The Importance of Cultural Humility in Palliative Care: Understanding Cultural Backgrounds

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Objectives

- Identify the steps to culturally sensitive palliative care
- Recognize the palliative care cultural skills needed by all clinicians
- Distinguish features of the Native American culture that impact palliative care
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
Cultural Humility

“In a multicultural world where power imbalances exist, cultural humility is a process of openness, self-awareness, being egoless, and incorporating self-reflection and critique after willingly interacting with diverse individuals. The results of achieving cultural humility are mutual empowerment, respect, partnerships, optimal care, and lifelong learning.”


Intersections of Race (Intersectionality)

“A way of understanding and analyzing the complexity in the world, in people, and in human events and conditions of social and political life and the self can seldom be understood as shaped by one factor. They are generally shaped by many factors in diverse and mutually influencing ways. When it comes to social inequality, people’s lives and the organization of power in a given society are better understood as being shaped not by a single axis of social division, be it race or gender or class, but by many axis that work together and influence each other.”

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 care
- Aware of power dynamics inherit and 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

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


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.”

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 govt
- 2020 census
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.


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).

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

<no_reply>c/o *Dee Le Beau Hein Cheyenne River CHAD

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

The Ojibwe Medicine Wheel

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
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

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.

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
- National Research Center on Hispanic Children & Families: http://www.hispanicresearchcenter.org/
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)