Beyond Cultural Competence: Practical Strategies for Culturally Humble Palliative Care in Indigenous and Diverse Populations

Jeanna Ford, DNP, APRN, ACNS-BC, ACHPN, FPCN, FCNS

Palliative Care Clinical Nurse Specialist

Clinic Director, University of New Mexico Health Sciences Center

Objectives:

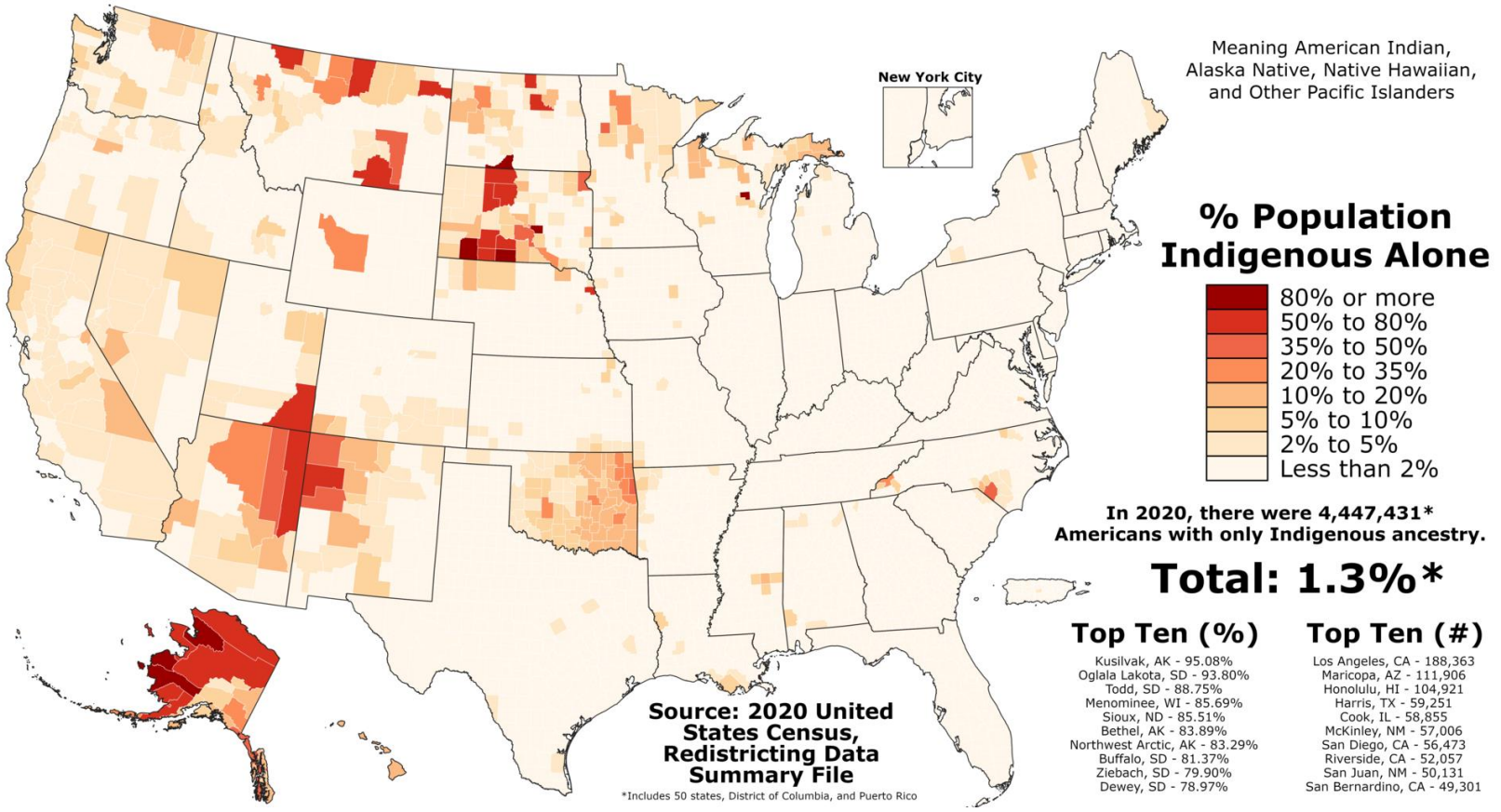
- Describe how historical and structural factors influence serious illness care for Indigenous patients.
- Recognize how implicit bias and communication patterns can affect trust, symptom management, and shared-decision making.
- Apply practical strategies to provide culturally humble, patient-centered palliative care across diverse populations.

Meet Susie…

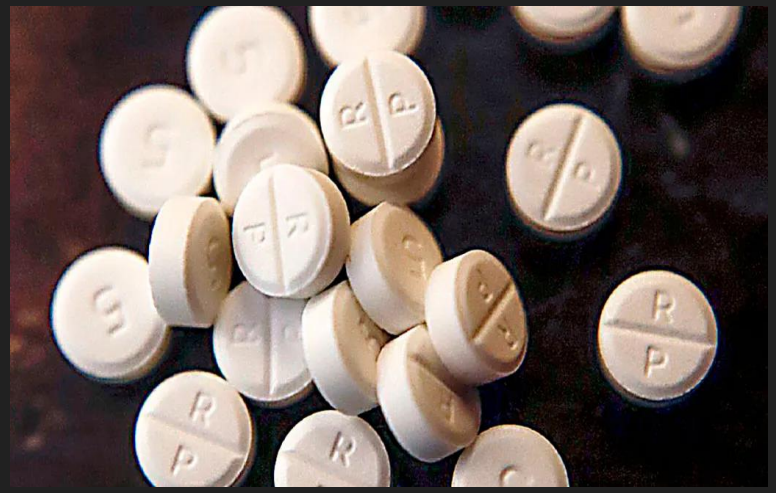
- 80-year-old Diné woman with metastatic melanoma
- Lived on the Navajo Nation in northeastern Arizona
- Traveled nearly 5 hours each way for oncology and palliative care
- Widowed, with her sisters serving as her primary caregivers
- Sought to balance quality of life with cancer treatment while remaining on her homeland

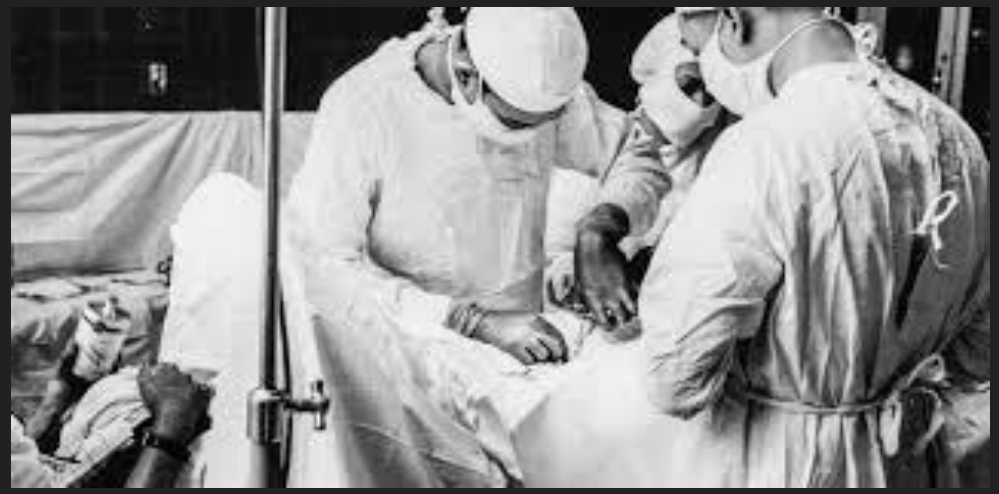
Why was Susie's care so complicated?

- Culture influences how patients experience serious illness.
- Structural barriers influence what care is available.
- Cultural humility requires understanding both.


New York City
Meaning American Indian, Alaska Native, Native Hawaiian, and Other Pacific Islanders
% Population Indigenous Alone
80% or more
50% to 80%
35% to 50%
20% to 35%
10% to 20%
5% to 10%
2% to 5%
Less than 2%
In 2020, there were 4,447,431* Americans with only Indigenous ancestry.
Total: 1.3%*
Top Ten (%)
Kusilvak, AK - 95.08%
Oglala Lakota, SD - 93.80%
Todd, SD - 88.75%
Menominee, WI - 85.69%
Sioux, ND - 85.51%
Bethel, AK - 83.89%
Northwest Arctic, AK - 83.29%
Buffalo, SD - 81.37%
Ziebach, SD - 79.90%
Dewey, SD - 78.97%
Top Ten (#)
Los Angeles, CA - 188,363
Maricopa, AZ - 111,906
Honolulu, HI - 104,921
Harris, TX - 59,251
Cook, IL - 58,855
McKinley, NM - 57,006
San Diego, CA - 56,473
Riverside, CA - 52,057
San Juan, NM - 50,131
San Bernardino, CA - 49,301
Source: 2020 United States Census, Redistricting Data Summary File
*Includes 50 states, District of Columbia, and Puerto Rico

Recent Historical Trauma

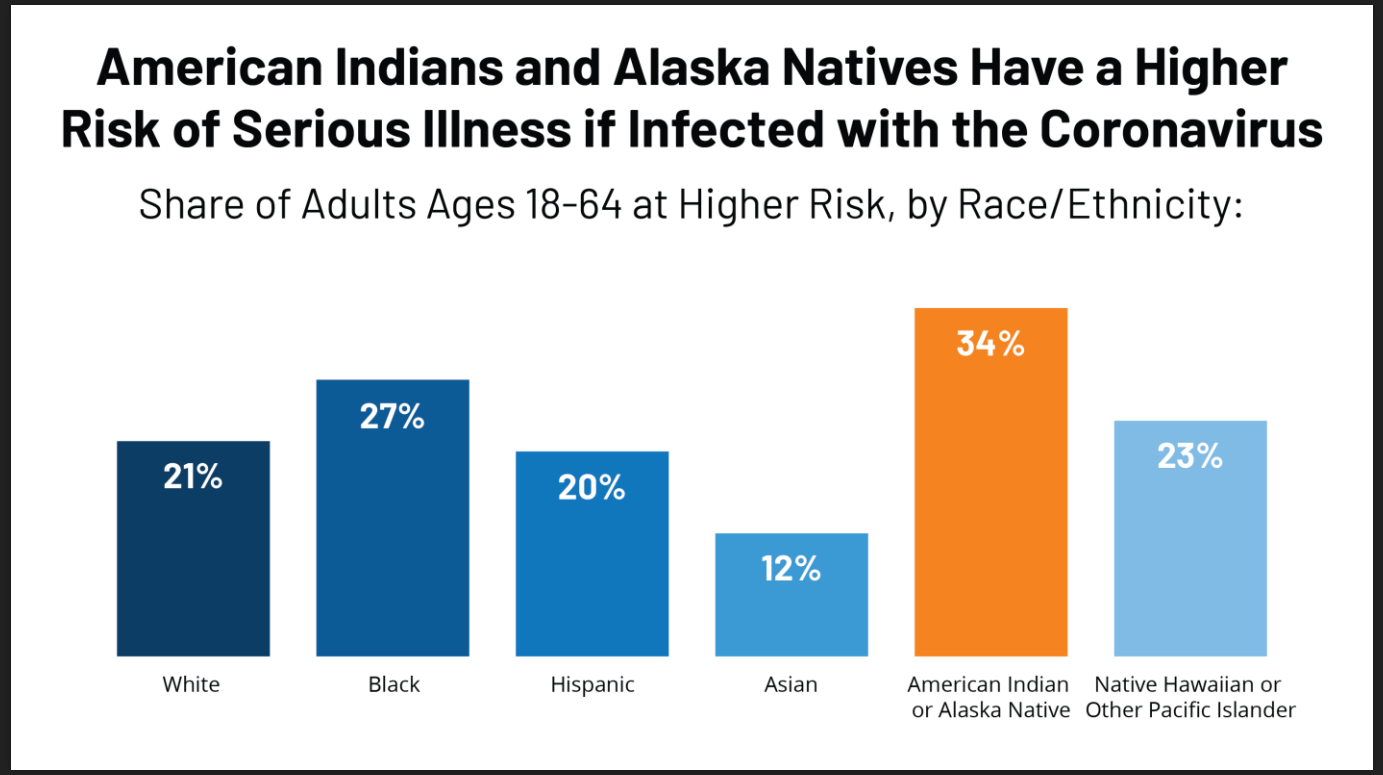




From Boarding Schools to The Indian Relocation Act of 1956

From Forced Sterilization to Opioid Crisis

COVID-19 Exposed Existing Health Inequities



The Consequences of Structural Inequities

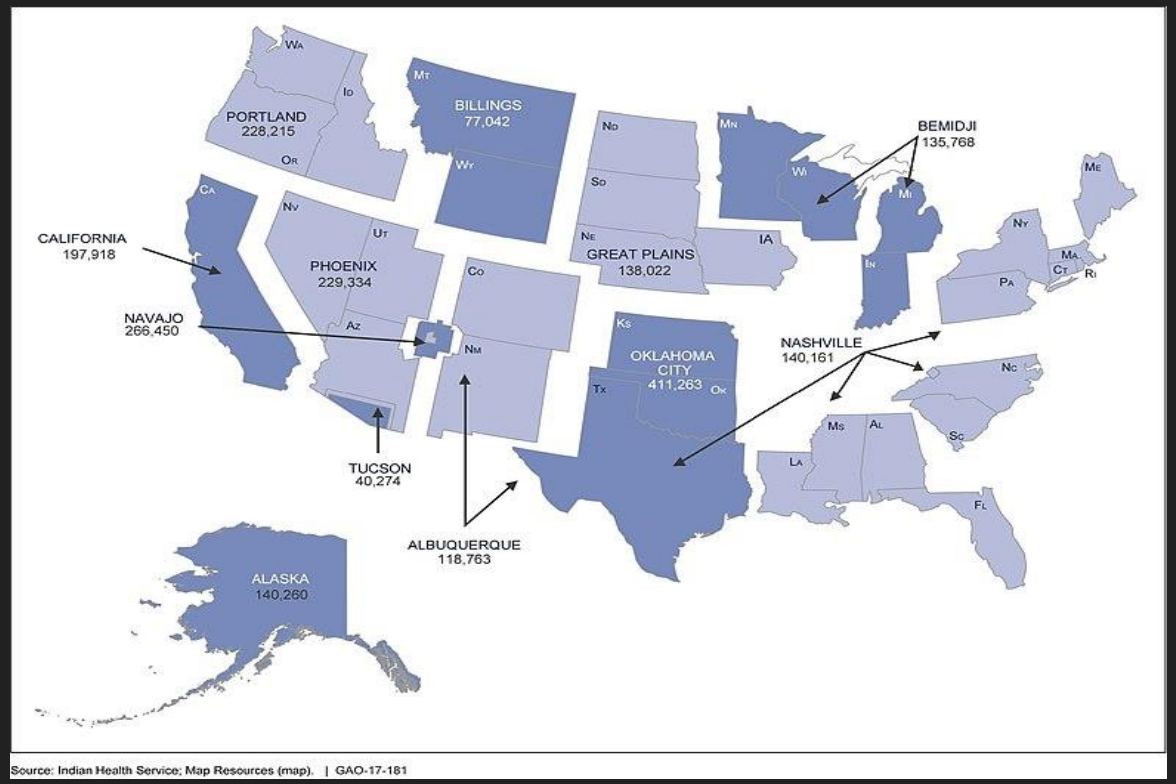
- Life expectancy is approximately **7 years shorter** than the U.S. White population.
- Higher mortality from diabetes, chronic liver disease, and unintentional injuries.
- Suicide rates remain disproportionately high in many Indigenous communities.
- Most deaths occur between the **ages of 15 – 50 years**.
- Many disparities are driven by social determinants of health, limited access to care, and historical inequities.

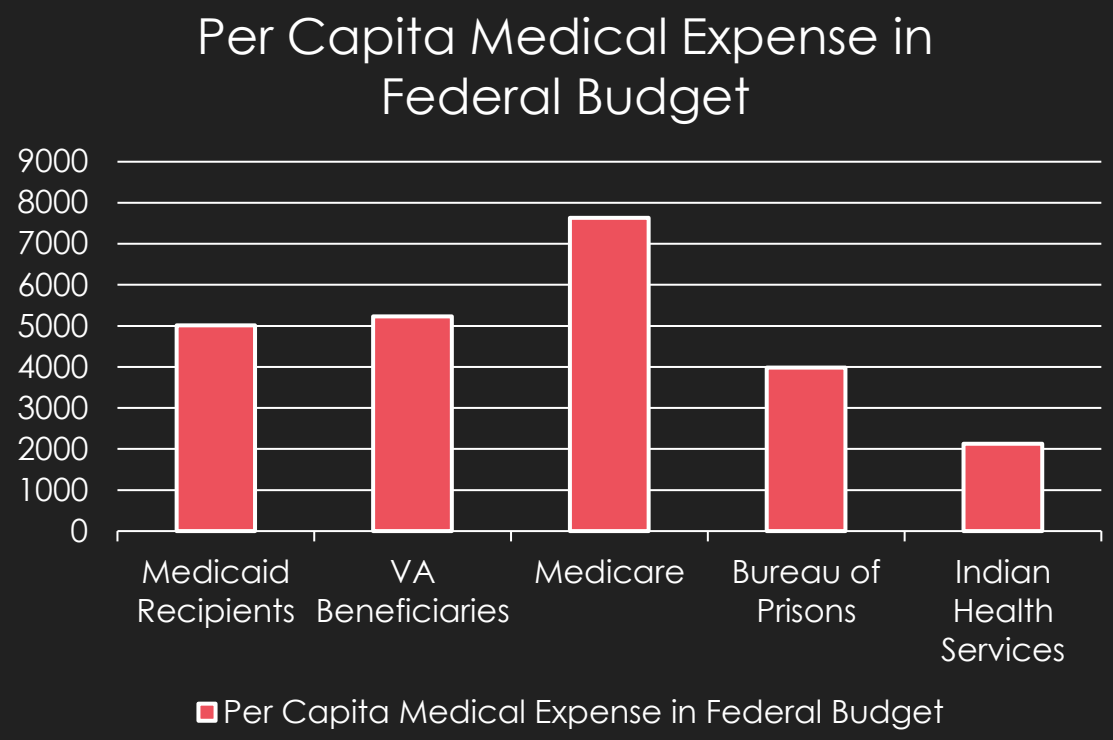
These disparities are not the result of culture. They are the result of inequitable systems, access, and resources.

Indigenous Youth

- Indigenous youth experience disproportionately high rates of suicide and trauma exposure.
  - Suicide is the 2nd leading cause of death – 2.5 times the national rate – in the 15 to 24 age group.
- These outcomes reflect historical trauma, poverty, isolation, child welfare involvement, and under-resourced systems.
  - The National Indian Child Welfare Association reports that Indigenous children are **overrepresented in foster care** – at more than 2.4 times the general population.
  - They have the 3rd highest rate of victimization at 11.6 per 1,000 children of the same race or ethnicity.
- Serious illness care often occurs within families already carrying cumulative grief.

Understanding the Indian Health Service





Healthcare Encounters:

Culture becomes meaningful only when it changes the clinical encounter.

Family and Shared Decision-Making

- Family-centered decision-making is common in many Indigenous communities.
- The people identified as "family" may not reflect Western definitions of kinship.
- Decision-making often involves multiple individuals rather than a single surrogate.
- Ask patients how they would like decisions to be made rather than assuming.

In my culture, my family structure looks a little different than the outside world. I don't have a great aunt because I call her Grandma. I don't have a great niece because she's my grandchild. It may seem complicated, but it's AMAZING! Let me show you.

Dominant Society	Vs.	My Culture
Great Aunt	becomes my	Grandma
Great Uncle	becomes my	Grandpa
2nd Cousin (male)	becomes my	Uncle
2nd Cousin (female)	becomes my	Auntie
Great Niece	becomes my	Granddaughter
Great Nephew	becomes my	Grandson

My own children call my 1st cousins auntie and uncle! That is super cool isn't it?! There's never a shortage of aunts and uncles in my culture!

We treat our nieces and nephews like our own kids.

Goals of Care

- **Before the conversation**
  - Explain the purpose of the discussion.
  - Ask permission before sharing serious information.
  - Explore the patient's understanding.
- **During the conversation**
  - Elicit values and goals.
  - Summarize what you heard.
  - Leave room for questions and reflection.

"Before we go, is there anything you want to tell me or share about your loved one…."

AMEN Protocol

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."

Providing Culturally Humble Care

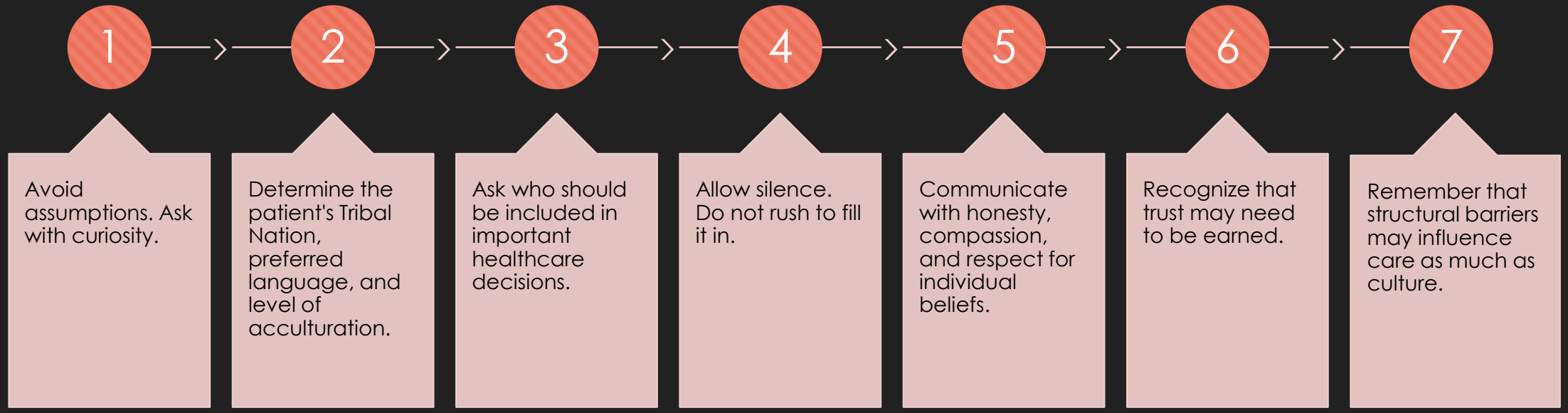
Good Habits:

- Listen more than you speak.
- Approach with curiosity, not assumptions.
- Ask before advising.
- Negotiate the plan of care together.
- Be comfortable with silence.

Bad Habits:

- Assuming beliefs or preferences.
- Interrupting.
- Dominating the conversation.
- Rushing difficult discussions.
- Trying to "fix" everything in one visit.

Pearls for Practice



Susie's Legacy.

- Susie died three days after returning home, surrounded by her family on the Navajo Nation.
- Her nephews carried her body through the mud to meet the ambulance because the roads were impassable.
- Culture did not determine Susie's experience. The healthcare system did.
- Cultural humility allowed us to understand what mattered most. Advocacy helped us honor it.

In Summary

- There is no single Indigenous culture. Every Tribal Nation, family, and patient is unique.
- Historical and structural inequities continue to shape healthcare encounters today.
- Cultural humility begins with curiosity, listening, and partnership, not assumptions.
- Our role is to provide care that honors what matters most to each patient, regardless of the barriers they face.

Resources

- https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/pdf/CMS-Literature-Review.pdf
- 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
- Marr L, Neale D, Wolfe V, Kitzes J. Confronting myths: The Native American experience in an academic inpatient palliative care consultation program. *Journal of Palliative Medicine*. 2012;15(1):71-76. doi:10.1089/jpm.2011.0197
- https://www.navajo-nsn.gov/
- https://www.ihs.gov/
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6175620/#:~:text=Doctors%20listen%2011%20seconds%20before%20interrupting%20patients%20according,the%20answer%20after%20a%20median%20of%2011%20seconds.
- Ford JA, Dahlin C. Cultural Advocacy for Indigenous Individuals With Serious Illness. American Journal of Hospice and Palliative Medicine®. 2024;0(0). doi:10.1177/10499091231224794
- Guthrie, R., Piromalli, C., & Ford, J. (2023, June 16). *Fast Facts #468 Serious Illness Considerations for Indigenous People of North America*. Palliative Care Network of Wisconsin. https://www.mypcnow.org/fast-facts/