Calling All Voices

Stories from Asian Community Members on Learning to Live Well with Dementia

"We can make a more inclusive society for individuals with dementia by having more people share their lived experience"

-Mario Gregorio,
living with dementia

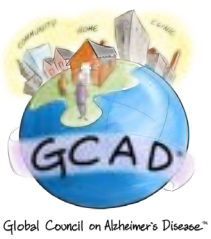

Table of Contents

3 Introduction

5 Acknowledgments

6 Dementia in the Asian Community

7 Addressing Stigma and Silence Around Dementia

- 8 Challenges: Stigma and Silence Pervade the Asian Community
- 11 Overcoming the Barriers: Raising Awareness and Fostering Conversations

14 Advocating for Cultural Humility in Dementia Care

- 16 Challenges: Care and Support Systems Lack Sufficient Cultural Humility
- 20 Overcoming the Barriers: Finding and Advocating for Cultural Humility

23 Finding Ways to Live Well with Dementia

- 24 Challenges: Guilt, Cultural Expectations, and Lack of Community Create Barriers to Living Well with Dementia
- 27 Overcoming the Barriers: Harnessing Community, Setting Boundaries, and Cultivating Joy

31 Call to Action

32 Resources

35 Works Cited

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Introduction

In 2021, the Global Council on Alzheimer's Disease (GCAD) and Dementia Action Alliance (DAA) co-authored a first-of-its-kind paper, *Hear Our Voices*. This paper shared insights from a series of interviews of people living with dementia and their care partners and sought to fill a gap in the literature by placing front and center their first-hand, authentic testimony.

As *Hear Our Voices* attempted to address one gap in the literature, it revealed another: the urgent need to hear from more diverse voices – voices that are too often marginalized, underserved, and unheard in dementia.

To address this gap, we launched Calling All Voices, a series of papers and podcasts dedicated to hearing and amplifying the distinct experiences of people living with dementia and care partners across diverse communities. In 2022 we were proud to launch *Calling All Voices: Stories from Black Community Members on Learning to Live Well with Dementia* and *Calling All Voices: Stories from LGBTQ+ Community Members on Learning to Live Well with Dementia*.

We are now delighted to share the latest installment in the series: *Calling All Voices: Stories from Asian Community Members on Learning to Live Well with Dementia*. In this paper, we provide a platform for the Asian community to share, in their own voices, their experiences living with dementia.

In the pages that follow, we share a set of "lived experiences" that we heard as we had conversations with nine members of the Asian community, one of whom is living with dementia and eight of whom are care partners. These individuals have been touched by different types of dementia and come from diverse backgrounds and geographical regions, including family heritage from three countries in Asia and current residence in five states and provinces across the U.S. and Canada.

In our conversations, we heard about challenges that people in the Asian community have encountered in their dementia journey. Some of these challenges are very familiar to the broader dementia community such as difficulties accessing care and receiving a timely diagnosis. Other challenges are more specific, such as a lack of cultural humility, specific and competent care, language barriers, and feelings of guilt and isolation connected to cultural expectations for elder care.

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We would, however, fail in our goal to hear and amplify these stories if we only shared challenges and difficulties. Throughout our interviews, we heard stories of perseverance, creativity, love, and dedication. And we heard invitations to join the advocacy efforts to support the Asian community affected by dementia.

We would like to thank the generous people who shared their experiences with us. The insights and stories they shared are the only reason this paper came to be. Together, they advance us toward a better, more equitable future for Asian individuals and families impacted by dementia.

From the outset, we would like to recognize the limitations of this paper. First, despite extensive outreach, only one of our conversations was with an individual living with dementia. Second, our nine interviews do not, and cannot, fully capture the vast diversity of experiences across the many cultures in the Asian community. Finally, our conversations were with Asian Canadians and Americans. Many of the conclusions and insights that follow will have limited global application.

We would therefore like to use this paper to **call all voices** of the Asian community to share their stories. Whether it's with GCAD, DAA, a support group, another person living with dementia, or anyone else, each voice propels us further along our collective journey of activism, compassion, and understanding.

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VP Patient Advocacy and Stakeholder Engagement,
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Acknowledgments

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We would also like to extend our deep gratitude to Jessica Luh Kim for her expert voice and the skill and compassion with which she led the conversations that became this paper.

Ron Beleno
Care partner in Ontario
Family heritage: The Philippines

Peter Wei
Care partner in California
Family heritage: Taiwan

Cris Charbonneau
Care partner in North Carolina
Family heritage: The Philippines

Neela White
Care partner in Ontario
Family heritage: South Asia

Mario Gregorio
Living with dementia in British Columbia
Family heritage: The Philippines

Wendi Yen Huestis
Care partner in New York
Family heritage: Taiwan/North America

Jessica Hsieh
Care partner in Ontario
Family heritage: Taiwan

Anonymous
Care partner in California
Family heritage: Taiwan

Mary Huang
Care partner in Ontario
Family heritage: Taiwan

Finally, we would like to acknowledge the many organizations and individuals who supported the recruitment of our participants and who have worked hard to shed light on this important topic. They include, but are not limited to, Alzheimer Society of British Columbia, Behind Our Science team, Care Registry, Dementia Friendly Pennsylvania, Gardena Valley Japanese Cultural Institute, LeadingAge California, McCarthy Fiduciary Services, Milken Institute, TaleGate, and The Key.

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Dementia in the Asian Community

The Asian community faces unique and growing challenges related to dementia. In the United States and Canada, the Asian community is the fastest growing minority group[1,2] with a projected threefold increase in the U.S. by 2050.[3] Currently, nearly one in ten Asian adults 65 years or older lives with dementia,[4] and as the Asian population continues to grow and age, so too will the number of people affected. Indeed, in Canada, by 2050, nearly a quarter of all people living with dementia will be of Asian descent, up from under one in ten in 2020.[5] Together, these numbers highlight the urgent need for targeted interventions and support.

Prevalence is not the only concern. Asian community members also face substantial systemic barriers to treatment and care. When receiving care, over one third of Asian Americans report experiencing discrimination[6] and nearly half believe that medical research is biased against people of color.[7] Further, language barriers coupled with a lack of linguistic and cultural competency in care systems makes it more difficult to access appropriate cognitive testing, diagnosis, and treatment.[6]

Within the Asian community, cultural stigma and standards for elder care can create barriers to living well with dementia. Dementia is often seen as an embarrassment, related to fate, and/or a natural part of aging.[8] These perceptions can heighten feelings of isolation and resistance to seeking medical care.[8] Many are also reluctant to consider long-term residential care options[9] which can increase the at-home responsibility of family care partners.

Despite these obstacles, there are reasons for optimism. Community-based programs and culturally specific initiatives are providing much-needed support and resources to Asian families.[10] Increased awareness and education efforts are helping to break down stigma and encourage earlier intervention.[11] These efforts are creating more resources and pathways for Asian individuals to live well with dementia.

This paper highlights the nuances of the challenges facing the Asian community impacted by dementia through firsthand testimony. It discusses stigma and silence, lack of cultural humility in care, and barriers to living well with dementia. But in equal measure, the paper showcases how Asian community members are responding to these challenges by raising awareness, advocating for culturally specific resources and care, and mobilizing support systems to develop pathways to living well with dementia.

Diversity Within the Asian Community

We would like to acknowledge and stress that the "Asian community" is incredibly diverse, encompassing dozens of nationalities in the Asia-Pacific.[12] Despite this diversity, Asians are typically grouped together as a monolith when it comes to health and wellness.[6] In reality, factors like dementia risk,[8] income, and education[6] can vary greatly across Asian populations.

While this paper uses the general term "Asian" and draws insights from only three of the many countries in Asia, we try to showcase and honor this heterogeneity.

We further encourage individuals from across the many Asian communities to share their voices and stories. Doing so will assist the critical effort to improve representation and recognition. We also call upon researchers and medical experts to conduct more nuanced studies and disaggregate data to better tailor treatment, support, and care.

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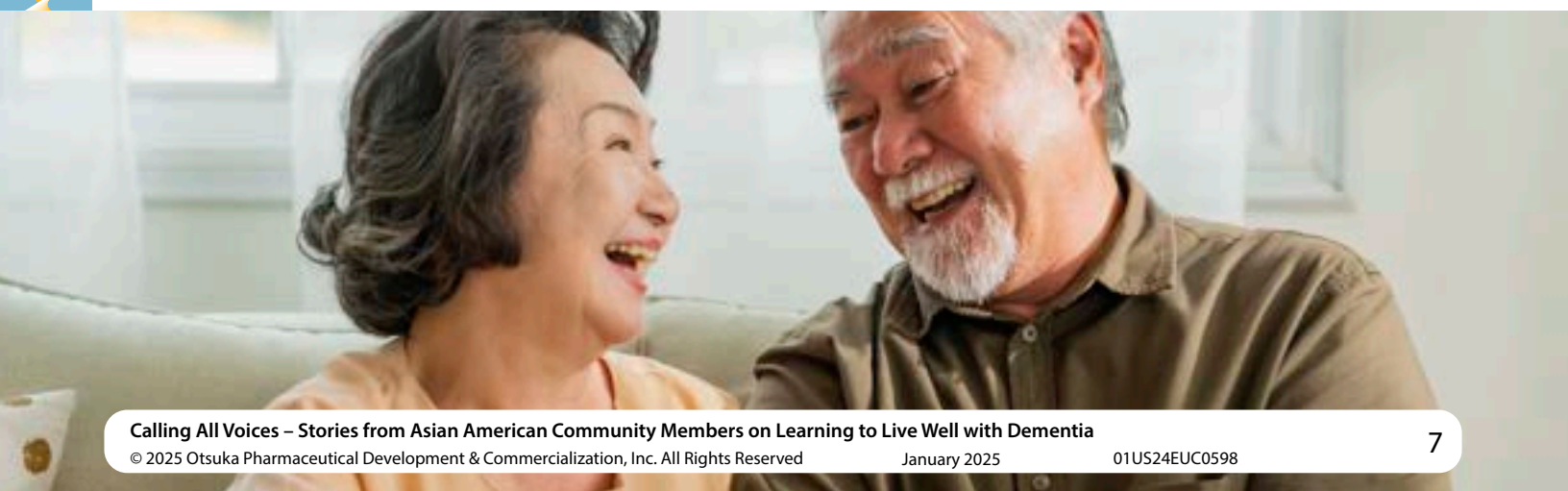
Addressing Stigma and Silence Around Dementia

> **Change will not happen if people are not aware.**
>
> **Mario Gregorio,** living with dementia

Stigma and silence around dementia pervade the Asian community. In one qualitative study, stigma was a common theme in nine out of ten interviews with Asian care partners[3] and Asian community members disproportionally feel dementia brings dishonor and shame upon a family.[13] These perceptions have tangible impacts on treatment, care, and well-being. Stigma can drive individuals to withhold information about their symptoms from healthcare providers, leading to delayed diagnosis and treatment interventions.[14] Silence allows misconceptions, like the belief that dementia is a normal part of aging,[7] to prevail, which further inhibits access to timely and appropriate care. Finally, as we heard from many of the participants, stigma and silence can drive feelings of loneliness, isolation, and shame in both the individual living with dementia and their care partners.

To combat the pervasive stigma and silence surrounding dementia, some individuals are speaking out about their experiences. They are addressing bias on local, national, and international levels, and reflecting on its personal and cultural foundations in their family and community. Every conversation, no matter how small, helps to raise awareness and erode the stubborn and deeply entrenched stigma that ensnares the dementia experience.



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Challenges: Stigma, Silence, and Lack of Awareness Pervade the Asian Community

Stigma

Stigma around dementia is common across many communities, though its origins can vary. In the Asian community, stigma is commonly rooted in religions and spiritual beliefs that associate dementia with past sins, bad karma, or an imbalance in energy.[15] Further, religion and belief systems like Confucianism – which place value on maintaining familial honor and reputation – can drive feelings of shame or dishonor within dementia.[13, 15] These sentiments were reflected in our interviews where we heard stories of individuals refusing to accept a dementia diagnosis and holding misconceptions about its origin.

"There are people who think that dementia is a punishment from God for misdeeds from the past and that all dementia is an inherited disease and therefore can be passed on to future generations. The diagnosis of dementia is a huge legal and financial burden for the family, especially for the oldest male child, and it can affect the marriageability of all children. So people deny their symptoms and resist seeking a diagnosis.'"

- Mario Gregorio, living with dementia

"In Asian culture you don't talk about personal stuff as much. There's a lot of stigma to admit somebody's declining."

- Mary Huang, care partner

"When we finally took mom back to the doctors for a diagnosis, I remember her running out of the office and down the main road with a lot of traffic. I was chasing her on foot and dad started chasing in the car. My mom was always one who wanted to look like the perfect Asian family, so I knew she wasn't in her right mind because she was making this huge scene because she wasn't willing to accept the diagnosis."

- Wendi Yen Huestis, care partner

When we went to the neurologist and my dad first heard mom's diagnosis of Alzheimer's, he left and never came back. He did not escort my mom to any more doctor's appointments. It got to the point where my mom started missing doctor's appointments because she just didn't have transportation."

- Cris Charbonneau, care partner

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Silence

For many members of the Asian community, dementia is shrouded in a secrecy that stems from stigma,[16] culture,[13] and misconceptions.[15] This silence – both within families and in the broader Asian community – ultimately perpetuates the very factors that cause it.

Maybe it's being immigrants, maybe it's just my parents' personalities, but they are very independent people. They strive to not share anything private with others. My mom didn't share her diagnosis with anybody. She didn't share it with former colleagues, her brothers and sisters, she never talked about it with us after her diagnosis. It was almost as if nothing happened. My dad was also very private about it, I think the only person he was able to confide in was myself and my mom's younger sister. In the Asian community, I just don't know if there is enough conversation."

- Cris Charbonneau, care partner

My mom's not comfortable sharing what happened. I think it's part of her personality, but I would say culture definitely has a part to do with it."

- Peter Wei, care partner

I do not know how she got Alzheimer's, maybe it does run on the Asian side of her family, but nobody would talk about it."

- Wendi Yen Huestis, care partner

We didn't tell anyone. My mom had always been a very private person. And we respected that. No one knew until she died. I think on the whole, minority people tend, especially of a certain generation, to keep the diagnosis as private as possible. People will say 'they died of old age' rather than the actual cause because somehow it's a negative thing. I think it's looked at as frailty, or you're not strong, you're not brave, you're not courageous. People think 'maybe this is karma.' But if it's not discussed, it's not understood."

- Neela White, care partner

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Spotlight: Dementia Bias Embedded in Language

Cultural stigma around dementia is often entrenched in the very language used to discuss it. In Mandarin, for example, dementia translates to "crazy catatonic,"[14] in other languages there is no direct term.[17]

> **I don't remember any term for dementia in the Filipino language. But people will use 'makulit' which means very repetitive - that is their term for somebody asking questions three or four times. Sometimes they call people with dementia crazy."**
>
> - Mario Gregorio, living with dementia

> **I'm not sure if there's a word for it, it's discussed more in hand gestures. Mom would use the word 'crazy', though she didn't mean it in a negative way."**
>
> - Ron Beleno, care partner

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Overcoming the Barriers: Raising Awareness and Fostering Conversations

Raising Awareness in the Broader Community

In response to the stigma and silence that often surround dementia, individuals in the Asian community are working to change cultural perceptions, bolster understanding, and improve the lives of people living with dementia. They are creating podcasts and awareness campaigns, sharing their stories, and educating their communities.

I participate in webinars and podcasts and public forums to create awareness about dementia. I also participate as a patient partner for several universities across Canada to help researchers and students understand the sensitivities and needs of people living with a disability. We need more people affected with the disease to share their lived experience. We need to have families not to hide their loved ones and share strategies on how to cope with daily living with a person with dementia."

- Mario Gregorio, living with dementia

I'm not shy - there was an opportunity to be interviewed in the paper, I asked my parents' permission, and have been working to bring some of these issues to my community."

- Mary Huang, care partner

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Sharing Amongst Friends and Family

Every conversation about dementia matters, and sometimes the most impactful ones are the small-scale, informal discussions between friends and family. This could include simply sharing the diagnosis, talking about care plans, exchanging tips on how to cope with change and challenging situations, and discussing resources that could be helpful on the dementia journey. Talking more openly about dementia can help reduce stigma and increase understanding and acceptance of dementia. It can also foster strong bonds of support and feelings of community which can help people live better with dementia.

"I bring it up all the time when I'm talking to someone."

- Wendi Yen Huestis, care partner

"I take all of my experience and make sure anyone I come into contact with can go forward with some knowledge of how to investigate, where to go, how to plan. These conversations shouldn't be these uncomfortable things. They should happen on Friday night when you go out for cocktails – 'hey, how are your parents doing? What do you think their plan is? Have you talked to them?'"

- Neela White, care partner

"We were the first in our network to go through this, but now people are now coming to me saying 'how do we handle this?'"

- Ron Beleno, care partner

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Spotlight: Discussing and Better Understanding a Person's Behavior

At times, people living with dementia may act and respond in ways that people, especially care partners, may not understand, find concerning or challenging, or perceive as "out of character" for the person.

Behaviors Associated with Dementia
People's behavior - actions, reactions, words, and gestures - may represent a variety of things. For a person living with dementia, their behavior could be an attempt to communicate an unmet need,[18] a response to their physical environment, or a reaction to the way others are engaging with them.[19] As we heard in our interviews, behavior can also be a reflection of an individual's past life, patterns, and preferences.[20]

"People think that all people with dementia are aggressive and hit people without provocation, that they do not want to take hygienic measures like taking a bath or brushing their teeth or changing clothes. People see the disease not the person with the disease. We need to see compassion and love when people tell us what they have. We need to have families not to hide their loved ones and share strategies on how to cope with daily living with a person with dementia."

- Mario Gregorio, living with dementia

For many of the family care partners we interviewed, having the opportunity to share experiences they found challenging (e.g., the person living with dementia getting lost, not recognizing them, changes in their mobility, or behaving in ways that the care partner did not understand or expect), helped the care partner better understand the changes, ease some of the emotions those situations evoked, reflect on what they learned from those moments, and realize they are not alone in navigating this part of the journey. Open, candid conversations about these experiences, instead of staying silent or overlooking them, can help people living with dementia and care partners work through them and seek help and resources when needed.

Community members share the ways in which they have responded to difficult situations associated with dementia that arose in their own circumstances:

"My mom has walked out of the facility a couple of times, fortunately she's safe and we enacted all the pieces in place to get her back into the apartment. We are now moving them both into more of an assisted living and memory care community [to get help and support]."

- Cris Charbonneau, care partner

"We got dad a walking treadmill and that helped [due to balance and mobility changes]. Then I got him a stationary bike because I noticed that he's not as stable, but when he rides the bike, it seems to help quite a bit."

- Peter Wei, care partner

"When we experienced challenges during sun setting time, we would use music to calm her down."

- Wendi Yen Huestis, care partner

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Advocating for Cultural Humility in Dementia Care

> **We need cultural competence to better care for families that come from different lived experiences**
>
> **Cris Charbonneau**
> Care Partner

Across the U.S. and Canada, Asian community members navigate challenges to receiving quality, culturally appropriate support. Language barriers are one such challenge. According to the American Society on Aging, over a quarter of Asian Americans report their English is "less than proficient." Among individuals born outside the United States, this number increases to over four in ten.[6] Additionally, while the vast majority of Asian Americans consider access to culturally humble care essential, fewer than two thirds believe that such providers are readily available.[21] Many of the individuals we interviewed also cite a lack of culturally specific resources such as support groups, brochures, and papers.

In response, community members share that they are advocating for themselves and their families and are finding ways to bring cultural humility and specificity into their dementia care. They also provide recommendations for healthcare providers on how to better serve the Asian community.

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Cultural Competency, Sensitivity, and Humility

Cultural competency, sensitivity, and humility are three interrelated terms that advance understanding of and appreciation for other cultures. They are loosely defined as follows:

Cultural Competence:

"The ability to understand, appreciate and interact with people from cultures or belief systems different from one's own."
(American Psychological Association)[22]

Cultural Sensitivity:

"Awareness and appreciation of the values, norms, and beliefs characteristic of a cultural, ethnic, racial, or other group that is not one's own, accompanied by a willingness to adapt one's behavior accordingly."
(American Psychological Association)[23]

Cultural Humility:

"A practice of self-reflection on how one's own background and the background of others, impact teaching, learning, research, creative activity, engagement, leadership, etc." (University of Oregon)[24]

Increasingly the healthcare field is shifting toward an approach based on "humility" rather than "competency" when engaging with other cultures. According to the Penn Medicine Center for Health Equity Advancement, there is rising concern that because cultural competency training "calls for one to memorize a set of traits connected to or a set of questions that you need regarding specific groups of people" it "enforces the idea that one can actually be 'competent' in a culture other than their own and that cultures are somehow monolithic and static."[25] In contrast, training providers in practices of cultural humility provides an "orientation to care that is based on self-reflexivity, appreciation of patients' lay expertise, openness to sharing power with patients, and to continue learning from one's patients" (Lekas, et al., 2020).[26]

While both terms hold value, we steer toward "cultural humility" in this paper to emphasize the importance of ongoing listening and learning.

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Challenges: Care and Support Systems Lack Sufficient Cultural Humility

Language Barriers

Language can be one of the most significant barriers to Asian individuals receiving quality and timely dementia care. Compared to other racial groups, Asian Americans have the highest level of limited English proficiency[14] and nearly a quarter cite language as a barrier to care.[21] Complicating matters, there is a shortage of bilingual healthcare providers[6] and thousands of Asian languages,[27] with many, like Chinese, having several dialects.[14] Together this creates barriers to patient-provider communication which is associated with worse health outcomes, reduced access to important health information,[28] and adverse psychological effects.[29]

When my grandma was tested for dementia, her doctor was white and he used tests that were in English. English wasn't my grandma's first language and she also had hearing problems. My mom went in as a translator for her but not all questions can translate well, there's a lot of nuances that get lost in translation, so she was not getting any of the answers correct. She said that because of the language barrier, the doctor was getting annoyed and just seemed like he wanted to get it over with. Her tests results said she had severe dementia when it was actually more moderate at the time. That was the only time that she ever got tested."

- Jessica Hsieh, care partner

Language is one of the barriers to care because some people, especially the elderly, didn't get a chance to become proficient in English when they immigrated. That is a big challenge and a factor in why they become hesitant to access services."

- Mario Gregorio, living with dementia

"It really came down to me to interface with all the healthcare professionals and translate for my mom. My mother isn't great with English. I think if she speaks to anybody in English, she gets nervous and her anxiety ratchets up. I can't imagine trying to navigate care if you are a first-generation family and you don't know the language very well. It's near impossible for us despite the fact that both my sister and I are well educated and fluent in English."

- Anonymous, care partner

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Spotlight: Reverting to First Language and Culture

Bilingual individuals with dementia may experience "language reversion," a process in which they lose proficiency in their acquired language and primarily revert to their native one.[30] In our interviews individuals also detailed family members believing they were back in their country of origin and adjusting their communication and behavior accordingly.

"Dad would communicate as though he's in the Philippines. He'd use the name of his church from the Philippines, not our church here in Canada. He felt more comfortable based on his childhood."

- Ron Beleno, care partner

"Ultimately, his English degraded and he defaulted back to Chinese because that's his native language. Then whatever is buried deep in his youth came back."

- Peter Wei, care partner

"Mom spoke four languages and she lost the ability to speak each language in the reverse order that she learned them. First she lost English, then Chinese and then Taiwanese."

- Wendi Yen Huestis, care partner

"There were moments where mom thought I was her nurse colleague, or I was her cousin. And she really thought that she was just back in the Philippines."

- Cris Charbonneau, care partner

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Lack of Cultural Humility in Care Settings

Members of the Asian community not only face language barriers in care, they also encounter a shortage of care options that represent and cater to their diverse and unique cultural backgrounds. The individuals we interviewed described being the only people of Asian descent in their care communities, an inability to find carers who spoke their language, and when there was Asian representation, the ways in which it fell short. This lack of culturally appropriate support can lead to negative health consequences and poorer quality of care.[31]

> **There were no facilities that focus on different ethnic groups. This is a challenge for seniors who came to Canada in the later stage of their life - because of the language barrier, fear of authorities, and the shame of stigma associated with the disease. We become invisible as a culture and as a consequence, there are no facilities available to cater to our needs."**
>
> - Mario Gregorio, living with dementia

> **As soon as we moved my parents into their center, we immediately had the director call and say, 'I'm not sure this is the right place for your mother, she is telling people that she is the care provider.' It was surprising to me to have a community with a number of seniors experiencing other forms of memory loss, cognitive decline, or dementia say to me that mom didn't belong. There isn't a lot of diversity where I live and no other seniors in that community that were people of color. I think it's really important when choosing a community that there be somebody that may understand their lived experiences, where they might see somebody that just simply looks like them, whether it be caregivers or others living there."**
>
> - Cris Charbonneau, care partner

> **We had a personal support worker [PSW] who was with us for over ten years. She was able to speak with my grandmother and do activities with her, but it was all in English. That made it harder for my grandma. I think if we were able to have a Chinese PSW, who could speak the language, that would have helped because her world was silent. She had hearing loss and she had very little meaningful social connections other than me and my parents. If she was able to have that connection maybe she wouldn't have progressed so quickly."**
>
> - Jessica Hsieh, care partner

> **The staffing is a problem at mom's care facility. They're down to one Chinese nurse who's there for five shifts out of 21. Same thing with the Chinese food. They have a Chinese floor but unfortunately a lot of people on that floor speak Cantonese. Mom speaks English and Mandarin so it was actually easier for her to be in the English speaking environment."**
>
> - Mary Huang, care partner

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Lack of Culturally Specific Support and Resources

In addition to the lack of language and culturally humble care, there is an absence of culturally aligned dementia resources and support for Asian community members. Despite community interest in resources and support services,[29] interventions that serve the Asian community are sparse, and those that do exist represent Asian sub-populations unequally.[15] For educational materials, even when they are linguistically accessible, they can be of inferior quality compared to English counterparts.[15] In support settings, the individuals we interviewed discussed a lack of cultural familiarity among those who are supposed to offer guidance, resources, and community.

"Most of the literature is focused on the North American audience and there is little in terms of publications or brochures that cater to the people with different ethnic or cultural backgrounds."

- Mario Gregorio, living with dementia

"I wish there was a support group for my mom with people who have a similar background, who maybe have gone through this, people who she can listen to, and she can relate to."

- Peter Wei, care partner

"People don't understand that in the Chinese culture, the family unit is much stronger than the regular family. They don't understand some of the cultural dynamics, don't have the context, and a lot of them don't bother to find out, they just use normal metrics. But it's not a one size fits all. When I was sharing some of my experience with a Mandarin and Cantonese speaking social worker, I didn't have to go into a lot of detail to explain, whereas with somebody who's not familiar with Asian culture, I have to because they don't understand."

- Mary Huang, care partner

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Finding Culturally Humble Care

In the face of inadequate cultural humility in care systems and available resources, the individuals we interviewed demonstrate fierce determination to find care that serves their needs. Individuals discussed finding providers and carers from similar backgrounds who could intuitively understand how to tailor communication and care without explicit instruction. They also shared solutions for helping people living with dementia connect to their culture in the absence of culturally specific care. The overarching message is clear: it is essential to keep individuals connected to their culture whether that be through food, language, entertainment, or cultural celebrations and festivities.

"I would always seek out the Filipino nurses - they know how to communicate based on what our concerns are. Some would bring dad a rosary since he's Catholic and say something like 'make sure that he keeps praying.' You feel like there's a trust, an ability to communicate,"

- Ron Beleno, care partner

"I found a caregiver who spoke Mandarin to my mom for two years. We were very lucky to have her, in Vermont a caregiver who speaks any Asian language is beyond amazing. She would make Asian food, speak to my mom in Chinese, and would dance with her and play Asian music because these are all things that my mom really loved."

- Wendi Yen Huestis, care partner

"The Chinese food at mom's care facility wasn't great and was only served at five out of the 21 weekly meals. So, I talked to the food service coordinator and said, 'at least buy some frozen dumplings and boil them' and she did end up putting them in rotation. I was basically talking to everybody. It's a quality of life thing."

- Mary Huang, care partner

"Our psychologist had immigrated from Taiwan as well. So he understood that cultural perspective. We didn't have to explain as much and that was a relief. He could also speak directly to my mother and she understood."

- Anonymous, care partner

"We try to take my parents to cultural events. There's Filipino mass at the Catholic church 25-30 minutes away, there's a Filipino restaurant that for a while we were taking my mom and dad to every Sunday. That was the place where my parents would literally sit for three hours and eat and shop and talk with people. I think that really helped to ground and reenergize them. It's important to outsource culture when it's not present directly in the care community."

- Cris Charbonneau, care partner

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Advice for Care Settings and Health Care Providers

Community members are making great strides to address gaps in care, and they call upon service providers to do the same. Individuals share that they would like service providers to make efforts to develop trust, to learn a few words of the individual's language, and to better understand the nuances and vast diversity within the Asian population.

"We cannot have a cookie cutter approach. Each ethnic community has a different perspective about dementia and how it affects their family. It is important to understand the differences. Some feel that it is a great thing to seek help. Some think dementia is a punishment from God and therefore there is no hope. Some fear authorities. It is very important to remember that an individual who is diagnosed with the disease is very different from another person diagnosed with the same illness."

- Mario Gregorio, living with dementia

"Physical touch is something that a lot of Asian cultures are uncomfortable with. So it goes a long way to ask for permission to touch, explain what you're about to do, or how you're going to help."

- Mary Huang, care partner

"It's essential to develop trust as soon as possible through care. We need spiritual and humble support. Many Filipinos value faith and doing the right thing so respond well to things like 'that's very good of you.' It's also important to be aware of the differences in the Asian community. For example, Filipinos are maybe closer to the Mexican and Spanish community than the Chinese community because we were colonized by the Spanish. While we share similarities like rice and noodles with Southeast Asia, I think culturally we're more similar to Mexico."

- Ron Beleno, care partner

"Learn a few phrases in their language, get to know their music, or maybe put programming they like on the TV. A lot of times in the nursing homes, that's all you can do. It's those little touches, whatever culture you're from, that make it more bearable and a little more comfortable."

- Anonymous, care partner

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Spotlight: Adopting a Practice of Cultural Humility and Competency

Practicing culturally appropriate care requires being sensitive to cultural customs, norms, and behaviors, and recognition that it is an ongoing, iterative process of learning and listening.

Example in Practice: Ensuring Strong Communication

Providers and carers should reflect on how cultural beliefs around hierarchy and respect for authority inform how members of the Asian community interact with them.

In the Asian community, individuals may nod their head during conversations to show respect and acknowledgement of the person speaking. Doing so has even been shown to increase likeability and approachability.[32] However, this does not mean the individual necessarily agrees with or understands the individual speaking.

Culturally humble providers should be keen observers of their patient's body language, ask questions, check in to ensure their communication is well received, and adjust communication practices as needed.

Asian community members often view providers as the figure of authority. As a result, community members may not speak up to voice concerns and may omit or not feel comfortable sharing important information.[33]

Culturally humble providers should work hard to build trust, check in frequently, and follow the lead of the individual and their family on the best practices for communication and reciprocity.

For more information:

Dartmouth Guide to Cultural Humility in Healthcare

- https://researchguides.dartmouth.edu/cultural_awareness
- Introduction to cultural humility in healthcare with a collection of web resources and books for further information.

Cultural Sensitivity for the South Asian Population - Workshop Presentation for Providers

- https://www.fraserhealth.ca/-/media/Project/FraserHealth/FraserHealth/Health-Topics/Mental-Health-Substance-Use/Cultural_sensitivity_for_South_Asian_community_dementia_diagnosis_webinar_slides.pdf
- Guide for providers on how to support South Asian patients with dementia and their family's with cultural sensitivity.

A Guide to Having Conversations About What Matters

- https://healthqualitybc.ca/wp-content/uploads/ConversationsMatterFINAL.pdf
- A guide for providers, patients, and family members on how to have effective conversations.

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Finding Ways to Live Well with Dementia

> **Social and cultural stigmas aside, do what you think is best for your family. Everything else can wait.**
>
> **Anonymous,** Care Partner

There are, undeniably, many barriers to living well with dementia—many of which are common across the dementia community—but some are particularly widespread within the Asian community. Feelings of guilt, isolation, and strong, enduring cultural norms that dictate care and support approaches, all present obstacles to living well, for both individuals living with dementia and their families. While this list is by no means exhaustive, it covers some of the most frequently shared challenges from these interviews.

In response, many of the individuals we interviewed share that they are setting boundaries, finding sources of connection, creating systems of support, and cultivating joy and meaning in their journeys.

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Challenges: Guilt, Cultural Expectations, and Lack of Community Create Barriers to Living Well with Dementia

Navigating Cultural Expectations Around Elder Care

Strong cultural expectations shape how individuals in the Asian community approach care and support surrounding dementia. The influence of filial piety—the Confucian concept of putting one's elders first and deferring to their judgement[34] —was apparent in most interviews, whether or not it was explicitly named. Individuals shared a deep-felt responsibility to be a care partner for their parents, in the way their parents wished to be supported, sometimes at the expense of their own financial and emotional wellbeing. As a result, individuals also expressed hesitancy around seeking help and considering other options for care and support including assisted living or long-term residential care communities. This is supported by data that show Asians comprise less than 2% of residential care community residents[35] in the U.S. despite making up around 7% of the population.[36]

Every piece of advice I received was 'Cris, you can't take this on, you need to put them in a home.' But they didn't understand my life. My parents said 'You never put us in a community, you never put us in a nursing home; that is not where we belong, that is not how we raised you. We sacrificed everything for you to be here and to have the opportunities that you have, this is what you owe us.'"

- Cris Charbonneau, care partner

In Asian families you grow up with a very strong sense of filial piety, a strong sense of your parents are right. So, when your parent has dementia, you have to approach things delicately."

- Anonymous, care partner

The expectation, especially within minority cultures, is that the daughters will take care of mom and dad, regardless of anything else going on in your life, you'll drop everything."

- Neela White, care partner

If you seek help, you therefore fail to provide for your parents. Sometimes, even if people cannot afford to support their parents, they will spend their own resources to look after them."

- Mario Gregorio, living with dementia

I don't think we ever really thought that we were caregivers. It was just something that we had to do. Something we were supposed to do. I think in Chinese culture, your parents raised you and then it's your turn to help them when they need it."

- Jessica Hsieh, care partner

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Guilt

As a result of strong cultural expectations around elder care, many individuals experience feelings of stress.[16] The individuals we interviewed shared they felt heaviness and guilt often for believing they were not providing enough support and/or for seeking out additional external help such as from in-home care, assisted living, or long-term care providers.

"In the Asian community parents send their children to school, spend all their savings so that their children can get an education. The children will feel like they have neglected their duty if they're not able to care for their parents, like they have failed to support their family."

- Mario Gregorio, living with dementia

"For Chinese people, it's one of the biggest insults to put one of your older loved ones in a home. That's like, the ultimate sin."

- Jessica Hsieh, care partner

"Just the guilt. The guilt of not doing enough or not doing it in the ways that they want it. Not having enough time, not having enough money. It just feels so lonely."

- Cris Charbonneau, care partner

"There's a lot of guilt for the person having to make the decision to put their loved one in long term care. For the person with dementia, there's such a fear of displacement, and being yanked from home and everyone and everything you know."

- Neela White, care partner

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Loneliness and Isolation

The dementia experience can feel lonely and isolating for many Asian families.[14] The individuals we interviewed share that their parents are culturally and linguistically isolated, that they didn't know others like them were out there, or that when they did attend support groups, there was no one who understood their cultural lens and experience.

"I never told anyone about my experience. It was hard to talk about even with friends I don't think they ever truly understood, and I didn't know of any support networks, I didn't realize that there were all these caregivers out there. I just thought I was the only person that's going through this."

- Jessica Hsieh, care partner

"I come to support groups and I think you are experiencing what I'm experiencing, but there's a lens in which my experience is different. Others have a collectiveness around their experiences – community, financial resources, and support networks. But it can be different when you're coming from an immigrant experience or a Filipino or Asian background."

- Cris Charbonneau, care partner

"I have a good friend whose father is also dealing with dementia and both of our fathers were sort of linguistically and socially isolated. I have to wonder if this is very Asian, because, especially in that generation, people had their friends, they had their circle. If they happened to find themselves outside that circle, it wasn't possible to form a new one. Either you're friends from childhood or you're not friends at all."

- Anonymous, care partner

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Overcoming the Barriers: Harnessing Community, Setting Boundaries, and Cultivating Joy

Setting Boundaries and Addressing Cultural Expectations

In response to the many cultural pressures to devote inexhaustible time and energy into care partnering, the individuals we interviewed shared a few stories and reflections. These include the importance of recognizing and accepting one's limits, understanding that seeking additional help does not mean one is lacking or unfilial, and learning to balance cultural expectations with what is realistically possible for one's unique situation.

"It's okay to say 'I am drowning in this. I need help.' That doesn't mean you love them less. That means you've come to a point where you are not able to provide the best care you can because it's too intensive. It's beyond your scope. You're saying 'This is the way I have to go, but I still love you. I'm still going to be here advocating for you.' Recognize that you, the caregiver, are doing the best job out there because you're the one doing it."

- Neela White, care partner

"I called my dad's family in Taiwan when we moved him into a care home and said 'Hey, this the way it is. We are at wits' end. We're the ones taking care of him and we had to make this work for us. If you have questions, or if you have concerns, please just talk to me.'"

- Anonymous, care partner

"It came to a point where I really had to think about building in some boundaries and recognize that with two working adults between my husband and I, caring for two younger kids, and caring for my older brother things were becoming overwhelming. So I moved my parents into a senior community that is a two minute drive down the street."

- Cris Charbonneau, care partner

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Finding Connection

As individuals living with dementia and their families contend with the plethora of challenges that can accompany the dementia journey, many have found support from their peers. Support groups, friends, counselors and social workers, can all provide opportunities to process feelings, give and receive advice, and cultivate safe and meaningful connections that facilitate and strengthen a person's well-being.

"I'm very fortunate to get invited to different support groups in my community and meet people with dementia together with their care partners. I think what most people diagnosed with dementia miss most is the connection with others. So, the simple act of conversation means so much to them."

- Mario Gregorio, living with dementia

"Mom got engaged with the Alzheimer's Society and she made friends with the counselor who was Asian, so that worked out pretty well."

- Ron Beleno, care partner

"I do these monthly calls with a former colleague who's now a friend of mine because her father also has dementia."

- Wendi Yen Huestis, care partner

"I have a really close friend who's going through the same thing. And it's really helpful for us, emotionally, because we're there to support each other. It's a therapeutic thing."

- Peter Wei, care partner

"A big support was a social worker at the nursing home. She was Japanese and I think her mother also had dementia. She would give me advice like 'just compartmentalize for now. It's not healthy forever, but this is how you get through it now.'"

- Anonymous, care partner

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Utilizing Systems of Support

Finding support systems that work for you is one of the best strategies for living well with dementia. For some families that means finding someone to assist with in-home care, for others it means asking for help from friends, neighbors, and family members. It can also mean making the decision as a family to consider other care and support options including assisted living and long-term residential care communities.

"I'm lucky that I live very close to a series of townhomes and I've gotten to know some of the young Chinese couples that live there. Whenever I need help with my laptop or with my other technical things, I just send them a message and in the evening after work, they will come and visit and chat and then give me a hand. In the wintertime, I do not worry about shoveling my sidewalk because the guys will help. Those little things may not mean much to other people, but for an elderly person, they help a lot."

- Mario Gregorio, living with dementia

"I have no problem asking for support, saying 'this is where we're at' and 'hey, can you actually bring us some food when you're passing by?' You have to ask because otherwise people who want to support don't necessarily know how."

- Ron Beleno, care partner

"We would have someone come about four hours every day to help grandma which was huge. They gave us a lot of the equipment we needed and they allowed us to have respite care. When they came on the weekends, me and my parents could go out and do what we had to do."

- Jessica Hsieh, care partner

"Through an organization, I hired somebody to come in every day for anywhere from five to eight hours, all students between the ages of 19 and 24 who had an interest in some kind of healthcare profession. They gave so much time, and attention, and patience. There was even one gentleman that my dad started calling his son, and this young man just thought it was great. They ended up staying at dinner for three hours and having conversations and the young man just really engaged people in ways that a lot of our elderly are not engaged with."

- Cris Charbonneau, care partner

"At a certain point, I admitted to myself 'I can't do this anymore – this is going to progress and I may not be able to keep her safe, I'm not able to provide 24 hour care.' I called every retirement home within a certain radius for an opening in memory care. We were fortunate to get into one in a timely manner. It was probably the first time I was able to breathe. I was able to become a daughter again instead of a caregiver."

- Neela White, care partner

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Finding Joy, Purpose, and Gratitude

Asian community members share that, just as they have experienced challenges in their dementia journey, they have also found joy, purpose, and meaning alongside them. Some have embraced practices that bring relaxation and purpose, and some share that the journey illuminated new parts of themselves. Many express gratitude for being able to give back to their parents and enjoy precious time in one another's company.

"I like to have a purpose every day. I like to walk and go for a swim three times a week. I love taking pictures of nature and everyday sceneries. I always love gardening; it's nice to have a space for quiet moments and be close to nature, it's a way to help calm the mind and lead a less stressful life."

- Mario Gregorio, living with dementia

"My experience as a caregiver allowed me to actually enhance some of the things that I didn't know were important to me – providing care, finding a way to support. I was able to meaningfully contribute to my dad's life, which I'm proud of. If he had experienced something like a heart attack instead, I wouldn't have had the time to contribute in the same way."

- Ron Beleno, care partner

"Being a care partner for such a long time gives me the opportunity for a long goodbye to my dad. So emotionally I'm going through the process, I'm seeing him every weekend and there are some great moments, and I'm so appreciative, so grateful, I get a chance to take care of my dad. He's taken care of me for such a long time, to give back and to do all I can to support, I think if anything, it gives me a little peace, there are no more regrets."

- Peter Wei, care partner

"Especially as the children of first-generation immigrants you know how much your parents have given up, it's an opportunity to give back. The silver lining was being able to spend time with him."

- Anonymous, care partner

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Call to Action

This paper shares a set of challenges facing the Asian community impacted by dementia and it highlights stories of how they are responding with perseverance, activism, and compassion. We would be remiss, however, to suggest these are their burdens to shoulder alone. Rather, it is the duty of the broader dementia community to step up, advocate, and push for change, in allyship with the Asian community. Based on our interviews with community members, we offer three calls to action for how the broader community can get involved. These outline ways each one of us can support members of the Asian community impacted dementia and, together, work toward a better, more equitable future.

1. Combat Stigma and Silence

a. Organize educational workshops and seminars within Asian communities to raise awareness about dementia, dispel myths, and reduce stigma.

b. Encourage and support individuals from the Asian community to share their experiences with dementia in public forums where they feel comfortable speaking out to promote openness and reduce the silence surrounding the condition. Such settings can include support groups, local Alzheimer Association or Alzheimer Society Chapters, Dementia-Friendly Community initiatives, faith groups, family circle, etc.

c. Produce and disseminate culturally relevant media content, such as videos, pamphlets, and articles, that address the stigma around dementia and promote understanding and acceptance.

2. Improve Cultural Humility in Care Systems

a. Educate yourself on what it means to be culturally humble, sensitive, and competent and the unique challenges and needs of Asian community members.

b. Advocate for efforts that bolster inclusivity within local health and care settings including culturally relevant activities, food, music, programming, etc.

c. Collaborate with and support Asian community organizations that are working to advance cultural awareness and understanding in health and care settings.

3. Fill the Resource Gap

a. Volunteer your time or resources to organizations that prioritize dementia care within the Asian community.

b. Advocate for increased funding for dementia resources in Asian communities through local, state, and federal channels. Attend town hall meetings, write letters to your representatives, and support initiatives that prioritize these needs.

c. Provide pro bono services if you have relevant skills or expertise. Offer translation, healthcare counseling, or event planning, to organizations that focus on dementia care in the Asian community.

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Resources

Resource Hubs

Discovery Center | Dementia Action Alliance
https://daanow.org/discovery-center/
Center of categorized resources that support living well with dementia including books and publications, links, apps, virtual programming, etc.
The Diversity Center includes books and publications, websites, and other resources.

Forward with Dementia: A guide to living well with dementia | Cognisance
https://forwardwithdementia.ca/
A comprehensive guide to living well with dementia, offering support and resources for those affected by dementia and their caregivers.

Articles, Newsletters, Videos

Perspectives on Longevity Newsletter | Blue Wing Advisory Group
https://www.bluewingadvisorygroup.ca/client-centre/perspectives-on-longevity-newsletter
Newsletter discussing important strategies around aging like financial planning for women and advice for maintaining independence.

Open Dialogue on Aging Series | Blue Wing Advisory Group
https://www.bluewingadvisorygroup.ca/client-centre/open-dialogue-on-aging-series
Video series on topics like protecting your wealth, accessing support following a dementia diagnosis, downsizing, and advanced care planning.

Generations Now – One Size Does Not Fit All: Asian Americans and Dementia Risk by Diane Ty, Raj Ahuja and Jennie Chin Hansen (January 10, 2023)
https://generations.asaging.org/asian-americans-and-dementia-risk-not-homogenous
An article discussing the unique dementia risks faced by Asian Americans and the need for culturally tailored approaches to dementia care.

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Personal Stories and Advocacy

Alzheimer's Disease International – My journey as a carer: From dragging daughter to a 'Dragon Daughter' (February 12, 2021)

https://www.alzint.org/news-events/news/my-journey-as-a-carer-from-a-dragging-daughter-to-a-dragon-daughter/

Lily Liu shares her story of caring for her mother with dementia and discusses the challenges faced by immigrant family caregivers and the empowerment she gained through information and support.

Cris Charbonneau | LinkedIn posts about her caregiving journey

https://www.linkedin.com/in/crischarbonneau/

Cris Charbonneau shares her personal experiences and insights about caregiving for a loved one with dementia, hoping to provide support and encouragement to other caregivers.

Navjot Gill | LinkedIn

https://www.linkedin.com/in/navjotgill21

Navjot Gill, a Ph.D. candidate in Public Health, specializes in Aging, Health, and Well-Being. She advocates for culturally inclusive dementia care and shares her personal connection to dementia through her grandmother's experience.

Websites

Cultural Safety Resource | Schlegel-UW Research Institute for Aging

https://the-ria.ca/wp-content/uploads/2024/02/Cultural-safety-resource_v04_20231215.pdf

A guide on cultural humility, safety, and trauma-informed care, offering practical tips for respectful, inclusive dementia care to improve care practices and outcomes for culturally diverse populations.

Alzheimer's Association

https://www.alz.org/help-support/resources/asian-americans-and-alzheimers

Webpage with information on dementia in the Asian community, resources, and ways to get involved

Dementia Action Alliance

https://daanow.org/

Organization where people come together to connect, form friendships, exchange ideas, learn, and create a better community in which to live with dementia or mild cognitive impairment (MCI).

The Value of Wrinkles

https://www.valueofwrinkles.com/

Easy to understand insights to equip grandchildren and adult children to care for their older loved one

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Research Papers

A culturally and linguistically tailored Community-Engaged Dementia Education Program (CEDEP) for the Houston Vietnamese American community | Miyawaki et al.

https://journals.sagepub.com/doi/10.1177/14713012231213911

A study on the effectiveness of a dementia education program tailored for the Houston Vietnamese American community, which emphasizes the use of culturally relevant materials and community engagement to improve dementia literacy.

Alzheimer's Disease and Its Related Dementias Among Asian Americans, Native Hawaiians, and Pacific Islanders: A Scoping Review | Lim et al.

https://pubmed.ncbi.nlm.nih.gov/32675416/

This scoping review examines the prevalence, risk factors, and caregiving experiences related to Alzheimer's Disease and related dementias among Asian Americans, Native Hawaiians, and Pacific Islanders.

'It's a lonely journey': caregiving experiences and psychosocial distress among Chinese American dementia family caregivers | Hong, et al.

https://www.tandfonline.com/doi/full/10.1080/13607863.2023.2285918

This is a study examining the emotional and psychological challenges faced by Chinese American dementia caregivers, emphasizing the need for culturally appropriate targeted intervention.

The Many Faces of Dementia in Canada, Landmark Study, Volume 2, 2024

https://alzheimer.ca/en/the-many-faces-of-dementia-in-canada-landmark-study-volume-2

An in-depth study exploring the diverse experiences of individuals with dementia across Canada, sharing experiences on the unique cultural and community challenges they each face.

Understanding the caregiving experiences of Asian Indian, Chinese, Korean, and Vietnamese American family care partners of persons living with dementia | Choi, et al.

https://www.tandfonline.com/doi/full/10.1080/13607863.2023.2252772

This study explores the caregiving experiences of Asian Indian, Chinese, Korean, and Vietnamese American family care partners, and provides insights into cultural influences on caregiving.

What Matters to Chinese and Korean American Dementia Caregivers: Navigating Cultural Influences in Dementia Care from Caregivers' Perspectives | Wang et al.

https://pubmed.ncbi.nlm.nih.gov/38427483/

This research discusses the cultural influences on dementia care from the perspectives of Chinese and Korean American caregivers and emphasizes the need to develop culturally tailored, person-centered programs.

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