Best Practices for Providing High-Quality Palliative Care for Diverse Communities

April 8, 2025

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National Seminar 2025

September 15-17, 2025 • Philadelphia, PA

capc.org/seminar

Presenters

Karen Bullock, PhD, LCSW, APHSW-C

Presenting on African American Communities

Stephanie Chow, MD, MPH

Presenting on Asian American Communities

Jeanna Ford DNP, APRN, ACNS-BCACHPN, FPCN

Presenting on Indigenous American Communities

Sasha Perez, MPH

Presenting on Hispanic/Latino Communities

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Why We're Here

- Committed to advancing Health Equity in Palliative Care
- Highlighting the importance of solidarity across diverse racial/ethnic communities amid growing challenges
- Learning from diverse perspectives to strengthen inclusive care
- Recognizing National Minority Health Month

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Providing Culturally Competent Palliative Care for Black Communities

Addressing Health Disparities, Cultural Considerations, and Best Practices

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Affiliations: **Endowed Professor of Social Work, Boston College**

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Community Overview & Terminology

Who makes up the Black Community?

- **Diverse ethnic & national backgrounds**: Includes African Americans, Afro-Caribbeans, Afro-Latinos, and African immigrants from various countries.
- **Preferred terms**: Black, African American (varies by individual, generation, and regional context).
- **Languages**: Primarily English, but also includes Creole, French, Spanish, and various African languages spoken by immigrants.

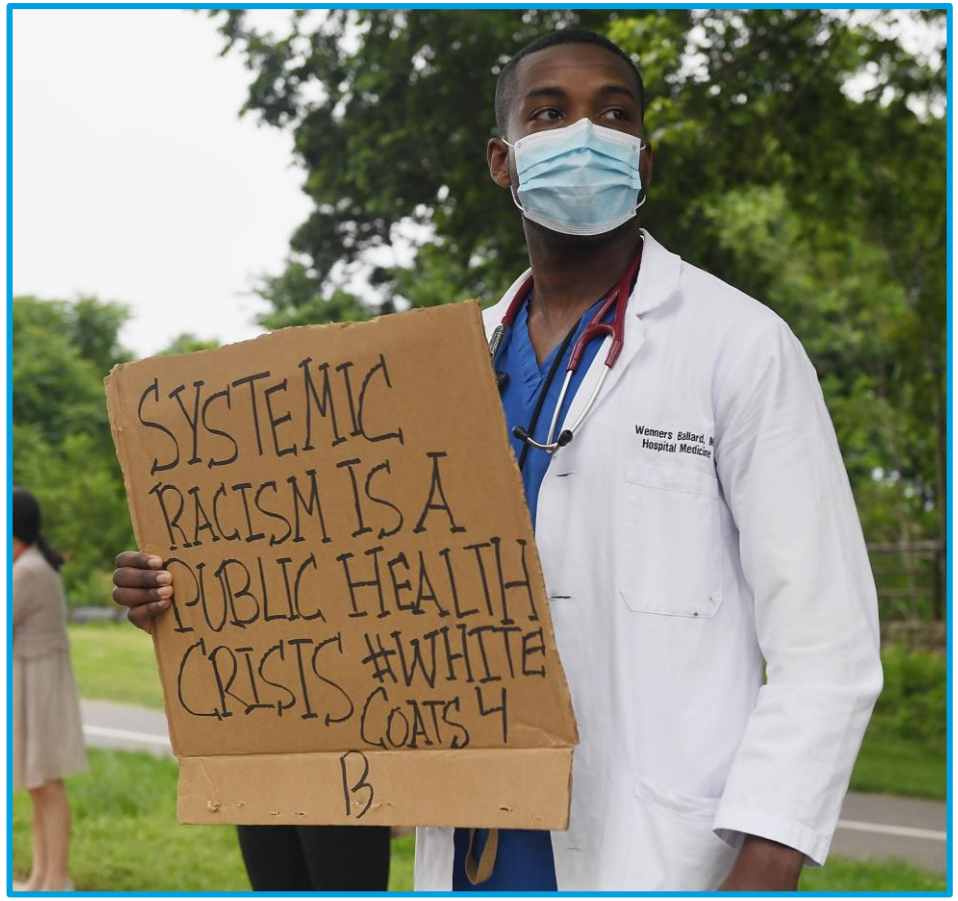
Common Misconceptions:

- **Black Americans are a monolithic group** – There is diversity in cultural traditions, health beliefs, and experiences.
- **Black patients reject palliative care due to mistrust** – While historical mistrust exists, systemic barriers may be perpetuated by provider bias and lack of culturally competent care also contribute.
- **Faith and spirituality mean a rejection of palliative care** – Many Black patients value both faith and medical care, it is important for providers to effectively engage in culturally competent conversations.

Community History

Historical & Structural Barriers to Healthcare

- Legacy of medical racism & experimentation (e.g., hospital segregation, Tuskegee study, forced sterilization, racial pain bias) contributes to mistrust
- Unequal access due to systemic discrimination and socioeconomic disparities
- Underrepresentation of Black providers and lack of culturally competent care
- Higher likelihood of pain undertreatment and implicit bias in symptom management
- Spirituality and faith often shape care decisions, impacting palliative care utilization



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Health Disparities in Serious Illness Care

- Black patients living with serious illness receive **poorer quality pain management** from their health care providers.
    - Other symptom management provided to Black patients living with serious illness is worse than that for White patients.
- Black patients with serious illness report poor-quality clinician-patient **relationships and communication**.
- Black patients are less likely to have **advance care planning (ACP) discussions** or documents, compared to White patients.
- Health care organizations providing care for people living with serious illness have identified **cultural competency training and workforce diversity** as areas in need of improvement.

https://www.capc.org/health-care-for-black-patients-with-serious-illness-a-literature-review/

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Care Experiences – Scoping Review

- Scoping review of the literature to categorize studies on care for Black patients living with serious illness and their family.
- January 2011 – June 2021
- 160 articles our of 433 articles screened
- 12% of 433: Intervention

- Most common topics focused on documenting disparities in access to services and life-sustaining treatment rather than investigating the root causes of disparities.
- Further research should examine the root causes of disparate care experiences.


The Experience of Black Patients With Serious Illness in the United States: A Scoping Review

Rachael Heitner, MPH • Maggie Rogers, MPH • Brittany Chambers, MPH, MCHES • ...
Diane E. Meier, MD, FACP, FAAHPM • Brynn Bowman, MPA • Kimberly S. Johnson, MD, MHS •
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My Lived Experience:

Navigating Serious Illness Care as a Caregiver

- My Mother
- My Caregiving Role
- My Actions as a Change Agent

Lived Experiences Matter:

- Older Adults, Historically Marginalized, Patient-Centered Care

Access to Palliative Care

Barriers to Access

- **Medical Mistrust & Historical Harms**:
  - Legacy of medical racism (e.g., Tuskegee Study, forced sterilizations, racial pain bias) fosters deep mistrust in the healthcare system, leading to late or limited engagement with palliative care.
- **Underrepresentation of Black Palliative Care Providers**:
  - Lack of racial concordance between patients and providers can contribute to communication gaps and reduced trust.
- **Spiritual & Religious Beliefs**:
  - Strong faith traditions emphasize divine intervention and healing, sometimes leading to a preference for aggressive treatments over palliative care.
- **Financial Strain & Policy Gaps**:
  - Black families are more likely to face economic barriers to accessing quality palliative care, including limitations in Medicaid/Medicare coverage for home-based care.

Solutions for Clinicians & Health Systems

- **Normalize early palliative care conversations**:
    - Build trust by integrating discussions into primary care visits rather than end-of-life crises.
- **Increase Black provider representation**:
    - Invest in pipeline programs to train and recruit Black clinicians in palliative care.
- **Engage faith-based and community organizations**:
    - Partner with Black churches and trusted leaders to provide education and culturally aligned support.
- **Address financial barriers**:
    - Advocate for Medicaid/Medicare reforms that expand coverage for home-based and community palliative care services.

Providing Culturally Competent Palliative Care for Asian American Communities

Addressing Health Disparities, Cultural Considerations, and Best Practices

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Special acknowledgement and thanks to: Kat Chow, Steven Chao, Noelle Marie Javier

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Community Overview & Terminology

What is the Asian American Community?

- We are non-monolithic
- > 50 countries, > 100 Different languages, ethnicities, religions
- 25 million Americans labeled into 1 group by our government
- Different decades of United States history and impact

Common misconceptions

- Perpetual foreigner
- “Yellow Peril”
- Model Minority
- COVID-19, “Asian Flu”

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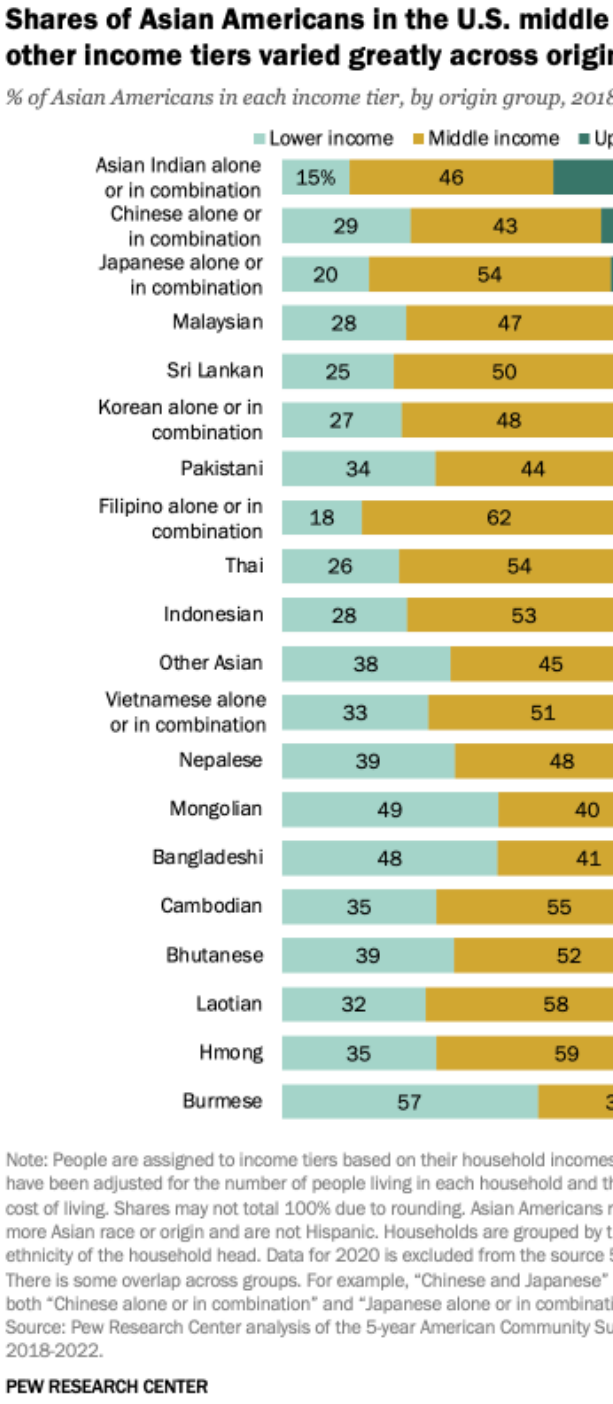

Community History

History and "Set-up" for discrimination, poverty, hate, isolation, fear

1765 first Filipino Americans settle in Louisiana	1848-1852 “Gold Mountain”	1850s "Coolie trade"	1863-1869 Transcontinental Railroad	1871 Los Angeles Chinatown Massacre
1875 Page Act	1882 (and 1892) China Exclusion Act	1941 Pearl Harbor, WWII	1942 Japanese internment camps	1982 Murder of Vincent Chin
1997 Bird Flu, "Asian Flu"…	2001 9/11 World Trade Center attack	2019 COVID-19	2021 Atlanta spa shooting	

Community History & Health Disparities

Key Health Disparity notes

- Cancer (ie. Liver, stomach, breast), Hepatitis B
- Diabetes screening criteria is different
- Heart disease, Hypertension
- COPD – smoking, tuberculosis
- Mental health as personal weakness
- 1 in 3 AAPI individuals faced racial abuse in 2023

- **Asian Americans are the only U.S. population suffering cancer as the leading cause of death**
- 1985 Heckler Report concluded that Asians — largely because they were all clumped into one group — were "healthier than all racial/ethnic groups in the United States."
- **Between 1992-2018 – just 0.17% NIH budget spent on research focused on AAPI, despite being the United States's fastest growing ethnic group**

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Lived Experiences:

- Reluctance to burden one's family with prolonged disease
- Stigmata of dementia and mental health
- Chronic pain as part of normal aging that should be endured
- Mistrust of Western science and fears of discrimination

Pew Research Center

Portrayed in books and movies:

- Earlier racist stereotypes: “*yellowface*” *"yellow peril"* *“dragon lady”*
- Books and movies: Joyluck Club, The Farewell, Crazy Rich Asians

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Access to Palliative Care & Systemic Solutions

Asian American Community	• Family-centric • Non-Monolithic! • Different decades of immigration = different lived experiences
Challenges	• Lack of knowledge and consequent fear of unknown • Cultural or family practice of withholding “serious news” for the patient • End-of-life discussion as "taboo" • Not wanting to burden loved ones with a prolonged illness • Mistrust of Western medicine and technologies
Opportunities for Clinicians and Health Systems	• Family-centered care • Use interpreters and culturally competent care models • Explore the unique cultural and religious beliefs and concerns • Educate and normalize early palliative care conversations in primary care

Providing Culturally Competent Palliative Care for Indigenous Communities

Addressing Health Disparities, Cultural Considerations, and Best Practices

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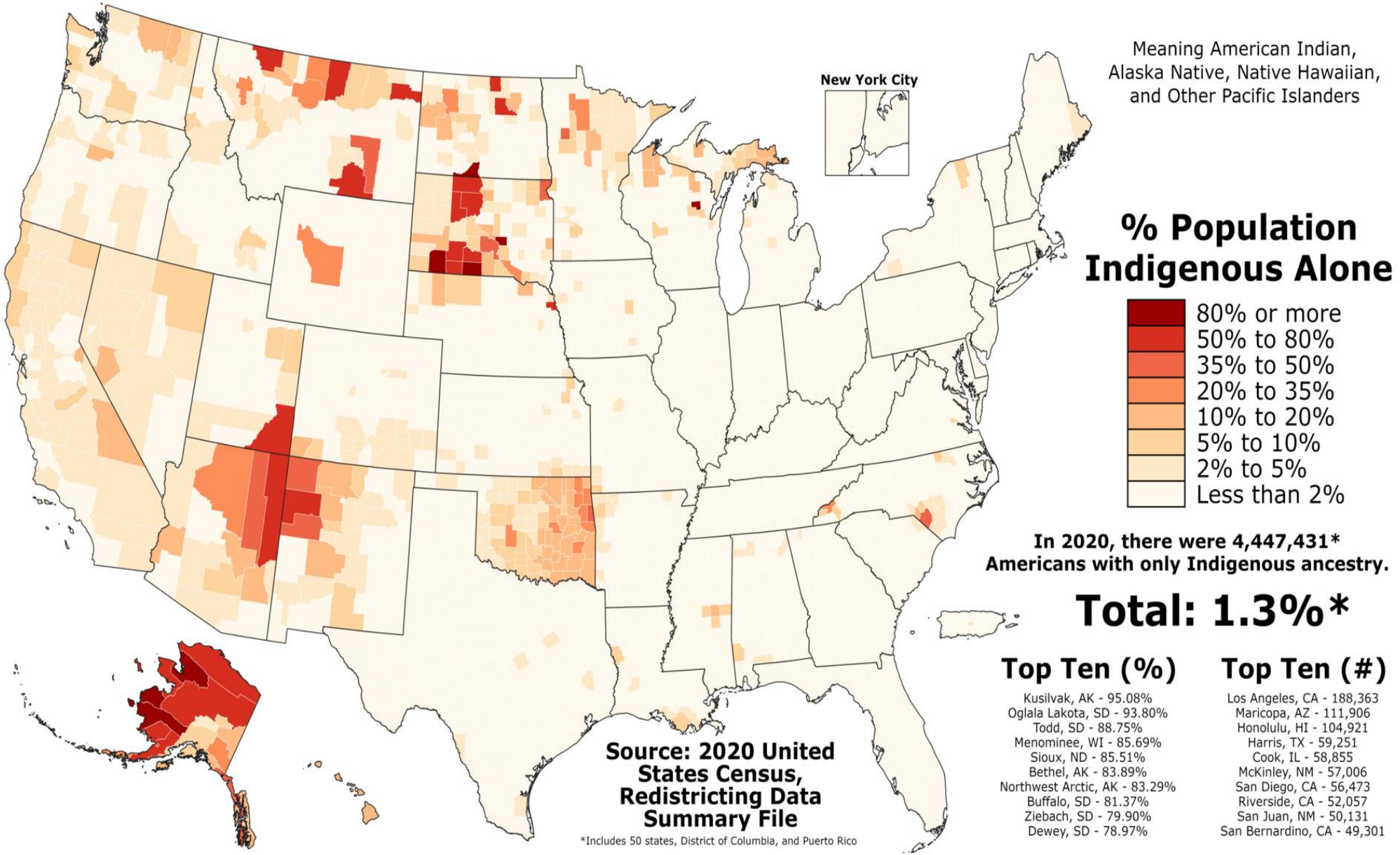
Community Overview

- The US government recognized **574** Tribes and Alaska Native entities in **37** US States.
    - This is important since only those federally recognized tribes can be eligible to receive health care services through tribal benefits and programs, including Indian Health Services.
- Nearly **2 million** Americans are members of the 574 federally recognized tribes and entities.
- **9.7** million people identify as Indigenous alone or in combination with another race group.
- ***Each Tribe is a sovereign nation with its government, life-ways, religions, traditions, and culture.***
- Preferred terms: **Indigenous**, **Native**, or asking what tribe, pueblo, band, or clan they are affiliated with.



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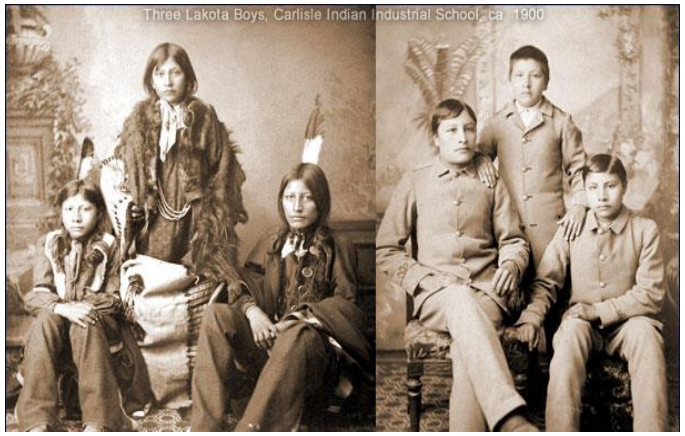
Community History with Recent Historical Trauma



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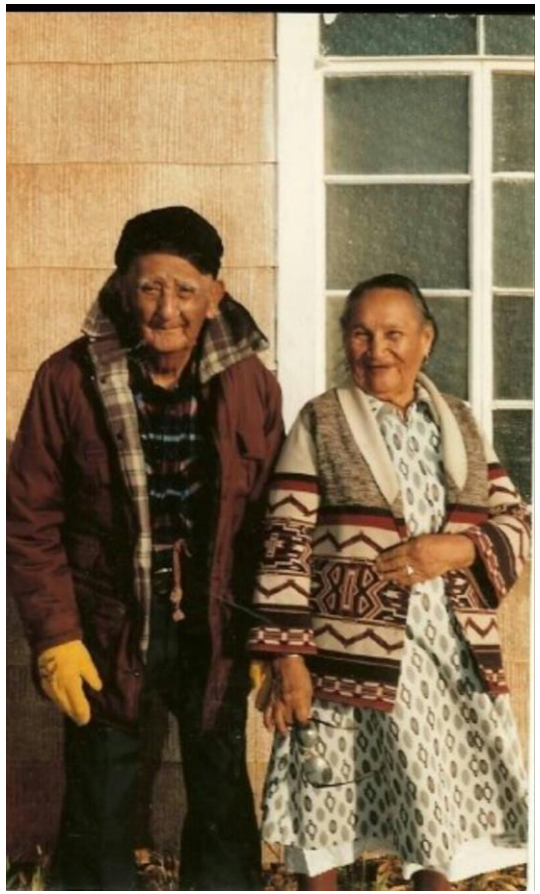
Health Disparities



Life expectancy for IA is ~7 years less than Caucasians living in the U.S.

The mortality rates are significantly higher compared to the general population, including all ethnicities.

Within the IA community, health risks are higher as well.

- Substance abuse is 638% higher than in the general population.
- Tuberculosis is 400% higher, accidental & unintentional death is 215% higher, suicide is over 90% higher, followed by homicide at 80% higher than the remainder of the U.S. population.
- The primary mortality risks are chronic liver disease, cirrhosis, diabetes mellitus type 2, unintentional injuries such as motor vehicle accidents and hypothermia, homicide, suicide, and chronic lower respiratory diseases.
- Most deaths occur between the ages of 15 – 50 years.

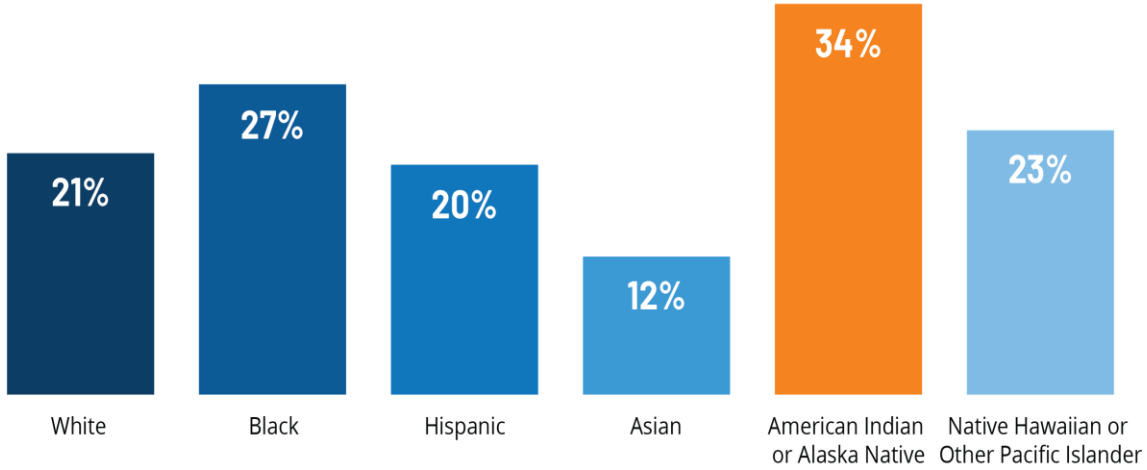
Indigenous Youth

- Suicide is the 2nd leading cause of death – **2.5 times the national rate** – in the 15 to 24 age group. In the US, between 1 in 9 and 1 in 5 report attempting suicide each year (CDC).
- Arrested at a rate of three times the national average, and **79%** of youth in the Federal Bureau of Prison's custody were Indigenous (Bureau of Justice Statistics, 2004).
- About 90% of all students attend regular public schools, and about **8%** attend schools administered by the Bureau of Indian Affairs (National Indian Education Association Statistics).
- Disproportionately suspended and expelled, representing less than 1% of the student population, only 2% of out-of-school suspensions, and 3% of expulsions (White House Native Youth Report).
- The national high school graduation rate hovers around **79%**, compared to over 94% for white students (including GED) (Childstats.gov).
- The National Indian Child Welfare Association reports that Indigenous children are **overrepresented in foster care** – at more than 2.4 times the general population – and 2 to 4 times the expected level are awaiting adoption.
- They have the 3rd highest rate of victimization at 11.6 per 1,000 children of the same race or ethnicity. In 2009, 7,335 were victims of child maltreatment (NICWA).
- In 2013, the rate of death among infants was the second-lowest among ethnic groups, at 401 per 100,000. However, Indigenous peoples had the 2nd highest death rate for children ages 1 to 4 and 15 to 19. (childtrends.org)

COVID-19

American Indians and Alaska Natives Have a Higher Risk of Serious Illness if Infected with the Coronavirus

Share of Adults Ages 18-64 at Higher Risk, by Race/Ethnicity:



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Access to Palliative Care

Attempt to facilitate goals of care conversation can be challenging when it is generally considered culturally offensive to discuss

- Explain purpose
- Assess knowledge and acceptance by asking questions
- Ask for permission to share an understanding of the situation
ASSURE NO HARM IS INTENDED AND YOU WILL CONTINUE TO HOPE AND TREAT THEIR LOVED ONE
- Assess goals
- Summarize

"Before we go, is there anything you want to tell me or share about the patient…."

Medicaid Recipients	$5,010
VA Beneficiaries	$5,234
Medicare	$7,631
Bureau of Prisons	$3,985
Indian Health Services	$2,130

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AMEN protocol: Affirm, meet, educate, no matter what

Affirm the patient's belief. Validate his or her position: "Ms. X, I am hopeful, too."

Meet the patient or family member where they are. "I join you in hoping (or praying) for a miracle."

Educate from your role as a medical provider. "And I want to speak to you about some medical issues."

No matter what, assure the patient and family you are committed to them. "No matter what happens, I will be with you every step of the way."

What should I do in practice?

- Determine tribal affiliation of patient and their family as well as degree of acculturation
- Primary and secondary languages should be determined as well as the level of education
- Soft tones and polite speech are appreciated by most individuals
- Do not interrupt the patient as they speak as long pauses may be part of communication
- Consents and decision making should include asking the individual if others need to be consulted
- Value is placed on personal autonomy but often the family will need to be included, written consents may be viewed with distrust
- Discussion of terminal illness with the individual and the family should be approached with compassion and respect for the culture and beliefs.

Providing Culturally Competent Palliative Care for Latino Communities

Addressing Health Disparities, Cultural Considerations, and Best Practices

Sasha Perez, MPH, PhD Student in Nursing

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University of Utah College of Nursing

Community Overview & Terminology

Who is the Latino Community?

- Diverse ethnic & national backgrounds
- Preferred terms: Latino, Latina, Latinx (varies by generation)
- Languages: Spanish, bilingual, Indigenous dialects

Common Misconceptions

- Latinos are a monolithic group – vast diversity exists
- Palliative care = hospice? – Many reject care due to misunderstandings
- Latinos don’t trust healthcare? – Barriers are structural & linguistic, not just mistrust

Community History & Health Disparities

Historical & Structural Barriers to Healthcare

- Limited access due to insurance gaps, immigration fears, language barriers
- Lack of culturally competent providers leads to mistrust
- Misinformation about palliative care – Faith & miracles often prioritized

Key Health Disparities

- Latinos are 1.5x more likely to develop dementia but are less likely to receive a timely diagnosis.
- Higher rates diabetes, cancer, CVD
  - Palliative care underutilized – Many engage late in illness

  →Pain & symptom management disparities – Under-treatment common

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Sources*
Alzheimer's Association Hispanic Americans and Alzheimer's, 2022
Rashid, M. et al, 2022

Navigating Palliative Care as a Caregiver

Challenges Faced and Lessons Learned…

Access to Palliative Care & Systemic Solutions

Barriers to Access:	Solutions for Clinicians & Health Systems:

• Lack of bilingual palliative care providers
• Familismo & Respeto: Family-centered decisions require engaging extended family
  • **Familisimo**: emphasizes family loyalty and solidarity and can lead to care being perceived as a moral obligation, especially in the case of women.
  • **Respecto:** related to the hierarchical relationships, such as, children are expected to listen to adults (e.g., the elderly, parents) and comply with their requests
  • Financial strain & policy gaps: Medicaid doesn't cover all caregiving needs
	• Normalize early palliative care conversations in primary care
	• Use trained interpreters & culturally competent care models
	• Expand community-based programs
	• Advocate for Medicaid/Medicare reforms to support home-based family caregiving

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Sources*
Stein et al, 2014
Van der Lippe, and Lippényi, 2020

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Takeaways

Shared Principles for Equitable Palliative Care

Acknowledge mistrust stemming from past harms and systemic inequities

Approach patients with humility and a commitment to rebuilding trust

Honor Cultural Values and Preferences

Listen first—let patients and families guide discussions on care

Respect traditions, spirituality, and decision-making preferences

Avoid Assumptions: cultural identity does not determine preferences

Engage in open-ended conversations to understand unique needs

Driving Systemic Change for Health Equity

- Support policies that improve access to Medicare, Medicaid, and palliative care services
- Advocate for culturally responsive and community-driven care models
- Build Inclusive Care Systems
- Ensure representation in healthcare leadership and workforce
- Implement ongoing training on implicit bias and culturally responsive care
- Commit to Continuous Learning & Partnership
- Collaborate with community leaders and patient advocates
- Recognize that equity work is ongoing—stay engaged and adaptable

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Q&A

Join us on the CAPC Circles platform to connect and engage with palliative care and serious illness leaders dedicated to advancing health equity! This is a space where you can share resources, ask questions, and participate in meaningful discussions anytime. We look forward to your contributions and can’t wait to foster a vibrant community together!

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Resources (Indigenous American)

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- https://www.cnay.org/resource-hub/fast-facts/
- https://www.advocatehealth.com/assets/documents/faith/cg-native_american.pdf
- https://www.fiercehealthcare.com/practices/amen-tool-helps-physicians-bridge-gap-between-science-and-faith
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Advancing Equity for Black Patients with Serious Illness

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