



## Why is Culture Important in Palliative Care?

- ▶ Decision-making and symptom management
- ▶ Patient's preferences, hopes, and values
- ▶ Each patient's unique physical, emotional, social, spiritual, and cultural needs
- ▶ Shapes one's experience of wellness, illness, dying and death



## Domain 6: Cultural Aspects of Care

(National Consensus Project Palliative Care Guidelines, 2018, p.38)

- Assessing and respecting values, beliefs and traditions
- Patient's own understanding of their health and illness
- Identifying our own biases (implicit and actual)
- Meeting culturally sensitive strategies
- Utilizing/ providing resources
- Respectful acknowledgement of /culturally sensitive support for patients and families





## Essential Palliative Care Cultural Skills Needed by All Clinicians

**Q: What is the impact of culturally- and linguistically-sensitive care on physical, social, emotional, and spiritual wellbeing of the patient and family/caregiver?**

- ▶ Cultural influences
- ▶ Patient and family decision making
- ▶ Approach to illness, pain, and suffering
- ▶ Grief, dying, death, and bereavement



## The role of the interdisciplinary team

- ▶ Respects patient and family cultural beliefs, values, traditional practices
- ▶ Build unique strengths on cultural identities
- ▶ Ensures environment, policies, procedures, and practices are respectful of culture
- ▶ Individualizes: Intersections of cultural uniqueness
- ▶ Attend training needed to increase cross-cultural knowledge empathy and humility
- ▶ Avoid imposing personal values beliefs and biases



## IDT Recognized Needs:

- ▶ Nonjudgmental of the patient and family
- ▶ Mindful of potential biases
- ▶ Conscious of historical trauma and
- ▶ Aware of power dynamics inherent in patient and family care
- ▶ Cultural practices, customs, beliefs, and values during serious illness
- ▶ Preference for IDT interaction and decision-making (communal, collective or individualistic)



## Communication and Language

- ▶ Patients preferred name, pronouns and gender identity
- ▶ Based on level of health literacy
- ▶ Verbal, nonverbal, and or symbolic means
- ▶ Cognitive capacity
- ▶ Learning or developmental disabilities
- ▶ Developmental stage across the lifespan

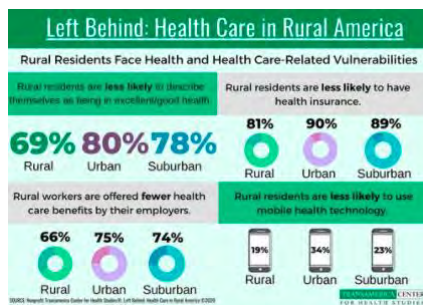


## Non-English Medical Communication Needs

- ▶ Linguistic diversity, medical interpreters, bilingual clinicians
- ▶ Family members are not placed in the role of interpreter
- ▶ Preferred ways of receiving materials and information
- ▶ Incorporate cultural representatives/brokers in the plan of care



## Rural, Frontier and Underserved Population



- ▶ Limited resources
- ▶ Complex needs of its socioeconomically disadvantaged and culturally diverse patient population
- ▶ Community capacity and resources are explored
- ▶ Comprehensive in-person assessment needs
- ▶ Advance Care Planning and goals of care planning in a way understood

## Cultural Interventions for Underserved Populations

- ▶ Telephonic and telehealth approach when needed
- ▶ Weekly nurse coaching sessions via telephone
- ▶ Intensive training in symptom management, as well as problem solving and decision-making skills supported.
- ▶ Coordination and connecting the patients and families to other resources
- ▶ Prompt clinical visits versus calling 911



## LGBTQIA

Welcome

This is a safe space for LGBTQIA+



**Gender expression: “The way individuals express or present to others their internal sense of masculinity or femininity.”**

Acquaviva K. LGBTQ-inclusive hospice and palliative care. New York, NY: Harrington Park Press; 2017.

**Gender identity: “One’s innermost concept of self as male, female, a blend of both or neither – how individuals perceive themselves and what they call themselves. One’s gender identity can be the same or different from their sex assigned at birth.”**

Sexual orientation and gender identity definitions | Human Rights Campaign. Human Rights Campaign. 2018. Available at: <https://www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-anddefinitions>. Accessed April 23, 2018.

## Cultural Dynamics When the Patient is a Child (or Adolescent)

- ▶ The role of the child and development age
- ▶ How culture defines the child status
- ▶ How parents share information with the patient, other children
- ▶ Help parents define being a good parent
- ▶ What impacts medical decision making
- ▶ Who makes decisions for the child based on culture
- ▶ Serious illness in utero, pregnancy and childbirth



Native  
American

Cultural Aspects  
in Palliative  
Care



# Native American Population

- ▶ 9.7 million (AI + AN)- survived tremendous hardship
  - ▶ We all share a history of experiencing untrustworthy behaviors
  - ▶ Can lead to mistrust in clinical setting, patience and relationship
- ▶ 2.9% of population 86.5% increase in past 10 years
- ▶ 324 reservations
- ▶ 574 federally recognized Tribes (>200 in AK), 63 state-recognized tribes
  - ▶ Unique relationship w/ US gov't
  - ▶ <https://www.ncsl.org/legislators-staff/legislators/quad-caucus/state-recognition-of-american-indian-tribes.aspx>
- ▶ 2020 census  
<https://indiancountrytoday.com/news/2020-census-native-population-increased-by-86-5-percent>



## Government to Government Relationship

- ▶ Tribal governments interact closely with the federal government through the Department of the Interior and the **Bureau of Indian Affairs**, but they are separate from state governments. Although tribal constitutions are based on the same form of democracy that the United States has incorporated into the U.S. Constitution, differences exist that reflect the history and circumstances of each tribe.
- ▶ <https://www.ndstudies.gov/gr8/content/unit-iv-modern-north-dakota-1921-present/lesson-4-alliances-and-conflicts/topic-1-indian-citizenship-and-indian-reorganization-act/section-3-tribal-governments>



## Acculturation, Assimilation and Amalgamation of Cultures

**Acculturation** is the process of cultural and psychological change that results following meeting between cultures.”

**Assimilation** refers to the process through which individuals and groups of differing heritages acquire the basic habits, attitudes, and mode of life of an embracing culture.

**Amalgamation** refers to a blending of cultures, rather than one group eliminating another (*acculturation*) or one group mixing itself into another (*assimilation*).



Sam, DL, Berry, JW. Acculturation: when individuals and groups of different backgrounds meet. *Perspect Psychol Sci*, 2010;5(4): 472-481.

## Common Threads Of Indigenous America

- ▶ **Values**
  - ▶ Provide for the family
  - ▶ Learn how to be helpful to our people
  - ▶ Perpetuate well-being
  - ▶ Elders and Children are of high importance in family structure
- ▶ **Customs**
  - ▶ Sharing food and story \* oral histories
  - ▶ Living and caretaking the land
  - ▶ Living with the seasons
  - ▶ Social ceremonies, memorials
  - ▶ Spectrum of practices, beliefs, more or less "traditional AI/AN"
- ▶ **Core Ideals**
  - ▶ Respect
  - ▶ Gratitude
  - ▶ Humility
  - ▶ Generosity
  - ▶ Humor



## Giving Back

- ▶ Distinct Practices across AI/AN
- ▶ Threads that connect us
- ▶ Earth Based people, she is the source of much of life
- ▶ Reciprocity, gifting, being balanced
- ▶ Give-Aways and sharing food
- ▶ Social Ceremonies:
  - ▶ Celebration with other's to be inclusive and belonging
  - ▶ adoption
- ▶ Specific Ceremonies:
  - ▶ Birthing
  - ▶ Welcoming
- ▶ Special Events
- ▶ Sun Dance \* tribe specific
- ▶ Memorial - always give back when they cross over
- ▶ -giveaways and share food



# Aspects of Native American Culture in Great Plains

## Language

Dakota, Lakota, Nakota \*(dialectical)

Oral History: story telling, oral history, songs

## Beliefs

Creator- monotheistic, spirit, ceremony

stages of life, naming, marriage, memorial, seasons)

Goodness of mankind

Relationships with relatives other nations, sky, water, earth, humans, plants, water and the universe (Mitakuya Oyasin)

Bringing pride and honor to self, family and nation

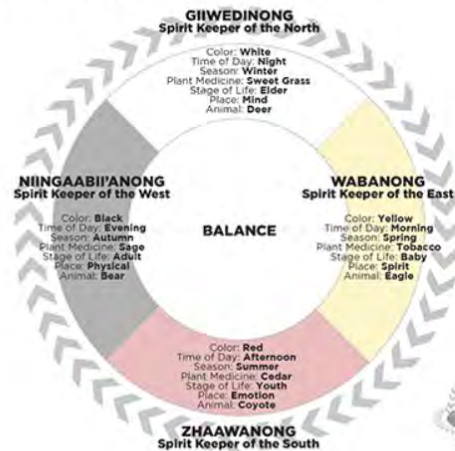
c/o \*Dee Le Beau Hein Cheyenne River CHAD



<http://www.americanfestivalsproject.net/pine-ridge-pow-wow>

## The Ojibwe Medicine Wheel

### OJIBWE MEDICINE WHEEL



► <https://seas.umich.edu/news/izhi-minoging-mashkikiwan-place-where-medicines-grow-well>

## Dakota Specifics

- ▶ ND AI/AN population
  - ▶ 40,970
  - ▶ #6 US
  - ▶ 4.9% population
  - ▶ Nearly 60% on reservation
  - ▶ 40% <20 yoa
- ▶ SD AI/AN population
  - ▶ 76,190
  - ▶ #3 US
  - ▶ County of Oglala Lakota is lower and unemployment 89% School dropout rate >70%

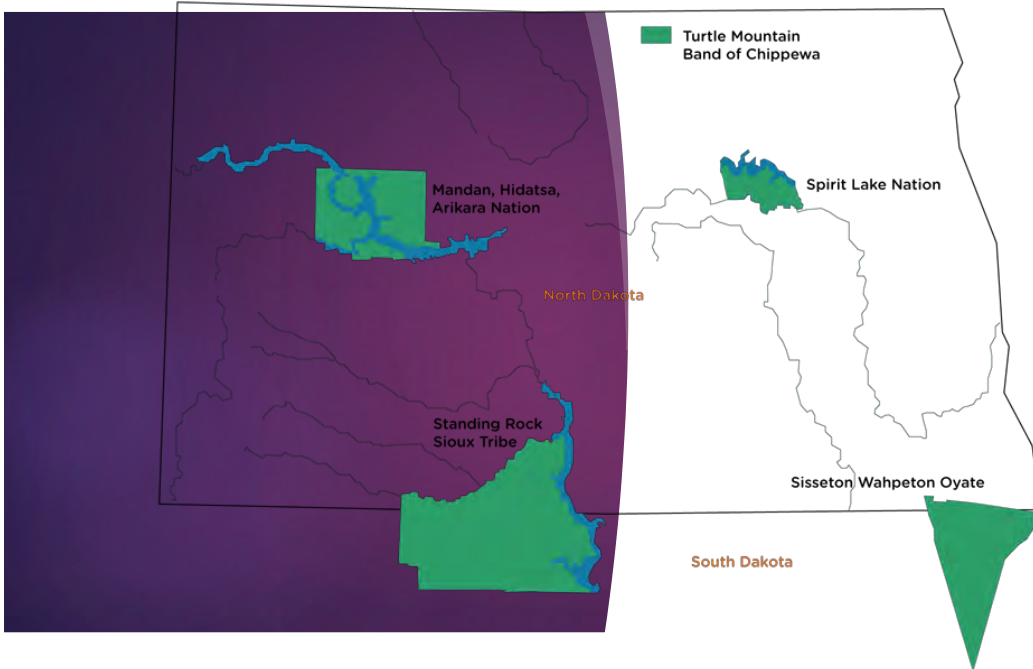


## ND Tribes

- ▶ Turtle Mountain Band of Chippewa Indians
- ▶ Three Affiliated Tribes: Mandan, Hidatsa, Arikara Nation
- ▶ Standing Rock Sioux Tribe
- ▶ Spirit Lake Nation
- ▶ Sisseton-Wahpeton Oyate Nation
- ▶ Trenton Indian Service Area

[Tribal Nations | Indian Affairs Commission, North Dakota](#)  
[Tribal Governments | North Dakota State Government - ND Portal](#)

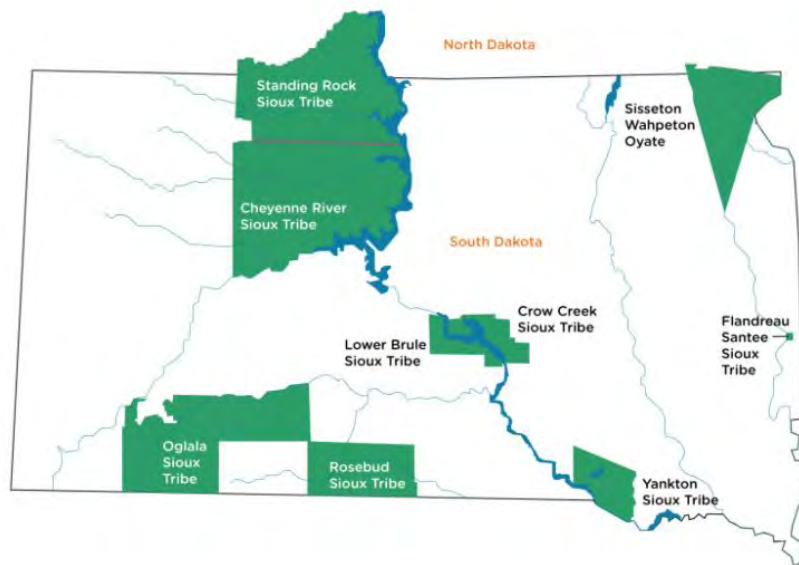




## SD Tribes

- ▶ Standing Rock Sioux Tribe
- ▶ Cheyenne River Sioux Tribe
- ▶ Sisseton Wahpeton Oyate
- ▶ Flandreau Santee Sioux Tribe
- ▶ Yankton Sioux Tribe
- ▶ Crow Creek Sioux Tribe\*
- ▶ Lower Brule Sioux Tribe
- ▶ Rosebud Sioux Tribe
- ▶ Oglala Lakota Tribe

<http://oglalalakotanation.org/>\*



## Historical Trauma in Real Time

- ▶ Place with rich and complex history
- ▶ Earth Provides
  - ▶ Source of life, strong medicine
- ▶ Reciprocity
- ▶ Important messages will repeat
  - ▶ More than asking it's being present
  - ▶ Trust the answers will come
- ▶ Knowledge is a constant
- ▶ Always learning and adapting
- ▶ Survivors, all of us come from place
- ▶ In our homeland



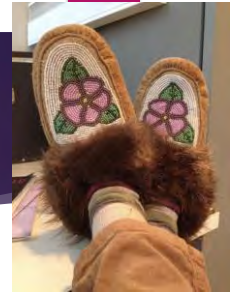
## Care for Our Elders/Wikanki Ewastepikte

- ▶ "Healthcare providers working with patients from other cultures need to move from broad generalizations about a culture to more specific information about a group or patient within that culture.
- ▶ Care for Our Elders began when a palliative care physician asked Associate Professor Mary Isaacson from South Dakota State University and her nursing students why American Indian patients from the western side of the state were traveling to Sioux Falls to receive palliative care and hospice care, when the majority of reservations are located in western South Dakota."





## Recommendations From Collaboration



- ▶ Care for Our Elders/Wikanki Ewastepikte
- ▶ Become aware of American Indian health issues , then speak with the spiritual healer or medicine man from a specific Lakota tribe. She asks how she can best approach a subject like Alzheimer's with a patient. When she meets with patients, she invites them to bring family members and other support.
- ▶ When delivering difficult news, healthcare professionals should ensure that family is present. It is also culturally appropriate to ask if they would like to pray before the discussion. The prayer can be generic and offered to the creator.
- ▶ American Indian patients should be encouraged to ask questions, as they often defer to the provider as a sign of respect.
- ▶ Providers should also be willing to take on the role of facilitator or encourager and leave the role of doer to the elders. Care for Our Elders works because it stems from what the elders want and need, not from what others want for them.
- ▶ In addition, program coordinators recommend involving the community every step of the way. Letting the community lead the program helps to ensure that it is done in the most culturally respectful way possible.
- ▶ [Ruralhealthinfo.org/project-examples/913](http://Ruralhealthinfo.org/project-examples/913)

## Preferred and Taboo Practices/Communication

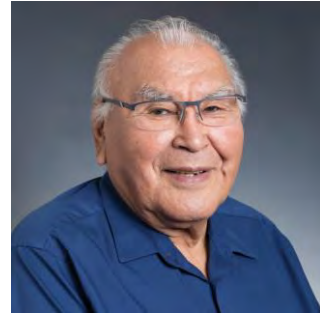
- ▶ Words, like dying or death
- ▶ Community resources and support
- ▶ Preferences related to physical contact
- ▶ level of health literacy prior healthcare experiences and impact on care
- ▶ perception illness and disability
- ▶ Beliefs are about pain and suffering
- ▶ Perceptions on seeking help
- ▶ levels of acculturation within the family
- ▶ use of traditional healing practices and traditional medicine or healers



## Value of Honoring Wishes

**“Our goal should be to help elders live out their lives in comfort, not taking medications they don’t need, and not living where they don’t want to.”**

ANTHC Andrew Jimmie Elder Committee Chair, Minto Village Council Chief, The Chairperson and Tanana Chiefs Conference representative to Alaska Native Health Board  
<https://anthc.org/>



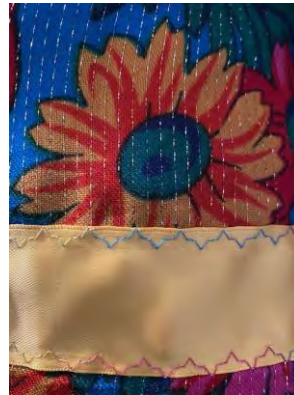
## A Palliative Care Program on a Native American reservation

- ▶ Registered nurses who provide hands on care and care coordination
- ▶ Social workers who also serve as translators for native-speaking patients and families
- ▶ Patient advocates from the community who help patients complete advance directives ( community health representatives/ACP facilitators)
- ▶ Dieticians who provide supplements to eligible patients and help with diabetes teaching and counseling
- ▶ A medicine man who offers spiritual support performing rituals for patients, family members, as well as the staff
- ▶ Guidelines Booklet\*



## Have a Similar History

- ▶ Were sovereign nations
- ▶ Experienced colonialism
- ▶ Continue to define what it means to us and our nations to now be sovereign again.



## Modern Medicine has Forgotten original instructions

- ▶ Sick Care, not health care
- ▶ "Ill to the pill"
- ▶ Medicines (origins in trad use) – pharma
- ▶ Neglects spiritual aspects and mystery of healing
- ▶ Crisis of fellow physicians
  - ▶ Dehumanizing too fast, unrealistic
- ▶ Transform story into healing story
- ▶ Bring to light and work on them together



## Case:

- ▶ 96 yo female with PMH DMT2 well controlled, HTN, cataracts, hearing loss, osteoarthritis of bilateral hips and bilateral knees presents via phone call, daughter (POA) reports she is “probably just stressed out because her close relative passed away and the funeral is later today” she reports her Mom is unable to leave the house due to sleeplessness and feeling “bum”. You hear them speaking back and forth in their traditional language.
- ▶ Upon further inquiry you are able to assess that she has recently run out of her medications (most notably ambien) and hasn’t been able to access her refill due to successive snowstorms and lack of transportation.

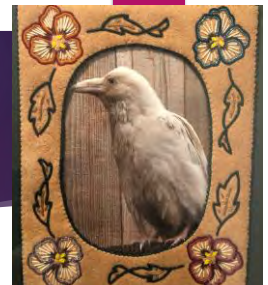


“ Our people know that the land and the language are one. If we lose one or the other we are no longer who we say we are.  
— Grandmother Rita Long  
Visitor Holy Dance

<https://www.grandmotherscouncil.org/who-we-are/grandmother-rita-long-visitor-holy-dance/>

## Plan?

- ▶ Thoughts?
- ▶ Ensure she is stable, home visit BP, I/Os, bring joy if possible
- ▶ Vitals: 135/82, HR 86, RR 18, HT 5”, Wt 110 BMI 21.48
- ▶ Stressed about funeral, grieving, “forgot to get her medicine” (but doesn’t actually have a reliable way to get her medicine.
- ▶ Facilitated coordinating with clinic/family/pharmacy to ensure on same page for medication refills and her priorities to participate in ceremonies.
- ▶ Attended ceremony and followed up to visit, share food and talk story about my experience
- ▶ Invite her family to participate in care, ensure her medication doesn’t run out, daughter has substance abuse and lives in the house at times.
- ▶ Counsel regarding safety of medications, consider lock box and other safety considerations, consult with CHA if available
- ▶ Medication arrives and she is able to attend future ceremonies and events with family



Meet your patients need, know where they are-



## References

- ▶ **National Center for Cultural Competence:**  
<https://nccc.georgetown.edu/>
- ▶ **National Consensus Project Palliative Care Guidelines (2018)**
- ▶ **Hmong Health:** <http://www.hmonghealth.org>
- ▶ **Chinese American Coalition for Compassionate Care:**  
<http://www.caccc-usa.org/en/aboutus.html>
- ▶ **Office of Minority Health Resources Center U.S. Department of Health and Human Services:** <http://www.minorityhealth.hhs.gov>
- ▶ **National Research Center on Hispanic Children & Families:**  
<http://www.hispanicresearchcenter.org/>



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## Native American Resources & References

- ▶ **Indian Country Media Network:**  
<https://indiancountrymedianetwork.com/>
- ▶ **[New care model provides options for those with serious illness. \(2022\)](#)**
- ▶ **[Lakota singers breathe new life into old Native songs \(2022\)](#)**
- ▶ **[Indigenous-Led Biology, Designed For Native Communities \(2021\)](#)**
- ▶ **[#YDL: Data empowers stories, changes health care systems \(2021\)](#)**

