



Bridging Worlds, Enhancing Care: Palliative Care for AAPI Dementia Patients & Families

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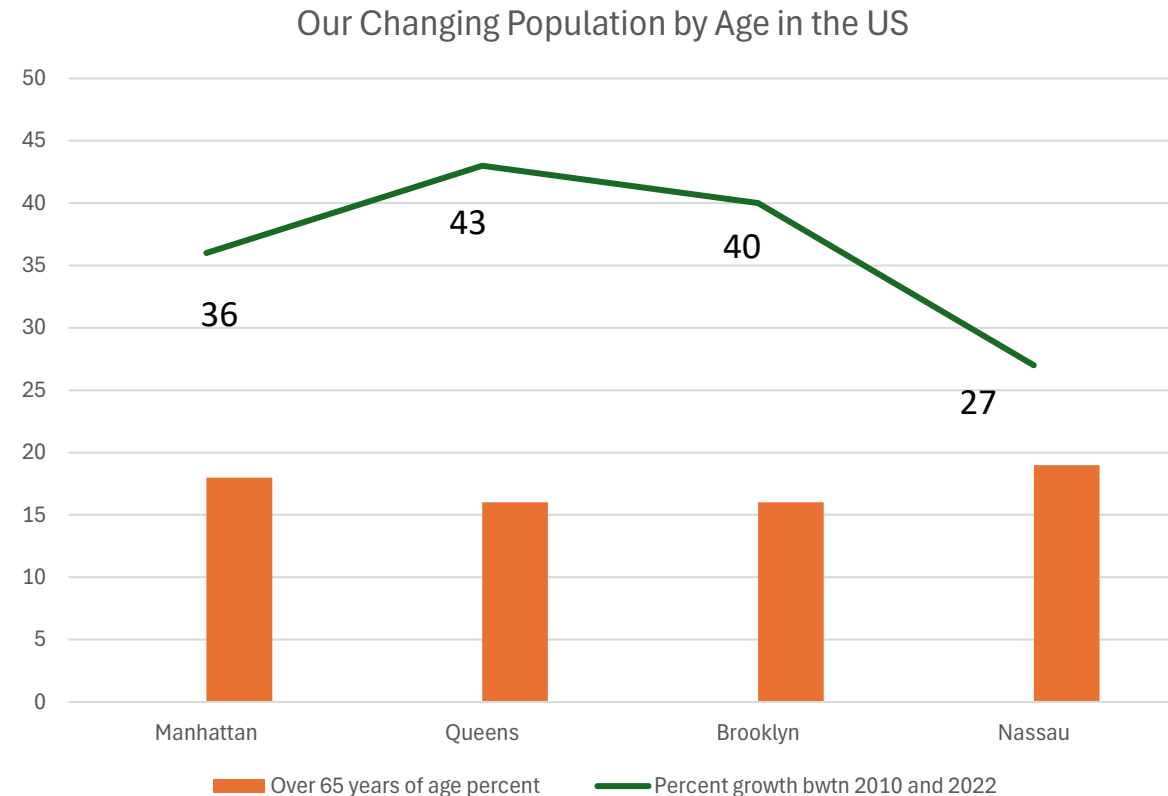
Advocate for vulnerable populations that include older adults and underserved; language and culture-concordant care; and educating the workforce on inclusive and equitable healthcare delivery.

Second generation Korean American



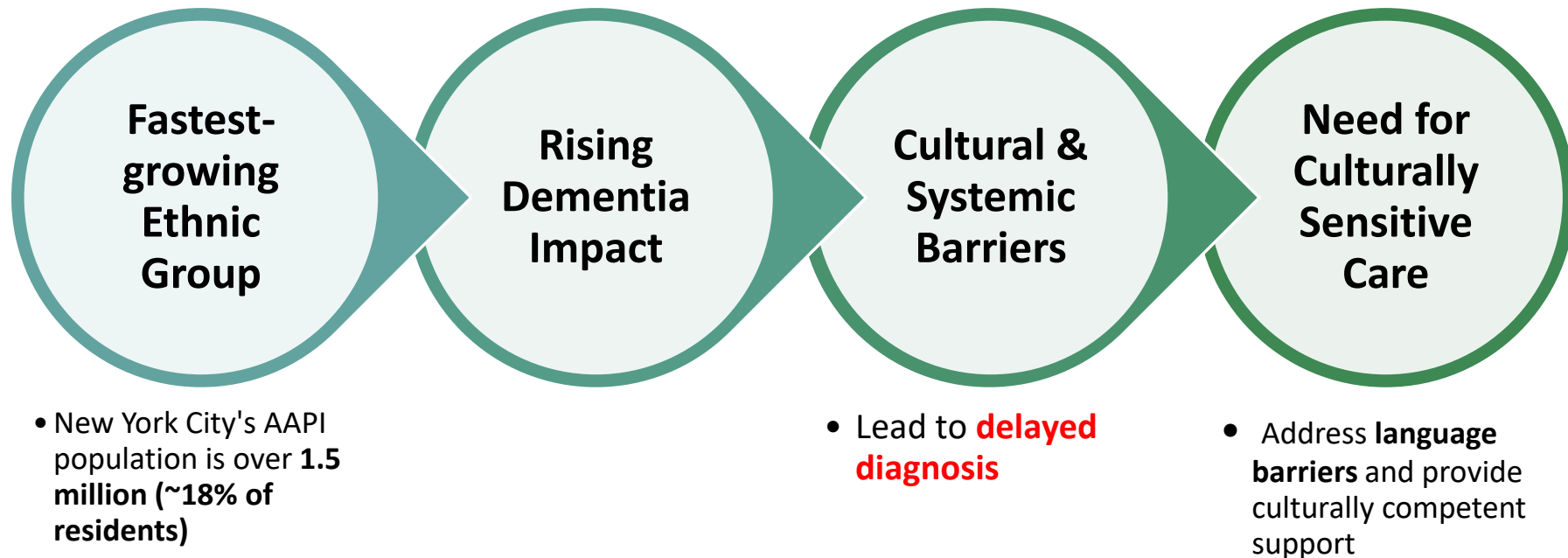
Aging Revolution: Age as the Primary Risk Factor for Dementia

65+ group was the fastest growing age group between 2010 and 2022 increasing by 42% in the US



[US population by year, race, age, ethnicity, & more | USAFacts](#)

Why are we talking about Dementia in the AAPI communities?



Vast diversity within "AAPI" Asian Americans and Pacific Islanders

Over 75 countries, 100 languages, and 50 ethnic groups

Definitions are fluid – language vs dialect

Constant evolution

Intersectionality

Cultural Bias

Cultural Humility



Learning Objectives

Define	Define culturally responsive communication within the context of dementia care
Identify	Identify key potential cultural values and communication styles
Recognize	Recognize specific communication challenges
Apply	Apply core palliative care principles
Use	Use strategies to enhance communication, build trust, and provide person-centered care



How does Dementia Impact Patients



Communication

- Difficulty finding words
- Trouble understanding spoken and written language
- Challenges expressing thoughts and emotions coherently
- Increased reliance on non-verbal cues (may also misinterpret)
- Repetitive speech or questioning
- Reverting to native language



Cognition

- Memory loss (recent)
- Impaired judgment and decision-making
- Difficulty with problem-solving and planning
- Disorientation to time, place, or person
- Reduced attention span and concentration
- Delayed bill payments
- Hygiene/eating



Behavior/Mood

- Changes in personality (increased suspicion, apathy)
- Agitation, restlessness, or anxiety
- Depression or social withdrawal
- Wandering or pacing
- Changes in sleep patterns (sundowning)
- Sometimes, resistive to care or easily frustrated



Mobility

- Slower walking
- Unsteadiness/poor balance
- Difficulty turning and getting up from chair/bed
- Shuffling gait
- Joint pain
- Increased risk of falls
- Clumsiness

Palliative Medicine

Focus on **support**, not just medical treatment.

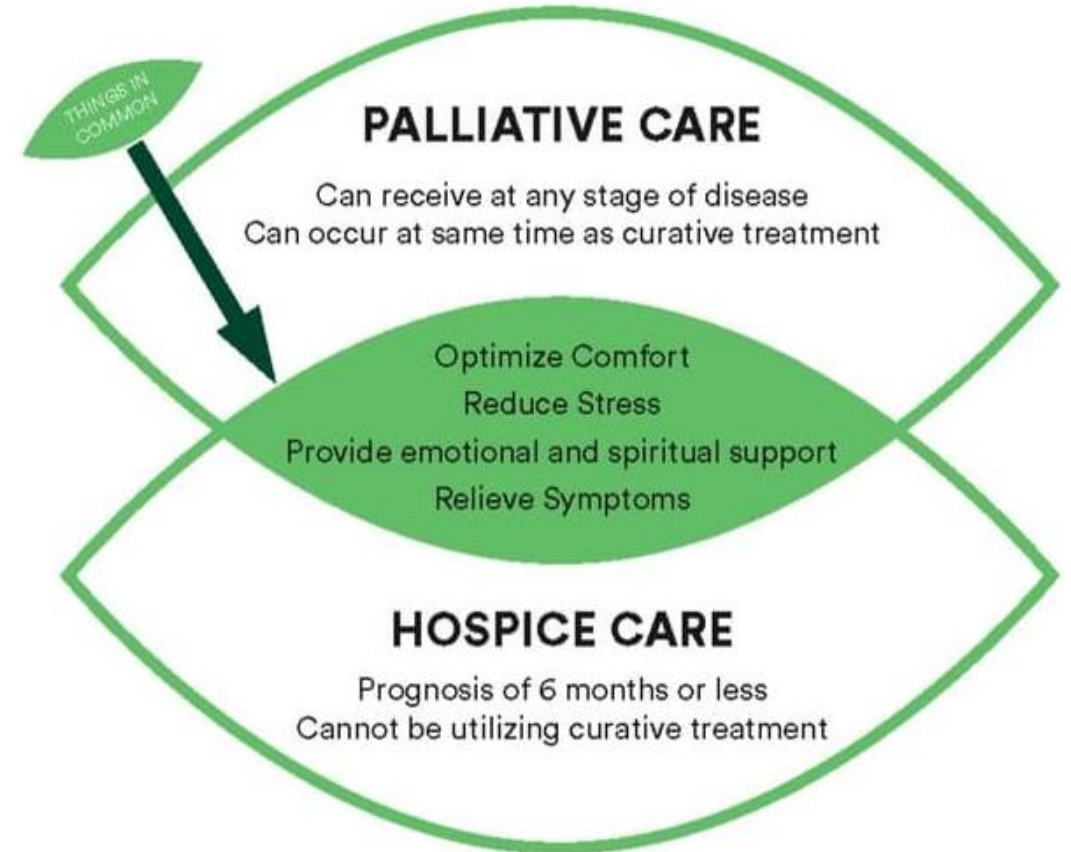
Emphasis on quality of life, comfort, managing difficult symptoms (physical, emotional, spiritual) to **LIVE** as fully as possible

Team approach (doctors, nurses, SWs, chaplains, *caregivers*).

Support for the **whole family**.

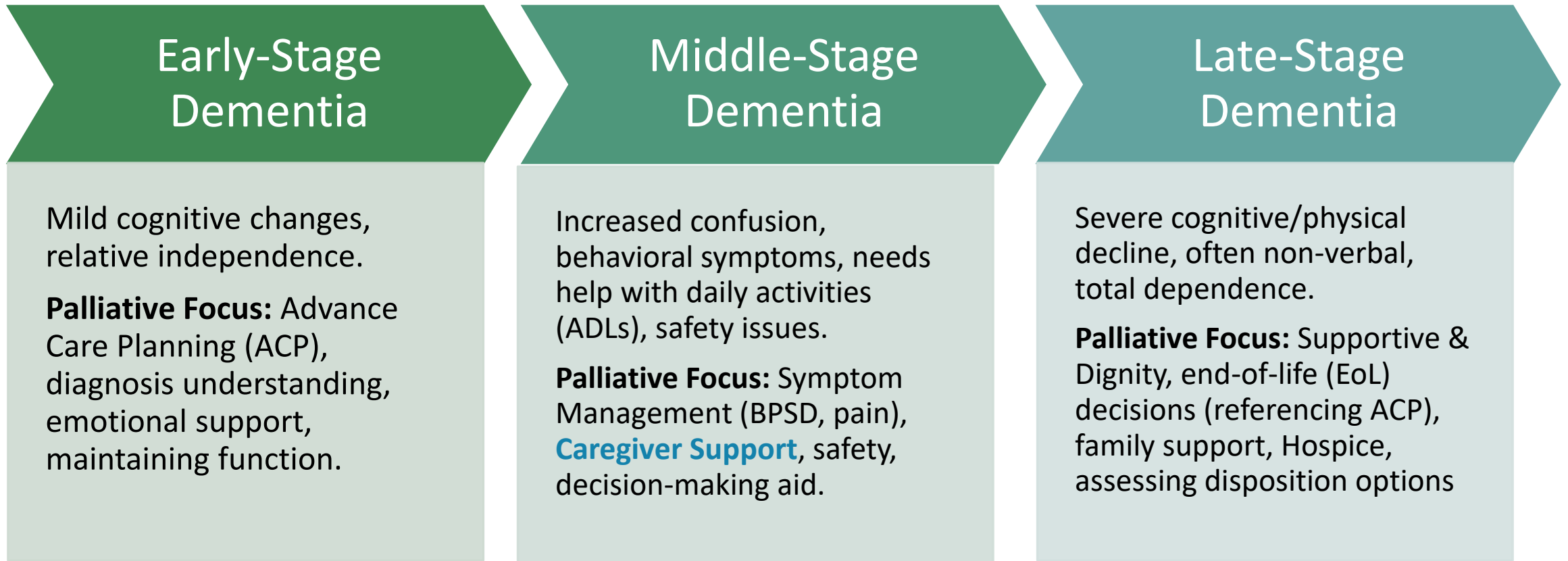
Can be provided alongside other treatments, at **any** stage of serious illness

Clarifying Goals of Care: Helping patients and families **understand** treatment options and make decisions aligned with their values and priorities.



Dementia Progression & Palliative Care Evolution

Enhance Quality of Life (Patient & Family) Throughout Illness



Key Evolution = Palliative needs shift from Planning → Management → Comfort.

The "Triple Challenge"

Dementia

Cultural/language Complexity

Need for Palliative Support



Health Disparities in Dementia & Palliative Care: Challenges for AAPI Communities

Delayed Diagnosis & Care-Seeking:

- Cultural norms often lead to seeking care later, impacting early intervention.

Significant Access Barriers:

- Languages other than English (~60% nationally), limit access to information and services.
- Shortage of providers who understand diverse AAPI cultural beliefs and practices regarding illness and death.

Unequal Service Utilization:

- Lower rates of accessing specialized support like palliative care and hospice compared to other groups.

Resulting Impacts:

- These barriers contribute to increased caregiver stress, potential isolation, and disparities in quality of life and end-of-life care experiences.

What is Culturally Responsive Communication?



Goes beyond cultural *competence* (knowledge)

Cultural Humility

Responsiveness



Focusing on the *individual* and *family* within their cultural context

Dementia in the AAPI Community

Family Structure & Filial Piety:

- Importance of family → collectivism vs. individualism, respect for elders, designated family spokespersons (eldest son), potential **caregiver burden**

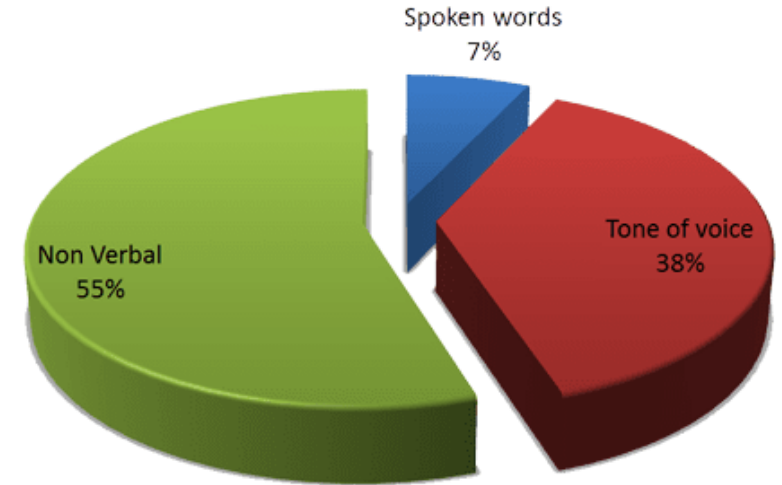
Communication Styles:

- Indirect communication, non-verbal cues, showing respect for authority

Stigma:

- Significant stigma surrounding mental illness, cognitive decline, and dementia
- Reluctance to seek diagnosis or receive support services

NON VERBAL COMMUNICATION



Dementia in the AAPI Community

Decision-Making:

- Family-centered decision-making common (vs. patient autonomy). Importance of involving key family members **early**

Disclosure & Prognosis:

- Views on discussing difficult news, terminal illness, or prognosis vary widely.

Beliefs about Illness/Suffering:

- Diverse explanatory models (karma, fate, imbalance, spiritual factors), role of traditional/complementary medicine.

End-of-Life Views:

- Diverse religious/spiritual beliefs about death and dying, impacting preferences for care (hospice, location of death)



Palliative Medicine Approach: Holistic Assessment

Importance of assessing beyond the physical:


- Emotional, social, spiritual, cultural needs.

Culture shapes the *experience* and *expression* of symptoms

- Pain, anxiety, depression

Culturally sensitive screening tools and *open-ended questions*.

- *Where is your pain, does it hurt anywhere, where does it bother you, are you uncomfortable?*
- *What does quality of life mean to you and your family right now?*
- *What are you most concerned/worried about?*
- *Who helps care for you?*



Aligning medical treatments with patient/family values and goals



Communication Strategies: Building Trust

Language Access:

- Use medically certified interpreters
- Ask patients, best not to use family members
- Many LEP patients (esp Asians) prefer live interpretation vs phone interpretation.

Video Remote Interpreter

- Great alternative
- Brief them beforehand.
- Speak directly to the patient.
- Check for understanding frequently



Steele H, Lehane D, Walton E, Mitchell C. Exploring patient preference regarding interpreter use in primary care. *Br J Gen Pract*. 2020 Jun;70(suppl 1):bjgp20X711557. doi: 10.3399/bjgp20X711557. PMID: 32554678.

Cho J. Interpreters as Translation Machines: Telephone Interpreting Challenges as Awareness Problems. *Qual Health Res*. 2023 Oct;33(12):1037-1048. doi: 10.1177/10497323231191712. Epub 2023 Aug 27. PMID: 37635440; PMCID: PMC10552352.



Communication Strategies: Practical Tips

Cultural Humility in Practice:

Acknowledge your own biases, approach with curiosity.

"Help me understand..."

Active Listening:

Pay attention to verbal and non-verbal cues. Validate emotions.

Respect & Rapport:

Address elders/individuals formally, show respect for family structure, take effort to build relationships.

Involve Family Appropriately:

Ask the patient/family who they want involved.

Acknowledge caregiver stress and offer support/resources.

Address Spiritual Needs:

Ask about religious/spiritual beliefs or practices important to them.

Connect with chaplains or community leaders if desired.



Addressing Dementia-Specific Challenges

Repetition/ Memory Loss:

Use calm reassurance, written cues, simple questions.

Validate feelings even if the statements are confusing.

Mobility and toileting

Enhance home safety to prevent falls, manage wandering and use mobility aids

Timed toileting, adaptive clothing, observe non-verbal cues

Behavioral Changes:

Frame as unmet needs or communication attempts.

Explore triggers (pain, fear, environment) – paranoid/suspicious

Connect behaviors to potential cultural interpretations or stressors.

Caregiver Support:

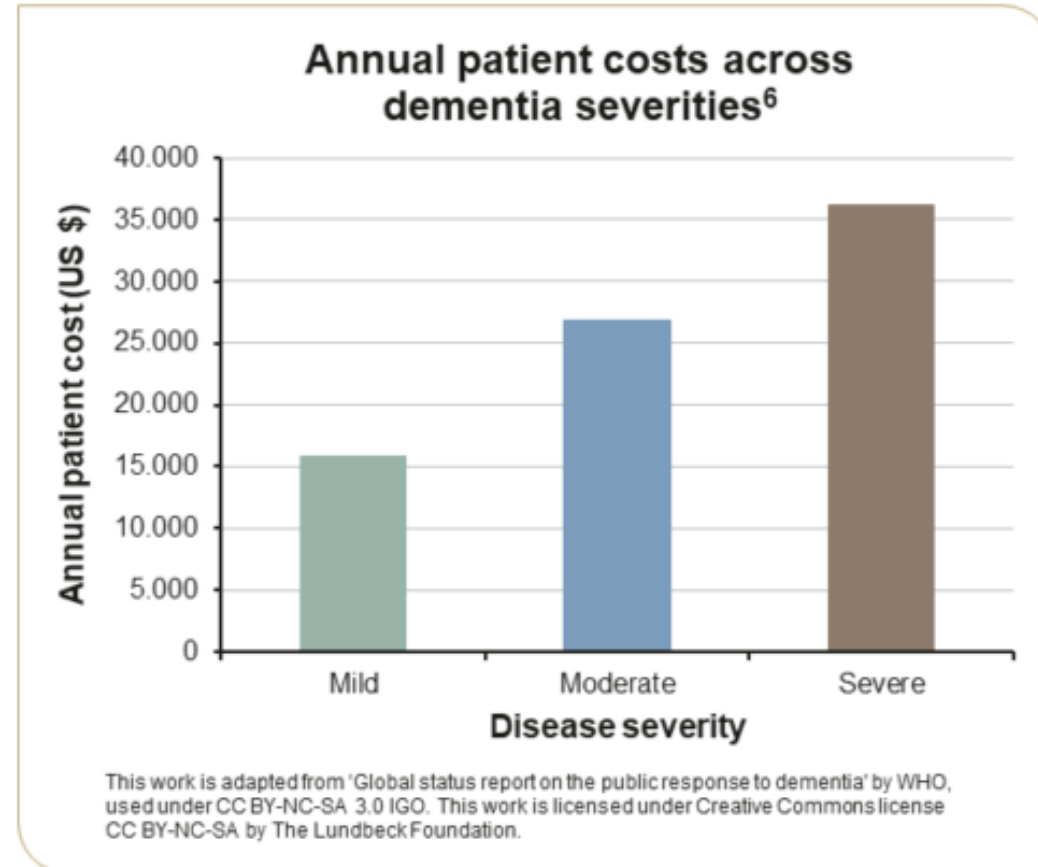
Recognize the immense burden, often falling on specific family members due to cultural expectations.

Provide resources and validation – may need aides and staff who speak the same language if LEP



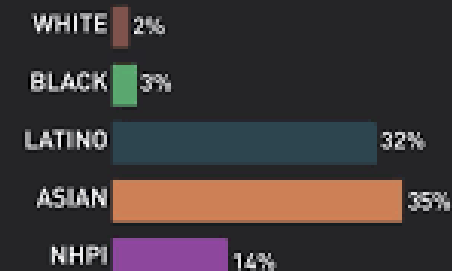
The burden of AD dementia increases throughout its course

- AD is a degenerative and progressive condition^{1,2}
- The rate of progression through clinical stages is variable and may be impacted by accompanying medical conditions³
- As clinical stages of AD advance and functional impairment worsens, individuals become more reliant on others for physical and mental support,⁴ consequently, caregiver burden increases⁵

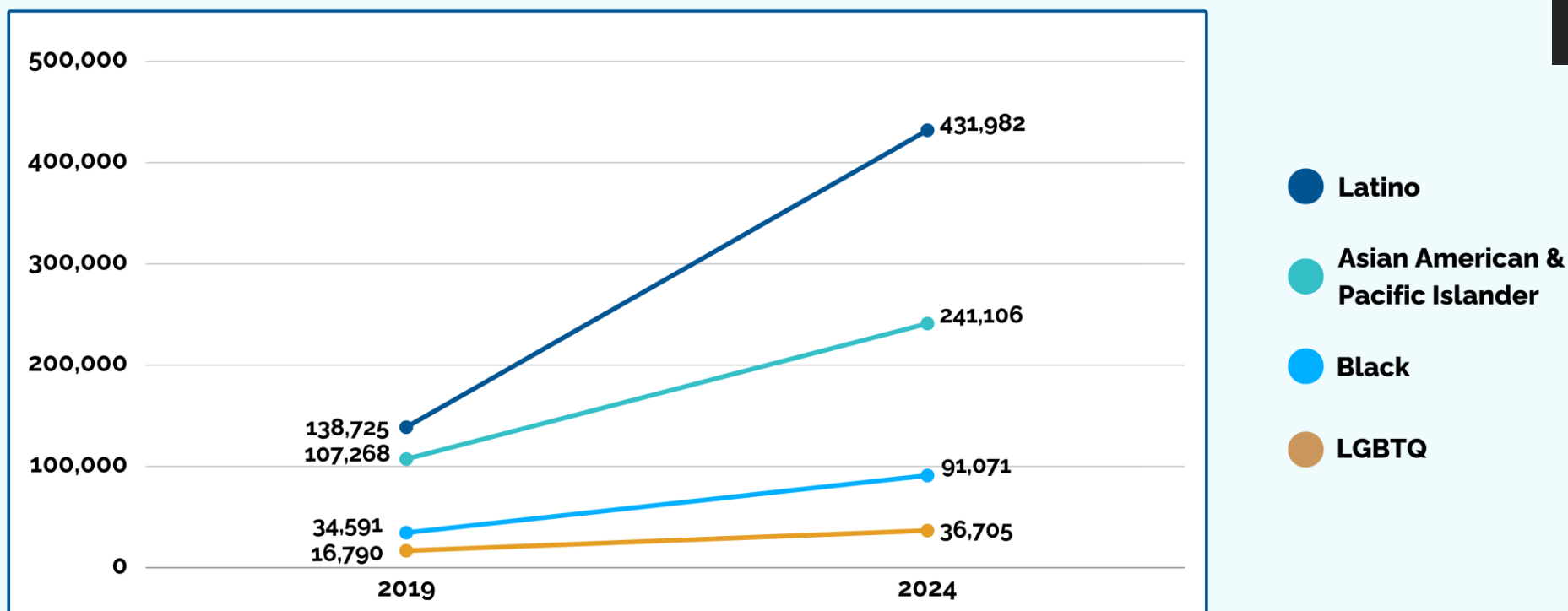


1. Atri. Med Clin North Am 2019;103(2):263–293; 2. Knopman et al. Nat Rev Dis Primers 2021;7:33;
3. Rikkert et al. Am J Alzheimers Dis Other Dement 2011;26(5):357–365; 4. Georges et al. Int J Geriatr Psychiatry 2008;23(5):546–551;
5. Alzheimer's Association. Alzheimers Dement 2023;19(4):1598–1695; 6. WHO. Global status report on the public response to dementia 2021

Limited English Proficiency



Increasing Burden of ADRD by 2040 in Groups Already Facing Disparities



Source: Alzheimer's Association, 2021 Fact Sheet (Alzheimer's and Latinos in California; Alzheimer's and Asian American/Pacific islanders in California; Alzheimer's and Blacks in California; Alzheimer's and LGBTQs in California)

Caregiver burden is multi-faceted

Caregivers of people living with dementia often report challenges with:¹

ADLs
(e.g., going to the lavatory and washing)



Behaviour
(e.g., agitation and aggression)

Unpaid care for people living with dementia in the US²

>11 million
individuals

\$340 billion
estimated cost



Behavioural symptoms can cause an **elevated caregiver burden** even when AD is **mild**³



59% of caregivers report **high to very high levels of emotional stress** associated with caregiving²

ADL=activity of daily living

1. Georges et al. Int J Geriatr Psychiatry 2008;23(5):546–551;

2. Alzheimer's Association. Alzheimers Dement 2023;19(4); 3. Kamiya et al. Geriatr Gerontol Int 2014;14(Suppl 2):45–55

Supporting the Caregivers

Recognizing Caregiver Burden:

- Unique caregiver stressors in the AAPI community
- (filial duty pressure, isolation, financial strain, lack of respite)

Palliative Care's Role:

- Palliative care explicitly assesses and supports caregiver well-being
- (emotional support, connecting to resources, validating their experience)

Navigating Family Conflicts:

- Experiences mediating disagreements about care goals or approaches among family members.

Isolated Seniors/Elder Orphans:

- Family estranged or overseas, no surviving family or friends, legal challenges

Aging Behavioral Health/OPWDD groups:

- Complex medical and legal challenges that complicate caregiver burden even more





Chinese advanced dementia patient with end-stage cancer – brother is primary caregiver refused care in the home



Chinese moderate dementia and end-stage liver disease patient whose daughter was trying to honor her wishes



Filipino end-stage dementia patient with new stroke appeared to not be able to eat but found out she wants only Filipino food



Filipino Parkinson's dementia patient with balance issues – husband withheld concerning symptoms – thought it was Karma



Japanese dementia couple with no children– husband bedbound with PEG, wife with cancer struggled with medical decisions for him and herself



Systemic Changes & Hopes for the Future

Promote Language and Culture Concordant Care

The Power of Teamwork

- Collaboration between physician, social worker, caregiver, interpreters, community organizations

When health services are customized to an individual's culture and language preference, providers can bring positive health outcomes for diverse populations



Languages of focus

Physician Champions: Drs. Isabella Park, Paul Lee, Angel Meng, Manish Sapra, Veena John, Harmit Kalia, Debbi Salas-Lopez, Bernardo Acevedomendez



On the Intranet

- Korean – 43
- Chinese (total 125)
 - Mandarin – 43
 - Cantonese – 37
 - Chinese – 32 (should be removed)
- Taiwanese – 5
- Shanghainese – 5
- Fukienese – 3



In Progress

- South Asian (total 466)
 - Hindi – 216
 - Urdu – 71
 - Punjabi – 53
 - Gujarati – 48
 - Bengali – 24
 - Marathi – 15
 - Malayalam – 14
 - Telugu – 13
 - Tamil – 12



Next to Consider

- Spanish – 564
- Hebrew – 169
- French – 111
- Russian – 105
- Italian – 75
- Greek – 54
- Arabic – 42



Academy of
Communication
in Healthcare

Unlocking and elevating age-friendly practices for an entire system.

Patients 65+ are on the rise
in Northwell Health's
23 hospitals and
830+ ambulatory sites.



**President and CEO
Michael Dowling
sets a plan in motion.**



**A new designated
position is created**
VP Aging and Supportive Care
Division of Geriatrics and Palliative Medicine

And partnered with the
Program Director
Department of Clinical Transformation



Together, they collaborate with Geriatrics and Palliative Medicine to identify practices to adapt for age-friendly care across the healthcare organization.

The GUIDE Program for dementia care



Comprehensive care for a complex illness

The Guiding an Improved Dementia Care Experience (GUIDE) model offers a comprehensive approach to dementia care, empowering patients and caregivers with personalized care and support.

Dementia presents unique challenges for both people living with dementia and their caregivers. The GUIDE Program, an initiative of the Centers for Medicare & Medicaid Services, offers comprehensive support and care to both patients and their caregivers. Northwell is honored to be among the first to participate in this innovative program.

We offer care and support both in-person and virtually (via telehealth).

NHPP Geriatrics and Palliative Medicine at New Hyde Park

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[Link to our website: The GUIDE Program for dementia care | Northwell Health](#)



Key Takeaways

- Aging Revolution is here
- AAPI communities are diverse; avoid stereotypes, practice cultural humility.
- Apply palliative care principles through a culturally responsive lens.
- Supporting the caregiver is crucial
- Utilize strategies:
 - Interpreters, open questions, involve family appropriately, build trust =
 - Effective communication is foundational to quality dementia care
- Advocacy Matters



Thank you

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<https://www.pbs.org/video/aging-in-america-survive-or-thrive-ykg0z3/>