

End of Life Conversations with the Asian American Community



Jaya Vijayan, MD, FAAFP, FAAHPM
Medical Director, Palliative Care
Holy Cross Health, Maryland

Outline



- ∞ Importance of advance care planning and end of life conversations
- ∞ Cultural considerations
- ∞ Barriers to ACP
- ∞ Case study
- ∞ Recommendations

What Americans Think



“This is how Americans say they want to die: at home, not in a hospital. We want to pray before we die or have people praying for us. We want the doctor who attends our final hours to be a friend, not merely a health care provider. We want less technology and more family and friends at our bedsides. We want less effort to prolong our lives and more attention to matters of the spirit.”

The Washington Post , Monday December 15, 1997

Dying in America



- ☞ Two Gallup Polls, one in 1992 and another in 1996, found 9 out of 10 respondents reporting that they would prefer to be cared for at home if they were terminally ill with six months or less to live (*Seidlitz et al., 1995; Foreman, 1996; NHO, 1996b*).
- ☞ 1992, U.S. mortality statistics showed about 57 percent of deaths occurring in hospitals.

National Library of Medicine: A Profile of Death and Dying in America

Advance Care Planning



- ☞ Improves quality of life by assisting individuals in recognizing their goals and preparing for end of life

- ☞ Reduces psychological burden on family when they need to make decisions for loved ones

End of Life Conversations – Why?



- ⌘ When seriously ill patients are nearing the end of life, they and their families sometimes find it difficult to decide whether to continue disease modifying treatment.
- ⌘ Ideally, the patient, their family and physician have held discussions about treatment options, chance of success, overall prognosis and the patient's quality of life during and after treatment.

Advance Care Planning



- ⌘ Physicians usually reserve these discussions for patients who are terminally ill or imminently dying, but people with chronic illness also need ACP.
- ⌘ 80-85% of people who die in the US are >65 yrs, and most die from chronic conditions such as heart disease, cerebrovascular disease, COPD, DM, Alzheimer's disease and renal failure.



It's always too early, until it's too late.

 *The Conversation Project, 2013*

Factors influencing ACP



- ∞ Age, Comorbidity, Functional Status
- ∞ Religiosity/ Spirituality
- ∞ Racial, Ethnic, Cultural background
- ∞ Literacy level
- ∞ Family

Cultural considerations



- ∞ Attitudes and beliefs associated with death and dying vary among countries and different cultural groups within the same country.
- ∞ Anticipatory decision making about end-of-life care is predominantly a North American concept.
- ∞ Attention to the different needs of cultural groups is essential for providing quality end-of-life care.
- ∞ Differences in attitudes are related to religious beliefs.

ThomasR, WilsonD et al: A Literature Review of Preferences for End-of-Life Care in Developed Countries by Individuals with Different Cultural Affiliations and Ethnicity. Journal of Hospice and Palliative Nursing Vol 10, No.3, May/June 2008, 142-161

Asian Americans nationwide

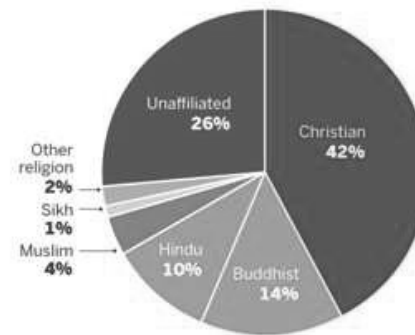


- ∞ US Census Bureau designates “Asian” as one race category
- ∞ Diverse
- ∞ Roots in more than 20 countries in East and Southeast Asia and the Indian Subcontinent
- ∞ Largest groups –
 - ∞ Chinese Americans are the largest Asian origin group (24%)
 - ∞ Indian Americans (21%)
 - ∞ Filipinos (19%)
 - ∞ Vietnam, Korea and Japan

A mosaic of faiths

Religious Affiliation of Asian Americans

% of Asian-American adults who say they are ...



2012 Asian-American Survey. Those who did not give an answer are not shown.

PEW RESEARCH CENTER



☞ **About a quarter of Asian Americans (27%) live in multigenerational households.** That's comparable to the share among all immigrants in the U.S. (28%), but higher than the share among Americans overall (19%). Asians who are immigrants are slightly more likely than U.S.-born Asians to reside in households with multiple generations under one roof (29% vs 23%).



NBC NEWS

Asian Americans are least likely of all racial groups to have an end-of-life plan, new study finds

Sakshi Venkatraman

May 19, 2023 · 3 min read



15

NBC NEWS

ISRAEL-HAMAS WAR

MEET THE PRESS

POLITICS

U.S. NEWS

WORLD

BUSINESS

HEALTH

NBC NEWS TPLINE

WATCH LIVE



ASIAN AMERICA

Asian Americans most likely to think about dying, but least likely to have an advanced care plan, new study says

After the pandemic and rise in racially motivated attacks, experts say more Asians are thinking about their end-of-life plans. But they aren't always saying them out loud.

Case 1



- ⌘ An 86 yr old Asian man with dementia, multiple hospitalizations for recurrent pneumonia was admitted to the hospital with sepsis due to pneumonia. His daughters did not want him to suffer, decided against CPR, but did not want to limit other medical interventions as they did not want to go against their faith tradition. They also report that he had previously said he wanted to live.
- ⌘ He developed multiple medical complications including gangrene of toes, abdominal wall infection with fistula formation and died after 65 days in the hospital.

Cultural Barriers to ACP



- ☞ Belief that talking about death may cause it (fatalism)
- ☞ Challenges in initiating communications
- ☞ Filial piety (duty to respect and care for elders and parents)
- ☞ Feelings of failure if they allow someone else to care for their aging parents

Shen JJ, Dingley C, et al, "Sociocultural Factors Associated with Awareness of Palliative Care and Advance Care Planning among Asian Populations", Ethnicity & Disease, Vol 30, Num 3, Summer 2020

Other barriers



- ❧ Language barrier
- ❧ Preference that family members be the recipients of diagnostic and treatment information.
- ❧ Open discussion of serious illness may provoke unnecessary depression or anxiety in the patient
- ❧ Direct disclosure may eliminate hope
- ❧ Speaking aloud about a condition, even in a hypothetical sense, makes death or terminal illness real because of the power of the spoken word

Case 2



- ⌘ A 78 yr old Asian woman with advanced pancreatic cancer is admitted to an inpatient hospice facility for pain management.
- ⌘ Staff observes the patient moaning softly and grimacing , appearing to be in pain. Family (daughter) says that she is not in pain and declines pain medication, saying that it sedates her. Patient defers communication to family.

Recommendations



- ☞ Demonstrate an interest in cultural heritage
- ☞ Include language interpreters as needed
- ☞ Ask patients how they would like treatment decisions to be made. At this point, the physician can determine the extent to which patients/family members wish to be involved in treatment decisions.
- ☞ Avoid stereotyping - Generalizations about specific cultures are not always applicable to specific patients.



Questions?