementia care among family caregivers of older first-generation Chinese Americans with dementia.[30]

The HBM presents the mechanism of people adopting preventive interventions for early diagnosis of a disease. The model has been prevalent since the 1950s in understanding the likelihood of people taking preventive actions.[29] Based on the HBM, the mechanism (Table 1) underlying individuals' decision on health-related behaviors is composed of several factors: (a) perceived threat, including susceptibility and severity, of the disease/problem (b) perceived benefits and barriers to adopting the behaviors, (c) perceived self-efficacy on achieving the preventive action, and (d) the cues to action, including media and peers, to encourage individuals to take actions.

The National Institute on Minority Health and Health Disparities (NIMHD) framework presents a comprehensive view of the determinants of health across four levels. Each level encompasses several domains, such as health behavior, physical environment, social environment, and healthcare.[30] The perceived benefits and barriers sections of the HBM were expanded by the NIMHD framework to encompass a wider range of factors that influence caregivers' experiences, as presented in Table 2.

Table 1. The mechanism of dementia caregivers seeking early diagnosis and early intervention for dementia based on the Health Belief Model



Note. Adapted from the Health Belief Model (HBM) by N. K. Janz & M. H. Becker.[29]

Table 2. The factors influencing dementia caregivers' burden by levels and domains based on the NIMHD framework

		Levels of influence			
		Individual	**Interpersonal**	**Community**	**Societal**
Domains of influence	**Biological**	**Age of caregivers**	**Biological vulnerability** Genetics, comorbidities, disabilities of family members **Biological mechanisms** Dementia symptoms of family members	N/A	N/A
	Behavioral	**Health behavior** Help-seeking behaviors of caregivers **Coping strategies** Caregivers' attitude toward taking care of dementia family members, self-efficacy of caregivers **Level of acculturation of caregivers**	**Family member's characteristic** Self-motivation of family members **Family functioning** Family cohesion, decision-making patterns, interactions between care recipients and caregivers **Work functioning** Employer-provided health insurance or paid leave	**Community functioning** Community cohesion, community social capital	N/A
	Physical/Build environment	**Personal environment** Whether caregivers have their	**Household environment** Distance to where family	**Community environment** Public facilities, high	Pandemic

		own place	members live, transportation, whether live in with family members, the family's house setting to accommodate dementia individuals	population density **Community resources** Adult day center, green space, spaces for group activities, transportation	
	Sociocultural environment	**Sociodemographic factors** English proficiency, education, employment **Individual cultural factors** Cultural identification, spiritual beliefs, level of acculturation **Response to discrimination** Cultural pride	**Social network** Spouses, children, siblings, relatives, friends **Family/Peer norms** Filial respect, historical family experiences **Interpersonal discrimination** Stigma of having dementia family members **Work environment** Flexible work hours	**Community norms** Community traditions, Community origins and history **Community structural discrimination** Public stigma, location of environmentally dangerous/unsafe Sites	**Societal norm** Dominant attitudes, filial respect, societal stereotypes **Societal structural discrimination** Asian xenophobia, model minority myth
	Health care system	Insurance coverage Health literacy Treatment preference Past treatment experiences	Patient-provider relationship Medical decision-making Clinicians' cultural competence	Availability of community Health services Availability of remote Community health services	Quality of dementia care Long-term health care Policies and laws
Health outcomes		Individual health	Family health	Community health	Population health

**Note. Adapted from the National Institute on Minority Health and Health Disparities (NIMHD) framework.[30] The bold fonts are subtitles of relevant topics that were mentioned in the interview guide.*

5. Methods

The qualitative approach was chosen to gain insight into the experiences and perceptions of Chinese American caregivers. A qualitative approach allows for a more nuanced understanding of participants' feelings and thoughts about dementia caregiving.[31] Purposive sampling and phone recruitment were used. One-on-one in-depth interviews were conducted using a semi-structured guide in three languages. Two coders employed deductive coding, and intercoder reliability was assessed. Thematic analysis was utilized. An English-Mandarin bilingual committee expert checked the identified themes. This study (STUDY00015663) was determined by the University of Washington Human Subjects Division (HSD) for meeting the exempt status.

5.1. Study Context

International Community Health Services (ICHS) is a community-based organization (CBO) serving underserved populations, in particular, the Asian American individuals in the Chinatown-International District, Seattle. ICHS offers the Program for All-Inclusive Care for the Elderly (PACE), a comprehensive care program funded by Medicare and Medicaid each month. They include healthy aging programs, health screening, rehabilitation, and discharge planning for clients aged 55 and over.

There were 96 members in ICHS PACE at the time this study started. Their median age was 84.5 years (IQR=81-88); 67.7% were female and 32.3% of male; mainly spoke Chinese

languages (55.2% Cantonese, 21.9% Mandarin, 16.7% Toishanese). Fifty-seven point three percent of the 96 members lived in surrounding neighborhoods, with or not with their family members; 38.5% were residents in the Legacy House, an assisted living facility affiliated with ICHS, and 4.2% lived in permanent long-term care placement affiliated with ICHS.

By analyzing the Rowland Universal Dementia Assessment Scale (RUDAS), Modified Barthel Index (MBI)) and PHQ-9 scores, we had a brief view of the cognitive, physical, and mental function of the ICHS PACE members.[32-34] The median RUDAS score was 25.5 (IQR=20-28), which falls within the score range (23-27) for mild neurocognitive disorder.[35] The MBI median was 90.5 (IQR=84-96). The PHQ-9 score had a low median of 1.0 (IQR=0-4). These scores indicated that approximately half of the PACE members had at least a mild level of cognitive disorder, moderate dependence, and none to minimal depression severity.

5.2. Sample and Sampling

The sample comprised caregivers of the ICHS PACE members. Purposive sampling was utilized to select prospective study participants.[36] The inclusion criteria were: (1) a family caregiver to a PACE member (i.e., care recipient), (2) provide care to a PACE member living in their home in the community, and (3) the PACE member with a RUDAS score of 27 or lower[35] which was considered to have dementia. A total of 24 eligible caregivers were identified.

5.3. Interview Guide

The semi-structured interview guide (Appendix A) grounded in the Health Belief Model (HBM) and the National Institute on Minority Health and Health Disparities (NIMHD) framework was used. The guide consisted of three sections designed for an approximately 30-45 minute interview. The first section of the interview was sociodemographic information, including age, occupation, family composition, and general caring conditions of their families. The second section focused on perceptions of aging and dementia. The last section asked caregivers to elaborate on the facilitators and barriers they experienced during the COVID-19 pandemic. To ensure accuracy and cultural sensitivity, the interview guide was designed in three languages (English, Mandarin, and Cantonese) and tested for language accuracy and potential follow-up questions. The Mandarin version was checked by the English-Mandarin bilingual and bicultural supervisory committee member. The student PI tested the interview guide in Cantonese informally through mock interviews with the ICHS's medical director and their interpreter to optimize language accuracy, interview questions, and predict potential follow-up questions.

5.4. Recruitment and Data Collection

The recruitment process started with sending a pre-notification announcement through ICHS's quarterly newsletter, followed by phone calls to the 24 prospective study participants.

Among them, six turned into voicemail three times and one prospective study participant only spoke Cantonese. Individuals who could not provide informed consent and were not available for a 30-45 minute interview were excluded. Seventeen provided verbal informed consent. One of the caregivers had an identity information error and was excluded from the final sample. The student principal investigator (PI) exhausted the prospective study participant pool. The response rate was 66.7% with 16 valid interviews. According to a study on thematic saturation in qualitative studies, 12 interviews would reach higher degrees of saturation.[37] The student PI found that saturation was reached with similar codes and themes appearing after completing the analyses of 16 interviews.[38]

The interviews were conducted remotely through encrypted phone calls, of which the communication approach caregivers were most familiar and comfortable with, between July 20th, 2022 and July 26th, 2022. The interviews were predominantly in a mix of Mandarin and Cantonese, except for one interview as the caregiver preferred English. The average phone interview length was 24 minutes and 24 seconds. The student PI was solely responsible for recruitment, obtaining verbal informed consent, arranging interviews, and conducting the interviews. The recruitment and data collection processes were independent of regular ICHS services, and caregivers were assured of non-interference from ICHS staff and that their access to ICHS services was unaffected by their participation.

5.5. Transcription and Initial Coding Process

The research team consisted of the student PI and a second coder. Both are bilingual and familiar with both Asian and Western cultures, and were enrolled in the University of Washington (UW) Master of Public Health (MPH) program when this study was conducted. Transcripts of the interviews were manually transcribed by the student PI in Traditional Chinese, and the Cantonese transcription was reviewed by an ICHS translator to ensure accuracy.

Using a deductive approach based on the HBM and NIMHD framework, a codebook (Appendix B) was developed. Transcripts were then organized and coded using Dedoose (version 9.0.46).[39] The student PI and the second coder coded the longest transcript together and reached a 62% intercoder reliability. This was determined by calculating the percentage of codes that were consistently applied by both coders (numerator) over the total number of quotes coded by either coder (denominator). Through the consensus meeting, it was clear that the coders had consistent interpretations of the text and the codes used. However, unlike the second coder who coded every relevant text regardless of the length of the response, the student PI did not code the text when it appeared to be duplicated ideas or not descriptive enough as quotes. The difference in coding approaches may have underestimated the intercoder reliability. Keeping the coders' discussion in mind, the student PI finished coding the rest of the transcripts.

5.6. Data Analysis

The study applied Braun and Clarke's thematic analysis, in which codes were organized, linked, and netted into a thematic map (Appendix C).[40] The student PI looked for patterns and connections between the initial codes and grouped them into potential themes during the mapping process. The student PI reviewed the themes and extracted potential excerpts from the transcripts. As suggested by findings in an exploratory study about translation from Cantonese to English,[41] the student PI was the only translator for the excerpts presented in the study narrative to maximize the trustworthiness of the study findings. The translated excerpts were reviewed by the bilingual committee member with expertise in qualitative research.

6. Results

This section describes the sample and findings from the one-on-one interviews, organized according to the research questions. Themes include family caregivers' perceptions of aging and dementia, as well as facilitators and barriers to caregiving at the individual, interpersonal, community, and societal levels.

6.1. Sample Description

All study participants were paid family caregivers sponsored by the PACE under the Centers for Medicare & Medicare Services (CMS). Their primary languages were Cantonese, Toishanese, Mandarin, or English. Their median age was 55 years (IQR=50-60.5); half of

them lived with the ICHS PACE member. Only one caregiver had no siblings. Half of the caregivers were daughters of the PACE members, two were daughters-in-law, and the rest were sons. The PACE members who were taken care of by the study participants had a median RUDAS score of 20 (IQR=17-21), indicating a suggestive of dementia.[35] Out of the 16 family caregivers, nine made the decision to leave their jobs (e.g., catering server and real estate renovator) to devote themselves full-time to caregiving. Two caregivers were housewives. The remaining five caregivers managed to balance their job responsibilities alongside their caregiving duties, holding positions as part-time catering server, real estate renovator, or real estate agent.

6.2. Perception of Aging and Dementia

6.2.1. Family caregivers expressed negative, neutral, and positive feelings toward taking care of family members with dementia.

Most of the caregivers reported neutral feelings, while few expressed negative or positive sentiments. One caregiver's positive expression stood out, as she felt grateful for the time spent with her mother who was in the last stages of life:

> *"I feel quite grateful… at least if there is something happens to her today, I will have no regrets because I accompany her to the end." – P16, lived-in daughter aged 50*

The fatigue experienced by some caregivers was attributed to the chaotic symptoms that care recipients with dementia exhibited, which could be trying on their patience.

"When you just start to take care of this type of older people who can be crazy, you would feel unhappy…" – P07, lived-in daughter aged 50

"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…" – P06, lived-in son aged 62

The majority of caregivers felt neither negative nor positive about providing care. It was considered as a responsibility or obligation. This sentiment was particularly apparent among sons or when the person was the only child.

"You still have to do it even when you don't want to… you still have to do it when you are in a bad mood. Just get it done and that's it." – P14, son aged 52, the only child

"To be honest… it's a very uncomfortable thing to take care of old people, but we have no choice, it's a job. It's also a responsibility, right?"- P17, son aged 52

6.2.2. Most caregivers were unfamiliar with dementia and genetic susceptibility.

Only two of the 16 caregivers expressed awareness of the inherent potential of dementia:

"I think it will happen to me eventually. (laugh) Who knows what! But... since it's genetic...I don't really know if it's genetic... but since my mom having, most likely I'll get it." – P01, lived-in daughter aged 60

"I suspect I may have it already because I heard it's genetic." – P14, son aged 52, the only child

Even when the questions were asked in their preferred language and using the spoken form suggested by the interpreter in the organization instead of the written form, most caregivers did not appear to be familiar with the term "dementia" and could not tell the difference between natural aging and dementia.

"I don't understand, not really sure what that [dementia] means." – P02, daughter aged 57

"I feel they [aging and dementia] are the same." – P03, daughter aged 67

Two caregivers tried to explain the difference between natural aging and dementia:

"Aging is natural, dementia is acquired." – P07, lived-in daughter aged 50

"People at least have a normal brain when aging, right? If they don't have a normal brain, then it's called dementia." – P14, son aged 52, the only child

The perception was limited to binary answers, such as natural vs. unnatural, or normal vs. abnormal. The scientific mechanism of dementia was not mentioned.

6.2.3. Most caregivers understood the impacts of the illness on cognition and dependency on living.

When asking about the impact of dementia, most caregivers could describe the decreasing abilities of judgment, communication, and dependency on others, as the following caregiver stated:

> *"The impacts… mainly about his abilities to judge, to communicate, and to do other independent activities of daily living are not as good as a normal person." – P05, liven-in son aged 48*

A caregiver described the impact of dementia on his father's daily life and his own questions about the meaning of life after observing the impact of this illness:

> *"Ahh…there is a huge impact on people. If it's me having dementia, I would rather die, there is no meaning in life. Just like a walking dead… not actually enjoying the life. [He] just eat and sleep, eat and sleep, it's machinelike, … do not have feelings … (silence)" – P14, son aged 52, the only child*

6.2.4. Most caregivers expressed high levels of self-efficacy in providing care.

The feedback about their confidence in caregiving was overwhelmingly positive. One caregiver said:

> *"I am quite confident. Temporarily speaking, at least I am taking good care of her in daily life. " – P16, lived-in daughter aged 50*

Another stated:

"Perhaps good? Things she wants to do, place she wants to go, seeing a doctor, things she wants to eat, anything she wants… all of them… we try our best to satisfy her. " – P13, lived-in son aged 68

Even those who did not explicitly express confidence in their caregiving expressed that they tried their best. One caregiver said:

"Hmm… she didn't complain to you guys, so I think I did it ok, right? Well, let me put it this way. I cannot say I did my…[pause] my work was so perfect or flawless. I feel like it's already good enough when a person could not get mad at old people some of the time" – P17, son aged 52

6.3. Facilitators to Caregiving during the Pandemic

6.3.1. Individual Level - Great coping skills and self-efficacy of caregivers facilitate dementia care.

When asked about how they coped with fatigue from caregiving, many caregivers exhibited optimistic and open-minded attitudes. For instance:

"Well… I guess I'm more a positive person? I feel it's ok for me. Would you say not tired at all? Of course you would, but it depends on how you cope and adjust [your attitude]." – P16, lived-in daughter aged 50

Some caregivers coped with love. Their motivation to provide care came from their affection and empathy for their loved ones. One caregiver explained:

"*It's hard. But if it's someone you care and love, it's easier. (laugh) Probably more patience? Even though, I think, human nature, sometimes it's frustrated, but as long as you understand and you remind yourself, ok, that's the illness, it's not her, then it's ok.*" *– P01, lived-in daughter aged 60*

Some caregivers emphasized the importance of adjusting their attitude and maintaining a positive outlook, while others recommended engaging in activities, such as running or listening to music.

"Adjust yourself! Go running, listening to music… that's it." – P07, lived-in daughter aged 50

Additionally, some caregivers acknowledged the value of releasing emotions or processing their thoughts internally.

"(sign)… 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 minutes." - P07, lived-in daughter aged 50

"Just don't fight back! When she says something, pretend like you didn't hear it, don't talk back. …just process a bit yourself, when you think it through, you can let it go. Isn't that right?" – P13, lived-in daughter aged 68

Each caregiver had their ways of coping to facilitate their caregiving.

6.3.2. Interpersonal Level - The care recipients' self-motivation to exercise and socialize influences the care provided by the caregivers

Some caregivers suggested that care recipients with a positive attitude towards socializing and participating in activities tend to have more engagement and motivation. They enjoyed attending the day center and engaging with peers:

"She can do some simple exercises, like moving around her arms and legs, clapping her hands, tapping on her legs, and rubbing her ears. She would do those stuff. She takes these types of stuff seriously, quite actively. Her motivation is fairly good [for these things]." – P16, lived-in daughter aged 50

"Actually, if there was no pandemic, she quite likes to go there [the Day Center for elderly]. She would do exercises there and catch up with other elderly. She is quite happy. " – P16, lived-in daughter aged 50

On the other hand, care recipients who preferred solitude or had specific hobbies and interests would not actively participate in social activities or day center programs:

"She played MahJong and liked to interact with people within the family. Did not like to interact with others." – P11, daughter-in-law aged 50

"I don't know [why she does not participate in the Day Center activities]… she has her preference or habits. She likes…would rather practice calligraphy, use an iPad, things like that. " – P17, son aged 52

Caregivers acknowledged and accommodated their family members' preferences and individualities. They adjusted their approaches to care in accordance with the care recipient's interests in social interactions at the time.

6.3.3. Interpersonal Level - Chinese American dementia caregivers heavily rely on their families and friends for support.

Except for one caregiver who was the only child, the rest of the 15 caregivers received support from their siblings. They shared caregiving responsibilities and took turns in providing care, as illustrated in the following example:

> *"[My sisters] used to take care of my mother. Now my mom lives with me, they sometimes come visit, prepare some food and bring it here. They still help… since I am the son… for changing positions and showering my mom, we, the Chinese, are still a little embarrassed about that, so my sisters come over to help me with these tasks." – P12, lived-in son aged 62*

Family members not only helped with caregiving tasks but also provided emotional support to the primary caregivers. Some spouses or children of caregivers were proficient in English, worked in the healthcare industry, or had knowledge about dementia symptoms. They helped caregivers make medical decisions and passed on their knowledge of dementia care to the primary caregivers.

> *"I'll tell my children every time when I am not happy. My children will explain to me that 'it's because grandma doesn't understand, but mom, you have lots of*

children to talk to, we can explain to you, then you know how to respond to grandma.' " – P02, daughter aged 57

"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. I don't understand English. So they help me if we have any language barriers." – P12, lived-in son aged 62

While family members were the primary source of interpersonal support, one caregiver mentioned receiving assistance from friends for translation purposes.

"I have no resources. Sometimes I have to ask my friends to help read mails for me because I don't understand English. So sometimes when you go out, you need to ask friends for help." – P06, lived-in son aged 62

6.3.4. Community Level - Transportations, interpretations, and community events facilitate dementia care.

Several caregivers mentioned previous obstacles they had encountered regarding transportation:

"I don't have so much time to drop him off and pick him up. If the travel time is long, what do we do when he pees or has bowel movements during that time? That day when he came home, as soon as he stepped in, he said he'd shitted on himself, I had to quickly clean up for him." – P14, son aged 52

Since all caregivers were clients of the ICHS, all of them expressed their appreciation of the transportation and translation/interpretation services provided by the ICHS.

"I was exhausted in those years. During that time, she went to see a doctor all the time. [Her wheelchair] did not fit in my car. Sometimes we drove 5 or 6 hours out there. She was tired sitting in the car; I was also tired. It was like this for several years. I was very tired. Until we met the ICHS and in the PACE program. I am more relaxed now. They have transportation, medication delivery; basically, everything is on point." – P06, lived-in son aged 62

"Now I go to ICHS, they have interpreters. "– P12, lived-in son aged 62

6.3.5. Community Level - Community-based organizations play a critical role in referring families to existing governmental resources.

The ICHS PACE program provided vital information to family caregivers about the Home Care Aide (HCA) certification required by the Washington State Department of Social and Health Services for paid caregivers and helped them become certified.

"I had no job for a half year in order to take care of her. I didn't know anything then. The ICHS told me how things worked… they gave me a verification letter. I applied for the government program, but then I was told no. 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." – P06, lived-in son aged 62

"I'm now at ICHS, they pay me, provide health care, and entertainment. They help solve any problem I have." – P12, lived-in son aged 62

As a result of HCA certification information, caregivers were eligible for governmental reimbursement for basic care training.

6.3.6. Societal Level - Caregivers' attitudes toward taking care of family members with dementia are hinted at by filial respect.

Filial respect, a value perpetuated in Chinese education and culture, influenced caregivers' attitudes toward taking care of family members with dementia on a societal level. It was constantly mentioned in the conversations as presented below:

"How to explain this… I do nothing special because we all grew up in China, and didn't come to the States until we were in our 30s. Our education then is different from the education now. My perspective is that is a should or a must. She is my mom! No matter how annoyed I am or whatever, I just want her to be happy, have a few happy years, that's it." – P12, lived-in son aged 62

"Well, you know… Chinese are like this, very responsible, no choice, we will still do it even when we don't want to. Basically, the Chinese are like this, you don't even bother to ask others. Our education and what we learn are all about this." – P14, son aged 52

"They are your family. I must provide good care to my parents, so nothing else [any fatigue] really matters. " – P15, daughter aged 56

"I do my best. I am not a professional, I just fulfill my obligation as what a son should do." – P17, son aged 5

"To be honest… would you say I have a huge sacrifice? Not really. After all, I'm just an ordinary person. For 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." – P05, lived-in son aged 48

Despite the challenges of caregiving, the caregivers consistently reiterated the concept of filial respect. They perceived caregiving to parents as an obligation and a vocation to offer exceptional care to their parents. One aspired to impart this custom to their offspring.

"How do I feel… how to say this… I feel it's what I should do. I am her son. My mom brought us up. However, it's hard work, sometimes it's really annoying… When that happens, I would sit down and eventually think it through. I guess it's what a son should be. It's annoying, but so be it! Just for however long she can live. I feel better after I think through. I also hope my children can treat me the same. I am setting a role model for them."- P12, , lived-in son aged 62

Conversely, when asking about the caregiver's expectation of aging, like their preference for long-term care facility or living with family, one gave a completely different picture of aging:

"Well... a facility, a nice one, hopefully. There is a place in Bellevue... it's called... oh god my memory...I forgot. You know, a nice, high-end one would be ideal, but I will not stay with my kids." – P01, lived-in daughter aged 60

"For me, I don't want my kids to need to care for me and all these things. I am ok that my mom give me burden, but I wouldn't give burden to my son. I want to take care of my mom, my in-law, but I don't want my kid take care me. " – P01, lived-in daughter aged 60

6.4. Barrier to Caregiving during the Pandemic

6.4.1. Individual Level - Taking care of family members with dementia impacts caregivers' freedom, jobs, income, and family lives.

To balance work and caregiving, every caregiver resigned from their employment to attend to their family members. Sacrificing personal leisure time was also a common occurrence, as illustrated by the following examples:

"Of course, I got impacted [by taking care of my mom]. I don't work right now because I cannot leave a step away from my mom. Let's why I can't work. "– P12, lived-in son aged 62

"Oh… of course, I sacrifice my free time. Well…I don't have free life when taking care my father." – P04, lived-in daughter aged 54

"I am forced to. I have no choice… Overall…I have no freedom, just like being stuck in a cage!" – P07, lived-in daughter aged 50

In addition to the inability to work, caregiving also constrained the caregivers' family lives and limited their opportunities to search for employment. Striking a balance between individual employment and income and caregiving proved to be a difficult challenge.

"First of all, if we [P11, P11's husband, and other relatives] don't take turns taking care of my [mother-in-law], I'd ask my husband to accompany her. How can this not affect my family life? Then, if I go looking for a job, I can't go for a whole day. I have to save some time to come home and cook for her." – P11, daughter-in-law aged 50

"My family's life is definitely affected. We basically are separate right now. So, for my relationship, my wife and I are already alienated, nothing I can do about it." – P06, lived-in son aged 62

"[My wife and kid say] I stay with my mom all the time and ignore our home. Everything… like not dining out, not going anywhere, just working around my mom every day. They all have something to say about it." – P12, lived-in son aged 62

When caregiving became the central focus of the caregiver's life, it became challenging to manage other relationships due to physical and mental exhaustion. Caregivers who lived with their care recipients to provide close care created physical distance from their own

families. Additionally, they might not have had the time or energy to maintain those relationships.

6.4.2. Individual Level - No sense of achievement keeps caregivers from being motivated and providing persistent care.

Care recipients with dementia may not remember or appreciate the dedication of caregivers. For example, one caregiver said:

> *"I bring him out twice a week. Sometimes we go to Chinatown, sometimes we go nearby. He would just eat. If I ask him on the next day whether he remembers going for Dim Sum yesterday, he'd say 'did you bring me to Dim Sum at all?'. " – P14, son aged 52*

This lack of appreciation from care recipients demotivated caregivers, as they feel their efforts were not recognized. Furthermore, when care recipients expressed hopelessness, it made caregiving even more challenging. As one caregiver described:

> *"Even though you take care of her… she doesn't know… always talks about that she doesn't want to live… but cannot die by her will, something like these. Would you feel good when you hear things like these? 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. I thought to myself if she goes elsewhere, who will take care of her as I do, right?" – P13, lived-in daughter aged 68*

6.4.3. Interpersonal Level - Functional declines and dementia symptoms make it hard to care for their family members.

During the interviews, caregivers frequently cited significant health events, such as strokes, falls, and surgeries, as tipping points for their care recipients. These events resulted in disabilities that required more intensive caregiving. For instance, one caregiver described how their mother's physical condition deteriorated significantly after suffering a stroke and fall:

> *"After she had a stroke [pause] she broke her arms, both of her arms, and I was with her at the Japanese nursing home and emergency room for four months. …So, I had no income at that time. It all relied on me to accompany her. She broke her arms, needed to be fed… and it's all on me… (blurry)… When I think about it, really, it was an extremely exhausting time. She was still recovering from the arm [fracture] when we went home. I was still taking care of her alone. It's everything. I had to feed her, [took care of] her toileting, sometimes the feces and urine were all over the floor… (sign)! At that time she would poo in inappropriate places, she was incontinent, it was the most exhausting time. This situation lasted for about one year. She gradually recovered. I still had to provide her with meals every day. I did not have any income. I had to borrow money everywhere from friends during that time (dry laugh). (sign) When I think about it, that time was really a nightmare." – P06, lived-in son aged 62*

Caring for disabled care recipients consumed more of caregivers' time and effort because caregivers were required to provide total care, including feeding and changing diapers. In addition to salient events, such as strokes or falls, even physical pain or discomfort could prevent care recipients from engaging in any activities, which made it harder for caregivers to manage a regular socialized life of care recipients:

> *"They [staff in the organization] did communicate with my mom, asked whether she wanted to go [participating in recreation activities]. But, she didn't really want to go because her legs and waist hurt when she walked. That's why she doesn't want to walk around." – P15, daughter aged 56*

Cognitive decline of the care recipients also posed challenges to caregiving. Caregivers had to make difficult choices to manage the required care and demand on their time:

> *"No, I don't let him go anymore. What if he doesn't remember how to get back? 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*

6.4.4. Interpersonal Level - Unclear about dementia symptoms in the family cause domestic arguments.

Paranoia symptoms were frequently mentioned in the interviews, and caregivers often struggled to respond to and manage these challenges. Two families faced similar situations but responded differently based on their understanding of the progression of dementia.

"What I'm most worried about is her being forgetful. How can we find the things when she forgets about them? She suspects others stealing her stuff when she cannot find it, so I tell the doctors and social workers, and anyone who I know about this issue. Our four siblings had been through an argument because of that. You blame me, I blame you, you ask if I took it, and I ask if you took it. I said, what I took [her] glasses for!. Now we know… At first, we thought it was taken by one of the our siblings, but actually it's my mom's forgetfulness." – P02, daughter aged 57

Caregiver P02's family experienced a domestic argument because the siblings initially did not understand the paranoia symptom. In contrast, Caregiver P10's family had a better understanding of the symptoms and developed their own strategy to cope with the frustrating and repetitive behaviors.

"Dementia is such a problematic issue for us younger generations. I can't help her, and she cannot remember anything by herself. She always says that my daughter-in-law takes my passport, or takes my permanent residency application forms… but my family and relatives all understand [her condition]. So… [they would say] let it go, we understand. She would say where is my ring? Who took my ring? …What the hell I took your ring for...(laugh) …I give her money every week, or for her birthday and Christmas… She still insisted I took them even after I explained it to her. So, then I

let it go, I cannot explain it clearly. I would just say 'yes, yes, I took them all.'

Sometimes it's easy to fool her!" – P10, daughter-in-law aged 58

6.4.5. Community Level –Spiritual groups or support groups play limited roles in caregiver's life.

When the caregivers were asked if they joined any faith-based or support groups to ease their caregiving burden, most of them mentioned not having any religious beliefs:

"I believe nothing but myself." – P06, lived-in son aged 62

"I don't need that [faith-based or supportive activities] because I have no religious belief. Like Buddhist… or others, I don't practice them." – P12, lived-in son aged 62

One of them had a neutral and passive statement about faith-based activities:

"I have no need [to participate in faith-based activities] now. No… I mean… I am not against it but also not in an urgent to participate." – P17, son aged 52

Two caregivers reported practicing Buddhism, with one attending classes and the other practicing in mind.

"hmm… yes, I attend classes at the Buddhist monastery." – P16, lived-in daughter aged 50

"We are all Buddhists, but not engaging in any [faith-based] activities. Just follow it in our mind, that's it." – P03, lived-in daughter aged 67

6.4.6. Societal Level - The COVID-19 pandemic limits community activities and disturbs families' care plans.

During the pandemic, many caregivers faced limitations in engaging in community activities due to quarantine and isolation regulations:

"She originally did physical therapy… it 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… (blurry)…This caused us a lot of affliction. We became depressed seeing her being depressed… now it's finally getting better." – P07, lived-in daughter aged 50

Despite the lifting of quarantine restrictions, caregivers still faced challenges in leaving their homes because of their fear of infection and the difficulty of complying with infection control measures by the family member with dementia.

"For the elderly, she is not willing to wear masks, not willing to cooperate. So Since COVID-19 started, I seldom bring her out." – P02, daughter aged 57

"I'm afraid she would be exposed to risks and infection, so basically not dare to step out at all." – P06, lived-in son aged 62

One caregiver mentioned that their siblings had initially planned to take care of their mom in a rotating order. However, the pandemic disrupted their routine and introduced many unpredictable factors that made it difficult to follow the original care plan.

"We take turns… who cooks for what days of the week, our family share the responsibility. Well… sometimes people got COVID, they were afraid of coming over. Or they had contact with people who got COVID, they could not come… Now my family is fine, but it is happening with her daughter and her son, so now it's us taking care of her… constantly disrupt our care plan." – P11, daughter -in-law aged 50

6.4.7. Societal Level - Asian xenophobia might increase the care burden.

When asked about Asian xenophobia, most of the caregivers felt the environment was "okay." One caregiver even stated, "I feel like in Seattle it's ok. Not sure how is the condition in other regions." Some caregivers and care recipients did not go out much even before the pandemic because care recipients were bedridden or not accustomed to going out. Despite caregivers did not mention Asian xenophobia very often, a few expressed their fear of being attacked due to anti-Asian sentiments.

"Perhaps some people would stare at you [pause] especially seeing some news… or witnessing some [incidents]… people were smashing stores in Chinatown, things were broken, right?…Not dare to go for a long time. I did not dare to do grocery shopping in Chinatown during that pandemic period." – P11, daughter -in-law aged 50.

6.4.8. Societal Level - The historical context of the home country and US immigration policy limit their human and social capital.

Caregivers who immigrated to the United States during China's cultural evolution from 1970-1980 were motivated to move due to their dissatisfaction with their political and historical background at the time. As one described:

> *"We were on the farms at school age. At working age, we ran into… the Cultural Evolution in China. After the Cultural Evolution, it started [the economic reform], the reform and opening-up. We definitely were part of the reform, but we were not part of the opening-up. Being sent for reform - we were part of it… at that time, think about that, who didn't want to escape? 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. But, at least I have the ability to feed myself. Just by myself, it's simple!" – P14, son aged 52*

Most of them were limited to blue-collar jobs. When the interviewer asked if Caregiver P08 had any siblings helping her take care of the family member, the caregiver stated:

> *"We have a younger brother, my dad's son, who is in China right now. He hasn't come yet… the [visa screening] has been postponed right now. No idea when he can come. We have already applied for more than 10 years." – P08, daughter aged 49*

Immigration policies and processes appeared to influence family support and resources available to some caregivers.

6.5. Summary

Family caregivers of individuals with dementia in the study experienced a range of emotions, mostly neutral with less binary feelings. Few recognized the genetic predisposition to dementia or even the term "dementia." Most caregivers acknowledged the significant impact of dementia on cognitive abilities and daily living independence but felt confident in their ability to provide care.

Coping skills and self-efficacy were individual-level facilitators of positive caregiving experience. In addition, care recipients' self-motivation and social engagement, and familial support were interpersonal-level facilitators. Transportation, interpretation services, community events, and community-based organizations facilitated care at the community level. Filial respect shaped caregivers' attitudes towards dementia care at the societal level.

For barriers to caregiving during the pandemic, a lack of achievement hindered their motivation for persistent care. Dementia symptoms and functional declines in the family members with dementia caused difficulties as interpersonal-level barriers. Spiritual groups or support groups were not prominent community resources for the caregivers. At the societal level, the COVID-19 pandemic limited community activities and disturbed care plans and Asian xenophobia increased the caregiver burden. The cultural and political circumstances of their country of origin, combined with the restrictive nature of US immigration policies, have constrained the human and social resources available to these caregivers.

7. Discussion

7.1. Perception of Aging and Dementia

Based on the HBM, caregivers' socioeconomic and cultural background would shape their perception of aging and dementia. Along with the cues to actions surrounding them, their perceptions would affect the behavior of seeking an early diagnosis or early intervention for dementia. In this study, the caregivers had various socioeconomic backgrounds and held jobs in non-health-related industries. They understood the severity of dementia and had self-efficacy through the practice of caregiving; however, lack of perceived susceptibility and lacked the ability to distinguish between natural aging and dementia. This result is consistent with previous research suggesting that Chinese Americans view dementia symptoms as a typical part of the aging process. As a consequence of this normalization and insensitivity towards dementia symptoms, Chinese Americans may not seek medical assistance or may wait until the disease has progressed significantly before seeking help.[42] This could be compounded by caregivers' lacking cues to action from family members in understanding dementia symptoms. Consequently, instances of domestic arguments may arise, which further contributes to potential delays in treatment.

As noted in prior research, a mere one-fourth of Chinese Americans recognized dementia as a mental illness, which was linked to having a greater knowledge level of dementia.[43] Additionally, targeted education for family caregivers of individuals with

dementia was shown to improve self-assessed confidence and reduce role strain, anxiety, and depression levels, as reported in a non-ethnic-specific study.[44] These studies, coupled with our findings, underscored the need for educational programs geared toward family caregivers.

7.2. Facilitators and Barriers to Caregiving during the Pandemic

Considering the NIMHD framework, the findings on facilitators and barriers to caregiving during the pandemic were synthesized with some previous studies and captured some nuances different from former research.

Literature has shown self-efficacy in symptom management and seeking social support, and problem-solving coping skills help reduce caregiver burden and distress.[45-47] Self-efficacy and coping skills are considered resilience factors of care burden.[47] Similar to the literature, this study's finding also shows the significance of self-efficacy in releasing care burdens and stress. Regarding the attitudes of individuals towards dementia, our study found a more neutral expression rather than the stigma commonly mentioned as a barrier to caregiving for dementia among Asian Americans in previous research.[12,48] Additionally, they exhibited empathy towards their care recipients. The findings at the individual level reinforced the importance of self-efficacy and coping skills while presenting diminished stigmatization of dementia.

At the interpersonal level, the findings captured the pattern of family members taking turns for caregiving and the effects of care recipients' physical and cognitive status on the

difficulty of caregiving. Previous qualitative studies capture family rotational caregiving patterns in South Africa, Asians in Singapore, and historically marginalized ethnic groups in Denmark.[49-51] Together the findings with different samples across national contexts speak to the critical function of family support in caregiving. For the impact of care recipients' health conditions, types of chronic conditions and cognitive status were found to influence their engagement in self-care behaviors, which potentially led to a higher care burden to caregivers.[52] Our findings showed while the care recipients' limitation in self-care was one of the obstacles to providing care to individuals with cognitive impairment or dementia, from the caregivers' point of view, care recipients' motivation made caregiving challenging in terms of social interaction engagement. Overall, the findings about the interpersonal level factors are consistent with the literature.

Regarding the community level, caregivers lauded the interpretation and transportation services while the significance of religion or faith support was not emphasized as much as in prior research. The federally funded PACE program implemented by ICHS was recognized as an important financial support for family caregivers. The ICHS played an important role in introducing the program to family caregivers and providing instructions that helped them become certified caregivers and eligible for payment. The findings highlight the importance of having a CBO available to assist Chinese immigrant caregivers. This CBO also addressed

the negative employment experiences faced by caregivers that have also been uncovered by the previous caregiver research.[24,28]

On the other hand, religious or spiritual supports were considered facilitators to relieving care burden in previous studies.[25,53] Through praying, attending church, or seeking religious advice, Vietnamese American dementia family caregivers and Singaporean dementia caregivers showed the smoothing effect of religion. Unlike the findings of these studies, religion or faith-based organizations were not mentioned much even when asked by the interviewer. The limited use of spiritual support groups might be attributed to the historical background of China and the CID in Seattle during the 1960s and 1970s. One caregiver explained that they were born during China's Cultural Revolution, a period when religion was not ingrained in the culture, and then migrated due to dissatisfaction with the government post-Cultural Evolution era. The historical context possibly contributes to the diminished emphasis on spiritual support. Additionally, during the construction of the highway Interstate-5 (I-5) in Seattle, the CID community experienced disruption as the highway tore through the area, resulting in the loss of their focal community church where older adults used to gather.[54] This infrastructure project severely disrupted the community structure of CID and interrupted regular community activities.[54] The recovery process took years, and many individuals in the CID community continued to experience the health impacts of the construction project.[54] The study participants were likely raised in an

environment without strong religious norms and subsequently migrated to a place where the community structure was disrupted, leading to the deconstruction of religious institutions during that period of time. Further research is needed to better understand the roles of spiritual groups/institutions in supporting dementia caregiving and caregivers among Chinese Americans.

At the level of society, the COVID-19 pandemic affects caregivers and care recipients at different levels. It disturbed families' rotational care plans and limited their social activities. Community activities were constrained by pandemic-related regulations. Other studies have shown that pandemic-related quarantines exacerbated care recipients' neurobehavioral symptoms, aligning with the findings of this study.[55,56] The limitations imposed by the pandemic not only hindered care recipients' social activities but also increased caregivers' stress due to the disruption of the rotational caregiving pattern within families. On the other hand, the Day Center at ICHS effectively implemented the approach of activity engagement in the community to foster a cohesive neighborhood and to support the cognitive function of PACE care recipients.[57] Through regular community engagement events like recreational activities, physical exercises, and nutrition support, the Day Center facilitated cognitive stimulation and social connection for older adults. It provided a valuable resource for caregivers before the pandemic. However, the initial limitations imposed by quarantine, isolation, and fear of infection hindered the full realization of community

engagement.[58] This phenomenon was observed not only among unpaid caregivers to people living with dementia in the UK but also among paid Chinese American family caregivers in our study. Consistent with prior research filial respect functions as a facilitator of caregiving due to its cultural significance.[28] While these caregivers were bound by filial respect to care for their parents, they held divergent views on whether to pass on this tradition to future generations. Recent research on Chinese immigrants aged 65 and above in Canada suggests that the expectation of filial respect has decreased over time.[59] This trend was also reflected in some narratives in our study. As cultural values evolve over time, the influence of filial respect on caregiving behaviors in Chinese Americans is likely to change. Community and governmental resources will become more important for Chinese Americans who need dementia care.

A new societal level barrier captured in the interviews was the constraints on their human and social capital in the US that stem from the historical context of their home country and US immigration policy. According to the Homeland Security Immigration Statistics in 2004 and 2021 (the earliest and the latest open resources), the employment-based Chinese immigrants greatly increased from 30.5% to 44.4%, the family-sponsored percentage dropped from 26.70% to 12.8%, and the immediate relatives percentage had also dropped from 40.9% to 32.2%.[60,61] Considering the changes in the composition of immigration mechanisms over

the two decades, it will be important to further explore the availability of human and social capital of new Chinese immigrants for their caregiving experiences.

7.3. Limitations

This study was primarily constrained by the scope and the nature of this project. It was an agency-based and practice-driven project for ICHS's service quality improvement. The study participants were all family caregivers whose parents were beneficiaries of the joint federal and state PACE program. Moreover, considering the inclusion criteria, their responses could only represent perspectives of partial Chinese Americans dwelling in the Chinatown-International District of Seattle. The findings limit the generalizability to Chinese Americans in other regions. The voices from third-party agency caregivers or facility caregivers, which are also crucial aspects of dementia caregiving, were not captured.

Due to the reimbursement mechanism, the state and federal governments jointly fund the ICHS PACE program and indirectly pay the family caregiver. Once they meet certain training criteria and apply to be an Individual Provider (IP) defined by the Washington State Department of Social and Health Services, they technically receive salaries from the ICHS. Although before the interviews it was emphasized that caregivers' responses would not affect their rights or their parent's rights and the quality of care in the ICHS, the employer/employee relationship with payroll involved might have affected the contents they would like to share.

This research is a qualitative study collecting data through interviews without other data such as quantitative information for triangulation. There are valid written Chinese or Cantonese instruments to assess cognitive status, care burden, and caregiver's quality of life (e.g., Mini-Mental State Examination (MMSE), ZBI, and C-DEMQoL[62-64]). We lacked the proficiency and professionals to convert written language into spoken language for data collection. As we observed and based on the experiences of the organization, caregivers would have not comprehended the question if it was not asked in spoken Cantonese.

7.4. Implications for Practice and Research

The study findings have various implications for practice and potential research directions. For practice, educational resources (e.g., information on the symptoms and techniques of caregiving) that address the specific needs of family caregivers and their family members related to dementia care are needed for Chinese immigrant families. Furthermore, there is a need for more organizational and governmental support, such as the PACE program and paid family caregiver mechanisms, to be widely implemented to alleviate the burden of caregiving on family members. Equally critical are community resources such as ICHS or similar organizations, as family caregivers may not be aware of these programs until introduced by organizations like ICHS. By promoting educational resources, governmental support, and community-based initiatives, a comprehensive approach can be taken to enhance

the well-being of Chinese immigrant families and improve dementia care within the community.

For research directions, it would be valuable to investigate the impact of the PACE program on caregivers' physical, mental, and financial burden across states that have implemented PACE. There have been evaluations of PACE within individual state. However, national-level, cross-state evaluations is currently lacking. Exploring the association between PACE and improved health outcomes, particularly among marginalized populations, could contribute to the broader implementation of PACE across the United States. Additionally, comparing outcomes among states that already have PACE could help identify variations and inform program enhancements. By pursuing these research directions, we can gain a deeper understanding of the potential benefits of PACE and inform evidence-based policy and practice in dementia care for older adults and their caregivers.

It is also imperative to conduct larger studies that explore the impact of dementia care on the health of family caregivers, beyond the Chinese American population. Chinese cultural norms and caregiving experiences may differ from other Asian ethnic groups, such as Indian and Filipino. Therefore, it is also essential to investigate the similar as well as unique challenges faced by other Asian American groups and to develop culturally sensitive interventions that address their specific needs.

The findings from the interviews had been shared with the ICHS PACE medical program director and staff on September 23rd, 2022. The presentation provided information for ICHS to optimize its Day Center program and further educational campaign for caregivers. The student PI had also presented and shared with public health scholars in a poster form at the UW MPH Practicum Symposium 2023 on April 12th, 2023. Community collaboration is essential for researchers and the community to unite and promote population health. The research team will disseminate the study findings through a peer-reviewed journal for increasing the visibility and voice of marginalized groups and promoting health equity.

Reference

1. Lowe L. *Heterogeneity, Hybridity, Multiplicity: Marking Asian-American Differences*. 2003.
2. U.S. Census Bureau. *2021 American Community Survey 1-Year Estimates Selected Population Profiles*. 2021. S0201. Accessed March 24, 2023. https://www.census.gov
3. U.S. Department of Health and Human Services, Administration for Community Living. *2021 Profile of Older Americans*. 2021. Accessed March 24, 2023. https://acl.gov/sites/default/files/Profile%20of%20OA/2021%20Profile%20of%20OA/2021ProfileOlderAmericans_508.pdf
4. U.S. Census Bureau. *Race and Ethnicity in the United States: 2010 Census and 2020 Census*. Accessed March 24, 2023. https://www.census.gov/library/visualizations/interactive/race-and-ethnicity-in-the-united-state-2010-and-2020-census.html
5. U.S. Census Bureau. *2017-2021 American Community Survey 5-Year Estimates Data Profiles*. 2021. DP05. Accessed April 26, 2023. https://www.census.gov
6. U.S. Census Bureau. *2017-2021 American Community Survey 5-Year Estimates Data Profiles*. 2021. DP02. Accessed April 26, 2023. https://www.census.gov
7. U.S. Census Bureau. *2017-2021 American Community Survey 5-Year Estimates Data Profiles*. 2021. DP03. Accessed April 26, 2023. https://www.census.gov
8. Yi V, Museus SD. Model minority myth. *The Wiley Blackwell Encyclopedia of Race, Ethnicity, and Nationalism*. 2015:1-2.
9. Becerra MB, Becerra BJ, Daus GP, Martin LR. Determinants of low health literacy among Asian-American and Pacific Islanders in California. *J Racial Ethn Health Disparities*. 2015;2(2):267-273. doi:10.1007/s40615-015-0092-0
10. McMurtry CL, Findling MG, Casey LS, et al. Discrimination in the United States: experiences of Asian Americans. *Health Serv Res*. 2019;54 Suppl 2(Suppl 2):1419-1430. doi:10.1111/1475-6773.13225
11. Paradies Y, Ben J, Denson N, et al. Racism as a determinant of health: a systematic review and meta-analysis. *PLoS One*. 2015;10(9):e0138511.
12. Liu D, Hinton L, Tran C, Hinton D, Barker JC. Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *J Cross Cult Gerontol*. 2008;23:283-299.
13. Wu B, Qi X. Addressing health disparities among older Asian American populations: Research, data, and policy. *Public Policy Aging Rep*. 2022;32(3):105-111.
14. Zhang L, O'Malley I, Cruz-Gonzalez M, Sánchez González ML, Alegría M. Factors associated with mental health service use among black, latinx, and asian older adults in community-based organizations. *J Appl Gerontol*. 2022;41(3):680-689.

15. Đoàn LN, Takata Y, Sakuma K-LK, Irvin VL. Trends in clinical research including Asian American, Native Hawaiian, and Pacific Islander participants funded by the US National Institutes of Health, 1992 to 2018. *JAMA Netw Open*. 2019;2(7):e197432-e197432.
16. Otobe Y, Kimura Y, Suzuki M, Koyama S, Kojima I, Yamada M. Factors associated with increased caregiver burden of informal caregivers during the COVID-19 pandemic in Japan. *J Nutr Health Aging*. 2022;26(2):157-160. doi:10.1007/s12603-022-1730-y
17. Messina A, Lattanzi M, Albanese E, Fiordelli M. Caregivers of people with dementia and mental health during COVID-19: findings from a cross-sectional study. *BMC Geriatr*. 2022;22(1):56. doi:10.1186/s12877-022-02752-x
18. Tsapanou A, Zoi P, Kalligerou F, Blekou P, Sakka P. The effect of prolonged lockdown due to COVID-19 on Greek demented patients of different stages and on their caregivers. *J Alzheimers Dis Rep*. 2021;83:907-913. doi:10.3233/JAD-210702
19. Rajagopalan J, Arshad F, Hoskeri RM, et al. Experiences of people with dementia and their caregivers during the COVID-19 pandemic in India: A mixed-methods study. *Dementia*. 2022;21(1):214-235. doi: 10.1177/14713012211035371.
20. Hindmarch W, McGhan G, Flemons K, McCaughey D. COVID-19 and long-term care: the essential role of family caregivers. *Can Geriatr J*. 2021;24(3):195-199. doi:10.5770/cgj.24.508
21. Yuan S, Zhang W, Yao Q, et al. The neuropsychiatric changes after COVID-19 quarantine in patients with cognitive impairment and their caregivers in Chongqing, China: A cohort study. *Front Aging Neurosci*. 2022;13:762907-762907. doi:10.3389/fnagi.2021.762907
22. Le TK, Cha L, Han HR, Tseng W. Anti-Asian xenophobia and Asian American COVID-19 disparities. *Am J Public Health*. 2020;110(9):1371-1373. doi:10.2105/AJPH.2020.305846
23. Wang D, Gee GC, Bahiru E, Yang EH, Hsu JJ. Asian-Americans and Pacific Islanders in COVID-19: Emerging disparities amid discrimination. *J Gen Intern Med*. 2020;35(12):3685-3688. doi:10.1007/s11606-020-06264-5
24. The National Alliance for Caregiving and AARP. *2020 Report Caregiving in the U.S.* Accessed May 25, 2023. https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf
25. Picco L, Abdin E, Chong SA, et al. Beliefs about help seeking for mental disorders: Findings from a mental health literacy study in Singapore. *Psychiatr Serv*. 2016;67(11):1246-1253. doi:10.1176/appi.ps.201500442
26. Yin H, Wardenaar KJ, Xu G, Tian H, Schoevers RA. Help-seeking behaviors among Chinese people with mental disorders: a cross-sectional study. *BMC Psychiatry*. 2019;19(1):373. doi:10.1186/s12888-019-2316-z

27. Burholt V, Dobbs C, Victor C. Social support networks of older migrants in England and Wales: the role of collectivist culture. *Ageing & Society*. 2018;38(7):1453-1477. doi:10.1017/S0144686X17000034
28. Vanderzee B. *A Qualitative Study of the Impact of the Caregiver Role on Lives of Informal Caregivers of Elderly Chinese Immigrants*. University of Washington; 2010.
29. Janz NK, Becker MH. The health belief model: A decade later. *Health Educ Q*. 1984;11(1):1-47. doi:10.1177/109019818401100101
30. National Institute on Minority Health and Health Disparities. *NIMHD Research Framework*. Updated April 15th, 2021. Accessed May 15th, 2022. https://nimhd.nih.gov/researchFramework
31. Ivey J. The value of qualitative research methods. *Pediatr Nurs*. 2012;38(6):319-320.
32. Storey JE, Rowland JT, Basic D, Conforti DA, Dickson HG. The Rowland Universal Dementia Assessment Scale (RUDAS): A multicultural cognitive assessment scale [published correction appears in Int Psychogeriatr. 2004 Jun;16(2):218]. *Int Psychogeriatr*. 2004;16(1):13-31. doi:10.1017/s1041610204000043
33. Fricke J, Unsworth CA. Inter-rater reliability of the original and modified Barthel Index, and a comparison with the Functional Independence Measure. *Aust Occup Ther J*. 1997;44(1):22-29.
34. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med*. 2001;16(9):606-613. doi:10.1046/j.1525-1497.2001.016009606.x
35. Forté S, Blais F, Castonguay M, et al. Screening for cognitive dysfunction using the Rowland Universal Dementia Assessment Scale in adults with sickle cell disease. *JAMA Netw Open*. 2021;4(5):e217039. doi:10.1001/jamanetworkopen.2021.7039
36. Tongco MDC. *Purposive Sampling as a Tool for Informant Selection*. 2007.
37. Guest G, Namey E, Chen M. A simple method to assess and report thematic saturation in qualitative research. *PLoS One*. 2020;15(5):e0232076. doi:10.1371/journal.pone.0232076
38. Fusch PI, Ness LR. Are we there yet? Data saturation in qualitative research. *Qual Rep*. 2015;20(9):1408.
39. *Dedoose*. Version 9.0.46. SocioCultural Research Consultants, LLC. http://www.dedoose.com
40. Clarke V, Braun V, Hayfield N. Thematic analysis. *Qualitative psychology: A practical guide to research methods*. 2015;222:248.
41. Twinn S. An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. *J Adv Nurs*. 1997;26(2):418-423. doi:10.1046/j.1365-2648.1997.1997026418.x
42. Lombardo NE, Wu B, Chang K, Hohnstein JK. *Model Dementia Care Programs for Asian Americans*. Springer Publishing Co; 2007.

43. Zheng X, Woo BK. Association between recognizing dementia as a mental illness and dementia knowledge among elderly Chinese Americans. *World J Psychiatry*. 2016;6(2):233.
44. Zimmerman S, Sloane PD, Ward K, et al. Helping dementia caregivers manage medical problems: Benefits of an educational resource. *Am J Alzheimers Dis Other Demen*. 2018;33(3):176-183. doi:10.1177/1533317517749466
45. Gonyea JG, O'Connor M, Carruth A, Boyle PA. Subjective appraisal of Alzheimer's disease caregiving: the role of self-efficacy and depressive symptoms in the experience of burden. *Am J Alzheimers Dis Other Demen*. 2005;20(5):273-280. doi:10.1177/153331750502000505
46. Aschbacher K, Patterson TL, von Känel R, et al. Coping processes and hemostatic reactivity to acute stress in dementia caregivers. *Psychosom Med*. 2005;67(6):964-971. doi:10.1097/01.psy.0000188458.85597.bc
47. Harmell AL, Chattillion EA, Roepke SK, Mausbach BT. A review of the psychobiology of dementia caregiving: a focus on resilience factors. *Curr Psychiatry Rep*. 2011;13(3):219-224. doi:10.1007/s11920-011-0187-1
48. Zhan L. Caring for family members with Alzheimer's disease: perspectives from Chinese American caregivers. *J Gerontol Nurs*. 2004;30(8):19-29. doi:10.3928/0098-9134-20040801-06
49. Smith L, Morton D, van Rooyen D. Family dynamics in dementia care: A phenomenological exploration of the experiences of family caregivers of relatives with dementia. *J Psychiatr Ment Health Nurs*. 2022;29(6):861-872. doi:10.1111/jpm.12822
50. Nielsen TR, Waldemar G, Nielsen DS. Rotational care practices in minority ethnic families managing dementia: A qualitative study. *Dementia (London)*. 2021;20(3):884-898. doi:10.1177/1471301220914751
50. Chan EY, Phang KN, Glass GF Jr, Lim WS. Crossing, trudging and settling: A phenomenological inquiry into lived experience of Asian family caregivers of older persons with dementia. *Geriatr Nurs*. 2019;40(5):502-509. doi:10.1016/j.gerinurse.2019.03.015
52. Iovino P, Lyons KS, De Maria M, et al. Patient and caregiver contributions to self-care in multiple chronic conditions: A multilevel modelling analysis. *Int J Nurs Stud*. 2021;116:103574. doi:10.1016/j.ijnurstu.2020.103574
53. Meyer OL, Nguyen KH, Dao TN, Vu P, Arean P, Hinton L. The sociocultural context of caregiving experiences for Vietnamese dementia family caregivers. *Asian Am J Psychol*. 2015;6(3):263-272. doi:10.1037/aap0000024
54. Bellamy-Walker T. 'Nobody Lives Here' exhibit sheds light on Chinatown International District before Interstate 5. *The Seattle Times*. Accessed May 28, 2023. https://www.seattletimes.com/entertainment/visual-arts/nobody-lives-here-exhibit-sheds-light-on-chinatown-international-district-before-interstate-5/

55. Leontjevas R, Knippenberg IAH, Smalbrugge M, et al. Challenging behavior of nursing home residents during COVID-19 measures in the Netherlands. *Aging Ment Health*. 2021;25(7):1314-1319. doi:10.1080/13607863.2020.1857695
56. Cagnin A, Di Lorenzo R, Marra C, et al. Behavioral and psychological effects of coronavirus disease-19 quarantine in patients with dementia. *Front Psychiatry*. 2020;11:578015. doi:10.3389/fpsyt.2020.578015
57. Tang F, Zhang W, Chi I, Li M, Dong XQ. Importance of activity engagement and neighborhood to cognitive function among older Chinese Americans. *Res Aging*. 2020;42(7-8):226-235. doi:10.1177/0164027520917064
58. Giebel C, Cannon J, Hanna K, et al. Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: A qualitative study. *Aging Ment Health*. 2021;25(7):1281-1288. doi:10.1080/13607863.2020.1822292
59. Zhang W. Perceptions and expectations of filial piety among older Chinese immigrants in Canada. *Ageing Soc*. 2022;42(3):497-520. doi:10.1017/S0144686X20000902
60. U.S. Department of Homeland Security. *Yearbook of Immigration Statistics 2004.* Accessed May 11th, 2023. https://www.dhs.gov/immigration-statistics/yearbook/2004
61. U.S. Department of Homeland Security. *Yearbook of Immigration Statistics 2021*. Accessed May 11th, 2023. https://www.dhs.gov/immigration-statistics/yearbook/2021
62. Wong SS, Fong KN. Reliability and validity of the telephone version of the Cantonese Mini-mental State Examination (T-CMMSE) when used with elderly patients with and without dementia in Hong Kong. *Int Psychogeriatr*. 2009;21(2):345-353. doi:10.1017/S1041610209008588
63. Lu L, Wang L, Yang X, Feng Q. Zarit caregiver burden interview: development, reliability and validity of the Chinese version. *Psychiatry Clin Neurosci*. 2009;63(6):730-734. doi:10.1111/j.1440-1819.2009.02019.x
64. Kuo MCC, Au KT, Li YS, et al. Validation of the Chinese version of dementia quality of life measure - proxy in care home residents with dementia. *East Asian Arch Psychiatry*. 2021;31(1):9-12. doi:10.12809/eaap2019
65. Dimick JB, Ryan AM. Methods for evaluating changes in health care policy: the difference-in-differences approach. *JAMA*. 2014;312(22):2401-2402. doi:10.1001/jama.2014.16153

Appendix A. Interview Guide

The Interview Guide

華語/粵語訪綱

-Greeting Caregivers-

-問候受訪者-

Introduction 介紹

Hello, my name is Erh-Chi, I am a RN and a UW Master of Public Health student. Today, I will interview you about your perceptions and experiences of taking care of dementia patients. Thank you for agreeing to participate in this interview. We really appreciate you taking the time to talk with us.

你好，我叫爾琪。我是護理師同時也是華大公衛系的研究生，謝謝你願意參與此次訪問，這個研究主要想了解失智症照顧者的認知跟照顧經驗，希望可以幫助整個華人社區以及幫助 ICHS 了解日後日照中心的設計方向。非常感謝你願意花時間跟我聊聊。

你好，我係爾琪。我係護理師同華大嘅公衛研究生，多謝你肯參與此次訪問，呢個研究主要想了解照顧者嘅認知跟照顧經驗，希望可以幫助成個唐人社區以及幫助國際了解日後日間活動嘅設計方向。非常感謝你肯花時間同我傾解。

In the interview, we will ask about your basic information, perceptions of aging and dementia, what makes it easier or more difficult for you to take care of dementia patients, and also your opinions and anticipation of the new version of the Day Center.

訪談主要有四大部分，第一部分會問一些基本資料，第二部分會了解你對老化跟失智症的認知；第三部分會詢問關於疫情期間照顧失智症病人的困難跟幫助；最後一個部分會詢問關於新的日照中心的看法。

訪談主要有四大部分，第一部分係基本資料，第二部分係你對於老化跟失智症嘅認知；第三部分係關於疫情期間照顧病人嘅困難跟幫助；最後嘅部分我會詢問你對於新嘅日間活動嘅睇法。

Complete Consent Process Before Starting Interview 知情同意過程

Before we start, I would like to go over the verbal consent process and address any questions or concerns you may have. The interview should take around 30 minutes and is completely voluntary. You can opt out at any time.

在開始之前我想要先取得你口頭上的同意，跟回答你的疑慮。這個訪談大概會花 30 分鐘的時間，完全採自願制，你如果不想參與可以隨時退出。

喺開始之前我想要先攞得你口頭上嘅同意，跟回答你嘅疑慮。呢個訪問大概會花 30 分鍾嘅時間，完全采自願制，你如果唔想參與可以隨時退出。

Would it be okay if I record the audio for this interview? The recording won't be shared with anyone other than me, and is used to aid notetaking. If at any point you want to make a comment off record, I will stop the recording and restart when you finish your comment.

請問您同意我錄音嗎？錄音檔案不會讓除了我以外的人知道，只是幫助我寫筆記、打逐字稿，這樣我在訪問過程中可以更專心的聽你說話。如果訪問過程中有一些內容你不想要被錄音，可以隨時告訴我，讓我按暫停，等你說完我才會重新開始錄音。	請問你同意我錄音咩？錄音檔案唔會讓除咗我以外嘅人知，只系幫助我寫筆記、打逐字稿，咁我喺訪問過程中可以更專心嘅聽你講話。如果訪問過程中有一些內容你唔想要被錄音，可以隨時講畀我知，讓我按暫停，等你講完我才會重新開始錄音。
Finally, I wanted to let you know that this interview is confidential, and all the interviews will be combined with information from other participants. Your responses will be anonymous. Do you have any questions or concerns before we begin?	
最後，我要再次強調，這次的訪談是保密的，所有的訪問內容會跟其他受訪者的整合在一起，所以你的意見或是回覆都是匿名的。 在我們開始之前你有沒有什麼問題或是擔心的地方？	最後，我要再次強調，呢次嘅訪談系保密嘅，所有嘅訪問內容會跟其他受訪者嘅整合喺一起，所以你嘅意見或系回覆都系匿名嘅。 喺我哋開始之前你有冇乜問題或系擔心嘅地方？
-START THE AUDIO RECORDER- **-開始錄音-** **Section 1: General Information** **第一部分：基本資料** To start, I am going to ask you for some general information. How old are you? How long have you been providing the care? What's your relationship with the care recipient? How's your family member's condition? Who else is involved in caregiving with you?	
首先我們從基本資料開始， 請問您今年幾歲？ 你照顧病人多久了？ 你跟他是什麼關係？ 他/她的病況如何？ 還有誰跟你一起照顧他/她，或是偶爾會來幫忙？	首先我哋從基本資料開始， 你今年幾歲啊？ 你照顧病人幾耐？ 你跟佢系乜關系？ 佢嘅病況點樣？ 還有邊個同你一齊照顧佢，或者偶爾嚟幫忙？
Section 2: Perception of Aging and Dementia **第二部分：老化與失智症的認知**	

Q1. [MAIN] What comes to mind when you think of aging? What comes to mind when you think of dementia?
[FOLLOW-UP] Are there any differences between these two for you? Who do you think might have dementia (susceptibility)? What are the impacts of dementia (severity)?
[PROBE] Please tell me more about that.

Q1. 對你來說老化是什麼？失智症是什麼？
對你來說這兩者有差別嗎？
你覺得誰有可能會得失智症？
你覺得失智症對人有哪些影響？怎麼說？

Q1. 對你嚟講老化系乜？
失智症系乜？
對你嚟講呢兩者有差咪咩？
你覺得邊個有可能會得失智症？
你覺得失智症對人有邊些影響？ 點講？

Q2. [MAIN] How do you feel about taking care of dementia patients?
[FOLLOW-UP] Do you have confidence in taking care of dementia patients?
[PROBE] Please tell me more about that.

Q2. 你照顧病人這幾年的心境如何？
你對於自己的照顧有自信嗎？為什麼？

Q2. 你照顧病人呢幾年嘅心境點樣？ 你對於自己嘅照顧有自信咩？點解？

Q3. [MAIN] What have you used to help with providing caregiving to your ___ [father, mother, in-law, etc.]?
[FOLLOW-UP] How do media, peers', and other families' opinions affect you?
[PROBE] Please tell me more about that.

Q3. 在照顧病人方面你周圍有哪些資源？（人、機構、補助等）
媒體、同儕、家人的意見會不會影響你的決定？
怎麼說？

Q3. 喺照顧病人方面你周圍有邊些資源？（人、機構、補助等）
媒體、同儕、家人嘅意見會唔會影響你嘅決定？ 點講？

Section 3: Facilitators and Barriers of Taking Care of Individuals with Dementia During the Pandemic
疫情期間照顧失智症病人的困難跟幫助

Q4. [MAIN] What makes it easier for you to take care of individuals with dementia during the pandemic?
Q5. [MAIN] What are the difficulties of taking care of individuals with dementia during the pandemic?
[FOLLOW-UP]
Individual level – What personal sacrifices have you made for taking care of ___? For taking care of ___, how would you describe your mental status? How does your English proficiency, education, and occupation affect you taking care of individuals with dementia?
Interpersonal level – How does taking care of individuals with dementia affect your job or your own family life? How do your family make decisions? How's your relationship with clinicians?

Community level – Any support from the community? What supportive groups or faith-based groups are you in?

Societal level – What's the community expectation of aging? Living in permanent LTC placement or living with family? Do you feel like you have the responsibility of filial respect?

[PROBE] Please take depth in it.

Q4. 疫情期間，哪些人、事、物可以幫助你照顧失智症病人？	**Q4.** 疫情期間，邊些人、事、物可以幫助你照顧失智症病人？
Q5. 疫情期間，照顧失智症病人有哪些困難？	**Q5.** 疫情期間，照顧失智症病人嘅困難有邊些？
為了照顧____你有犧牲哪些個人願望？	為咗照顧____你有冇犧牲咩個人願望？
為了照顧____你的心理負擔如何？	為咗照顧____你嘅心理負擔點樣？
你的英文能力、教育、以及職業是否影響你照顧病人？怎麼說？	你嘅英文能力、教育、以及職業有冇影響你照顧病人？點講？
照顧____有沒有影響到你的工作跟家庭？怎麼說？	照顧____有冇影響到你嘅工作跟家庭？
你們家是怎麼做醫療決定的？	你屋企系點樣做醫療決定嘅？
你們跟醫師或醫療機構關係如何？	你哋跟醫生或醫療機構嘅關系點樣？
你有沒有接觸任何社區資源？例如一些支持性團體、宗教團體等等？他們是如何幫助你的？	你有冇接觸任何社區資源？例如一些支持性團體、宗教團體等等？佢哋點樣幫助你？
這個社區對於老化的期望是什麼？住安養院？跟家人一起住？	呢個社區對老化嘅期望系乜？住安養院？同屋企人一齊住？
你覺得你有盡孝道的責任跟壓力嗎？你對於孝道的看法是？	你覺得你有盡孝道嘅責任跟壓力咩？你對於孝道嘅睇法系？

Section 4: Thoughts on the Day Center

第四部分：對日照中心的建議

Q6. [MAIN] What is your ideal day as a caregiver like?

[FOLLOW-UP] What services do you expect ICHS PACE Day Center to provide? How can those services help you?

[PROBE] Any other thoughts on the future design of the new Day Center?

*Added

Did you receive any day center services before the pandemic?

What's your perception of a Day Center?

你作為照顧者理想的一天是什麼樣子？請形容一下。	你作為照顧者理想嘅一天系乜樣？形容一下？
你期望 ICHS 日照中心提供什麼服務？這些服務可以如何幫助你？	你期望國際嘅日間活動提供乜服務？呢些服務可以點樣幫助你？

Conclusion 結論

Thank you for your valuable insight and time. Again, all information is kept confidential. We'll use this interview to help optimize the future program design of ICHS, and it's beneficial to the whole Asian and Pacific Islander populations. Is there anything else you'd like to add before we conclude? Thank you so much for your contribution! Have a nice day.

感謝你寶貴的意見跟時間。再次聲明，這個訪談內容會完全保密，我會好好整理跟分析所有的訪談內容用來優化 ICHS 未來的設計，同時你的意見也對於整個亞裔族群很有幫助。結束訪談之前，你有沒有什麼話想說，或是補充剛剛沒想到的部分？非常感謝你的貢獻！祝平安健康！

感謝你寶貴嘅意見跟時間。再次聲明，呢個訪談內容會完全保密，我會好好整理跟分析所有嘅訪談內容用嚟優化國際未嚟嘅設計，同時你嘅意見也對於成個唐人社區很有幫助。結束訪談之前，你有冇乜話想講，或系補充方才冇諗到嘅部分？非常感謝你嘅貢獻！祝平安健康！

-Stop recording-

-停止錄音-

Appendix B. The Codebook

Code Name	Description
aging_expectation	The expectation toward aging by caregivers and the elderly.
aging_expectation_caregiver	The expectation toward aging by caregivers.
aging_expectation_patient	The expectation toward aging by the elderly.
barriers	Factors exacerbate dementia caregivers' burden in different levels, including individual, interpersonal, community, and societal level.
barrier_individual	Factors exacerbate dementia caregivers' burden at individual level.
barrier_interpersonal	Factors exacerbate dementia caregivers' burden at interpersonal level.
barrier_community	Factors exacerbate dementia caregivers' burden at community level.
barrier_societal	Factors exacerbate dementia caregivers' burden at societal level.
change_due_to_pandemic	The changes have been made regarding caregiving by the pandemic.
change_due_to_pandemic_external	The changes have been made regarding caregiving by the pandemic due to external reasons like Asian xenophobia.
change_due_to_pandemic_internal	The changes have been made regarding caregiving by the pandemic due to internal reasons like physical or cognitive degenerations.
facilitators	Factors ease dementia caregivers' burden in different levels, including individual, interpersonal, community, and societal level.
facilitator_individual	Factors ease dementia caregivers' burden at individual level.
facilitator_interpersonal	Factors ease dementia caregivers' burden at interpersonal level.
facilitator_community	Factors ease dementia caregivers' burden at community level.
facilitator_societal	Factors ease dementia caregivers' burden at societal level.
medical_decision	The description of how individuals' families make family medical decisions.
modifying_factors	Factors affect individual beliefs in dementia care, including socioeconomic status, cultural, and demographic background.
cutural_background	Cultural background affects individual beliefs in dementia care.
demographic_background	Demographic factors affect individual beliefs in dementia care.
socioeconomic_status	Socioeconomic factors affect individual beliefs in dementia care.
patient_description	The description of patients' conditions including physical, mental, cognitive, and social emotional domains.
patient_description_cognitive	The description of patients' conditions regarding cognitive status.
patient_description_mental	The description of patients' conditions regarding mental status.
patient_description_physical	The description of patients' conditions regarding physical status.
patient_description_socioemotional	The description of patients' conditions regarding socioemotional status.
perception	The perceptions toward aging, dementia, and their difference.
aging_description	The descriptions of aging defined by caregivers.

caregiver_feeling	The feelings of dementia caregivers.
dementia_description	The descriptions of dementia defined by caregivers.
perceived_self_efficacy	The caregivers can express self-efficacy on taking care of dementia individuals.
perceived_threat	The caregivers can perceive the susceptibility or severity of dementia.
perceived_severity	The caregivers can tell the severity of dementia.
perceived_susceptibility	The caregivers can tell the susceptibility of dementia.
salient_event	Events posing significant changes on patients' lives.

Appendix C. The Thematic Map