Palliative Care Considerations in Native American Culture

JEANNA FORD, MSN, APRN, ACNS-BC, ACHPN
Cultural Considerations

- Culture – learned & shared values, beliefs, norms, and life ways of a particular group that guide their thinking, decisions, actions in patterned ways. Cultures is shaped over time in a dynamic system in which beliefs, values, and lifestyle patterns pass from one generation to another (Leininger, 1994).

- Culture goes beyond race and ethnicity

- This definition of culture is multidimensional, encompassing such components as gender, age, differing abilities, sexual orientation, religion, and socioeconomic factors

- Each of these components play a role in shaping individuals response to life, serious illness, and death
Considerations Cont..

- No one has more or less culture than anyone else
- Culture determines notions of common sense
- Culture is passed from generation to generation without being articulated
- Cultural traditions affect us even if we do not actively participate in them
- The influence of culture in our lives may not be recognized
Personal Reflection

- What is your cultural background?
- What elements of this background do you express or believe?
- How much does this background affect you in ways that you may not be conscious of?
- How aware are you of western attitudes towards EOL?
- How deeply do you hold these attitudes?
- What are the attitudes of the hospital, team, and profession towards EOL?
- How much of these attitudes have you personally absorbed?
Diversity of Native Americans

- There are 562 federally recognized Native tribes, nations, bands, pueblos, communities, and native villages in the United States.

- Approximately 229 of these are located in Alaska, the rest are centralized throughout 33 states.
There are 34 tribes that their tribal headquarters are located in Oklahoma.

Prior to colonization there were an estimated 112 million Native Americans.

Today there is an estimated 5 million natives left.
Historical Overview
Pre-1492: Pre-Columbian Period: In the thousands of years preceding contact with Europeans, Native Americans lived in organized societies within their own form of governments.

1492 – 1828: Colonial Period: European colonies moved on east coast and acquired land under the doctrine of discovery. Disease were introduced and tribes began to dissipate.
1828 – 1887: Removal, Reservation, and Treat Period: As the US population and military strength grew, so did pressure on eastern tribes to move west. Seeking to obtain more land, the US government embarked on aggressive military campaign throughout the West and relocating tribes to reservations.
The Battle of Little Bighorn
Sand Creek Massacre
Wounded Knee Massacre
The Washita River Battle
Battle of Fallen Timbers
1887 – 1934: Allotment and Assimilation Period: Settlers' increasing desire for the land within reservations and the push to assimilate Indians into mainstream American life led to the General Allotment Act of 1887. This Act (Dawe’s Act) dictated the 90 million acres (2/3 of reservation land) were taken from tribes and given to settlers as “surplus”, with little to no compensation to tribes.
1934 – 1945: **Indian Reorganization Period:** The federal government, under the Indian Reorganization Act of 1934, ended the discredited policy of allotment.

1945 – 1968: **Termination Period:** Congress decided that federal recognition and assistance to more than 100 tribes should be terminated. Public Law 280, passed in 1953, imposed state criminal civil jurisdiction over tribes in California, Minnesota, Nebraska, Oregon, and Wisconsin. Termination of federal assistance created economic disaster for many tribes resulting in millions of acres of valuable natural resources land being lost through tax forfeiture sales. Federal policy emphasized the physical relocation of Indians from reservation to urban areas.
1968 – Present: Self-Determination Period: A resurgence of tribal government involvement in Congress and in the federal courts ended the termination era and promoted the development of a policy self-determination and self-governance. With the Education Assistance Act of 1975 tribes began to rise up and take control over their own destinies.
Current Health Trends
Health Facts

- Estimated 5.2 million people in the U.S. that identified as a NA in 2010 census
- 15% increase in life span over past 30 years
- Life expectancy for NA is 7 years less than for Caucasians living in the USA
- Death rates are much higher than the average populations including all ethnicities
Native Youth

- Considered the highest risk population in America

- Youth reside on reservations which are socially isolated from the mainstream culture

- 50% of native youth graduate high school nationwide

- 15% are involved in gang activity compared to 8% of Latino youth and 6% of African American youth
Statistical Percentages

- Alcoholism is 638% higher
- Tuberculosis is 400% higher
- Diabetes Mellitus is 291% higher
- Unintentional injury is 215% higher
- Suicide is 91% higher
- Homicide is 81% higher

- Large portion of deaths occur between the ages of 15 – 50 years of age
Major Mortality Risks

- Chronic liver disease
- Cirrhosis
- Diabetes mellitus
- Unintentional injuries (MVA & Hypothermia)
- Homicide
- Suicide
- Chronic lower respiratory disease
- NA living with more chronic illnesses and have less access to health care for many reasons
Indian Health Services

“Health Services provided by the federal government for Indian people are not a gift. They are the result of business arrangements between two parties that resulted in a pre-paid health plan. The health plan was prepaid by cession for their entire lands…”

Insurance coverage in 2010
- 36% of Native Americans had private health insurance coverage
- 24% relied on Medicaid coverage
- 33% had no health insurance coverage
## Resource Disparities

### Per Capita Medical Expense in Federal Budget

<table>
<thead>
<tr>
<th>Program</th>
<th>Expense</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid Recipients</td>
<td>$5010</td>
</tr>
<tr>
<td>VA Beneficiaries</td>
<td>$5234</td>
</tr>
<tr>
<td>Medicare</td>
<td>$7631</td>
</tr>
<tr>
<td>Bureau of Prisons</td>
<td>$3985</td>
</tr>
<tr>
<td>Indian Health Services</td>
<td>$2130</td>
</tr>
</tbody>
</table>
“Patients and families are faced with many difficult challenges at the end of life. Not only are they faced with the unknown of the disease process and the dying process, they are often thrust into the unfamiliar realm of healthcare with its medical jargon and constant requests for care decisions.”

No matter what beliefs or cultural values a person or family holds, death is a difficult transition.

Practitioners then face the challenge of meeting both the physical and cultural needs of their patients at this transition.
Elders
  - Matriarchal

Familial Ties
  - Differing lineage

Privacy
  - May not share news patient or family

Group Decision
  - Family members to be involved in medical decision making
Evidence Shows...

- Majority of tribes do not talk about terminal illness for fear that talking about it will cause it to happen

- A study was done and 86% of Native Americans interviewed considered advance care planning a dangerous violation of traditional Navajo values

- “culturally offensive and potentially harmful”
Common Errors

- Talk to much
  - More than 50% = dominating conversation

- Make Assumptions
  - Safer to ask questions

- Meeting run on too long
  - Over an hour
  - No clear general goal
What should I do in practice?

- Approach with a spirit of inquiry
- Listen carefully
- Ask the right questions
- Negotiate treatment plan
Rituals

- Blessings
  - Cedar or sage smoke
- Paintings
  - Cheyenne's do after death
- Children involved, siblings
  - Bathing, Dressing
- Wake
  - Back to the home or church night before burial family stays up all night - prayers, songs, stories
- Burning of personal belongings
  - Mattress, clothing, etc
- Burial time
  - Some need to be buried within time frame
Algorithm for Palliative Care in Native Americans

- Determine tribal affiliation of the dying individual and his/her family and their 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
Summary

- Culture expands beyond ethnicity.
- Native American population is regionally/nationally widely diverse.
- There has been recent historical trauma that has affected the view mainstream society.
- Considerations of the cultural diversity and trust issues is important when addressing palliative and end of life.