

Cultural Relevancy of Palliative & End-of-Life Care: Conversations with Indigenous Elders

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Faculty Disclosures

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Objectives

The learner will be able to:

- Articulate the challenges for establishing palliative/end-of-life care programs in reservation communities.
- Describe culturally appropriate approaches needed to discuss advance directives and advance care planning with Indigenous elders.

The Reality of Disparity

- Native American/ American Indian (NA/ AI) Statistics
- Nationally:
 - Diabetes – 2.3 times
 - Obesity – 1.6 times¹
- South Dakota specific:
 - Diabetes – 12.2% / 6.6% / 5.7%
 - Obesity – 39.8% / 28.3% / 32.2%^{2,3}





Heart
Disease^{5,6}



Cancer^{5,6}



Diabetes⁷



Alcoholism⁷

Death

Access to Care

Palliative & End-of Life Care⁸

0.3%--AI/AN⁹

80.9%--Caucasian⁹



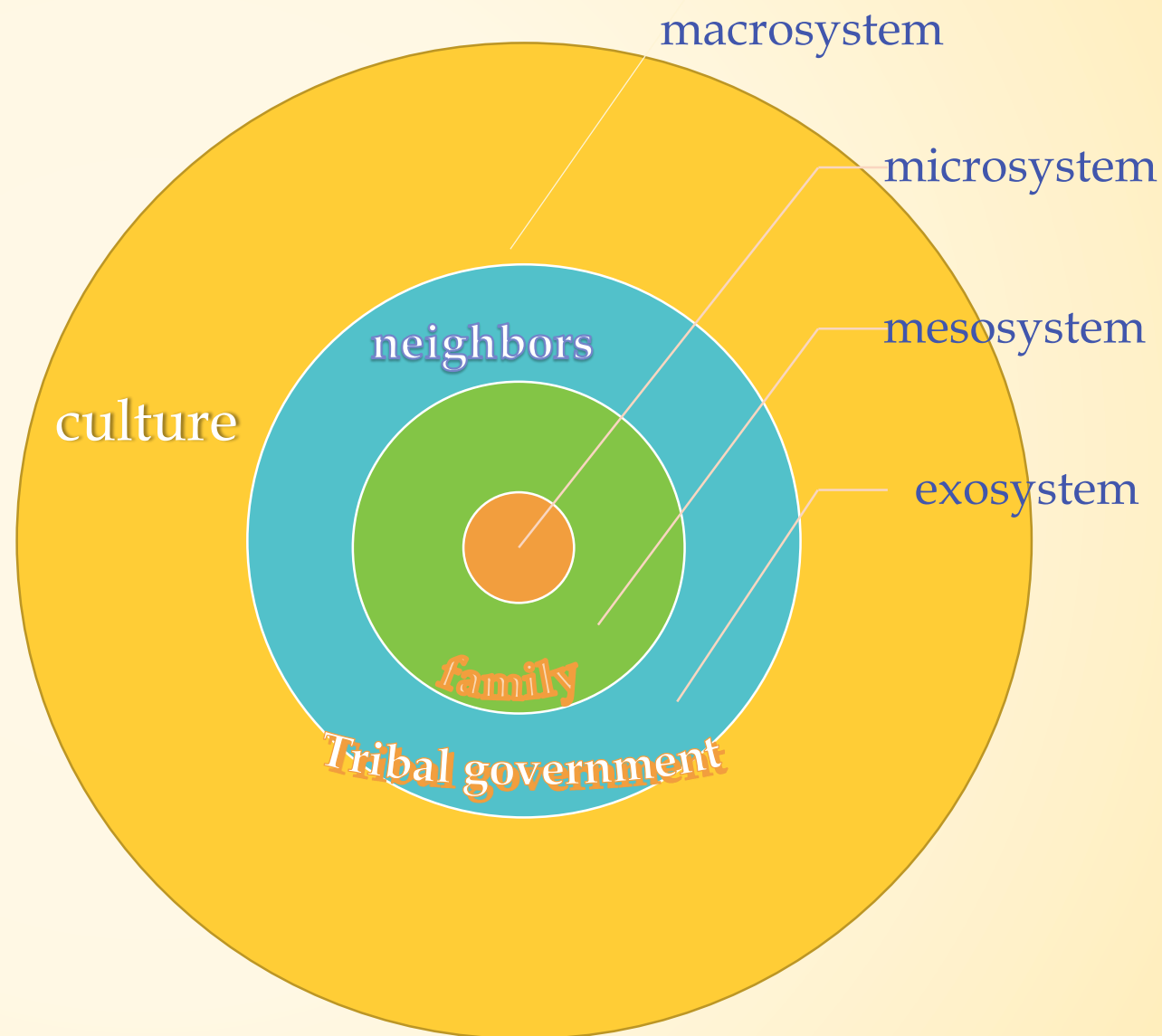


Purpose

Share findings from a collaborative study with NA/AI elders and health educators regarding palliative and end-of-life (EOL) care and the preliminary framework of a culturally relevant palliative care program.

Design

- Community-based participatory research (CBPR)
- Ecological Systems Theory (EST)^{13,14}
- Research Questions:
 - What is palliative/EOL care?
 - What are the advantages/disadvantages to establishing palliative/EOL care on the reservation?



Focus Groups



- First gathering:
 - What is palliative care?
- Second gathering:
 - Application of 4 components of palliative care.
- Third
 - Application to National Consensus Project guidelines.
- Fourth
 - Soothing feelings.
- Final
 - Synthesis of meetings to unified whole.

Findings



Opportunities

- Mandatory cultural awareness training for ALL Indian Health Service (IHS) employees.
- Exploration of tele-health capabilities.
- Establishment of a homecare program.
- Palliative/EOL training for IHS personnel.
- Advance directive education for elders.

Opportunities

- Cultural Awareness
 - “When you understand the language, you understand that way of life. Through that you can understand or help the person in hospice.”
 - “You have to understand where they came from...they (non-Indians) realize what happened to the Indigenous population and that we are still healing...these are the things that we see because of that today...the alcohol, the drugs, the high suicide rates, the child abuse...this all adds up because of historical trauma.”
 - Dakota’s Story



Opportunities continued...



- **Advance Directive Education**
 - “As it is families go through a hardship losing a loved one. It’s tough, but I see in my time, everything was done culturally and families came to agreement and they take care of[it] the way it should be done. They all sat down...Last week there was a 3 day court hearing...some had to be escorted from the courtroom. This isn’t the Lakota way.”
 - “I think the living will belongs in a larger audience where elders gather.”
 - It needs to be determined at the first visit who in the family is the primary decision maker, when the patient does not wish to make decisions or no longer able to make decisions.

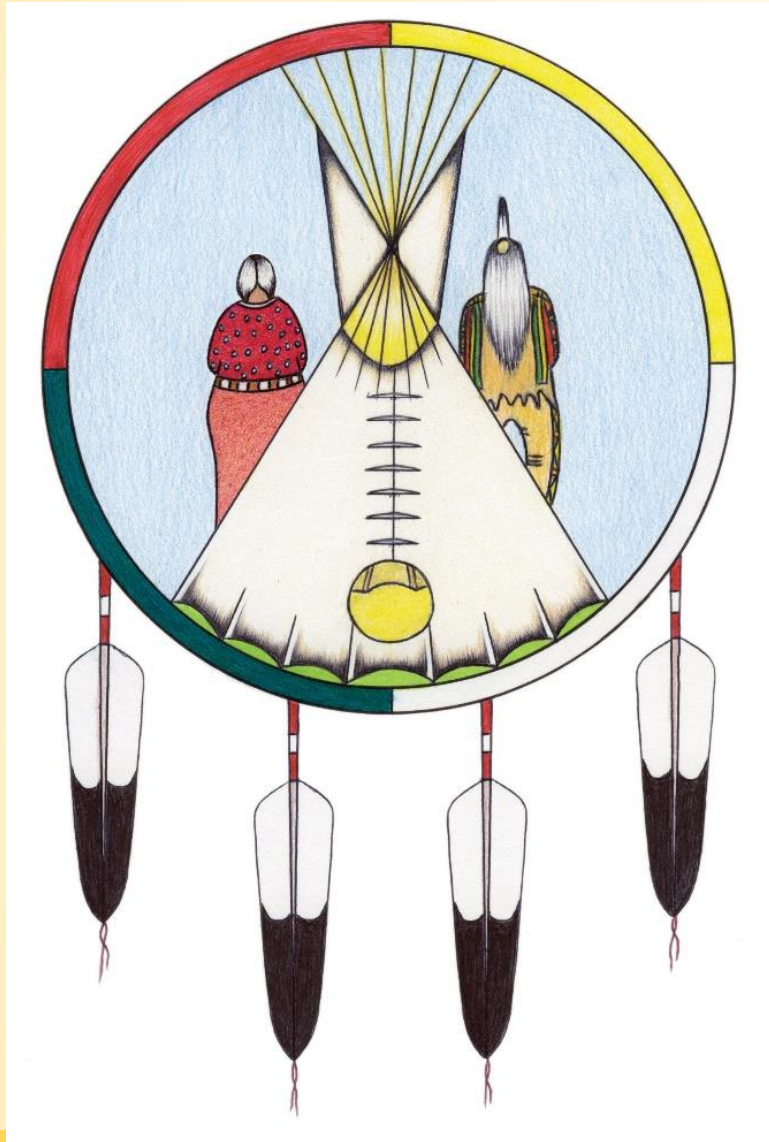
Challenges



Discussion

- CBPR/EST Design
 - Philosophical underpinnings of hospice/palliative care with participants.
 - Determining if hospice/palliative care was culturally congruent with the Lakota way of life.
- What did I need to understand?
 - Tribal Council issues and realities.
 - Sovereign Nation status
 - Tribal relations with Indian Health Service

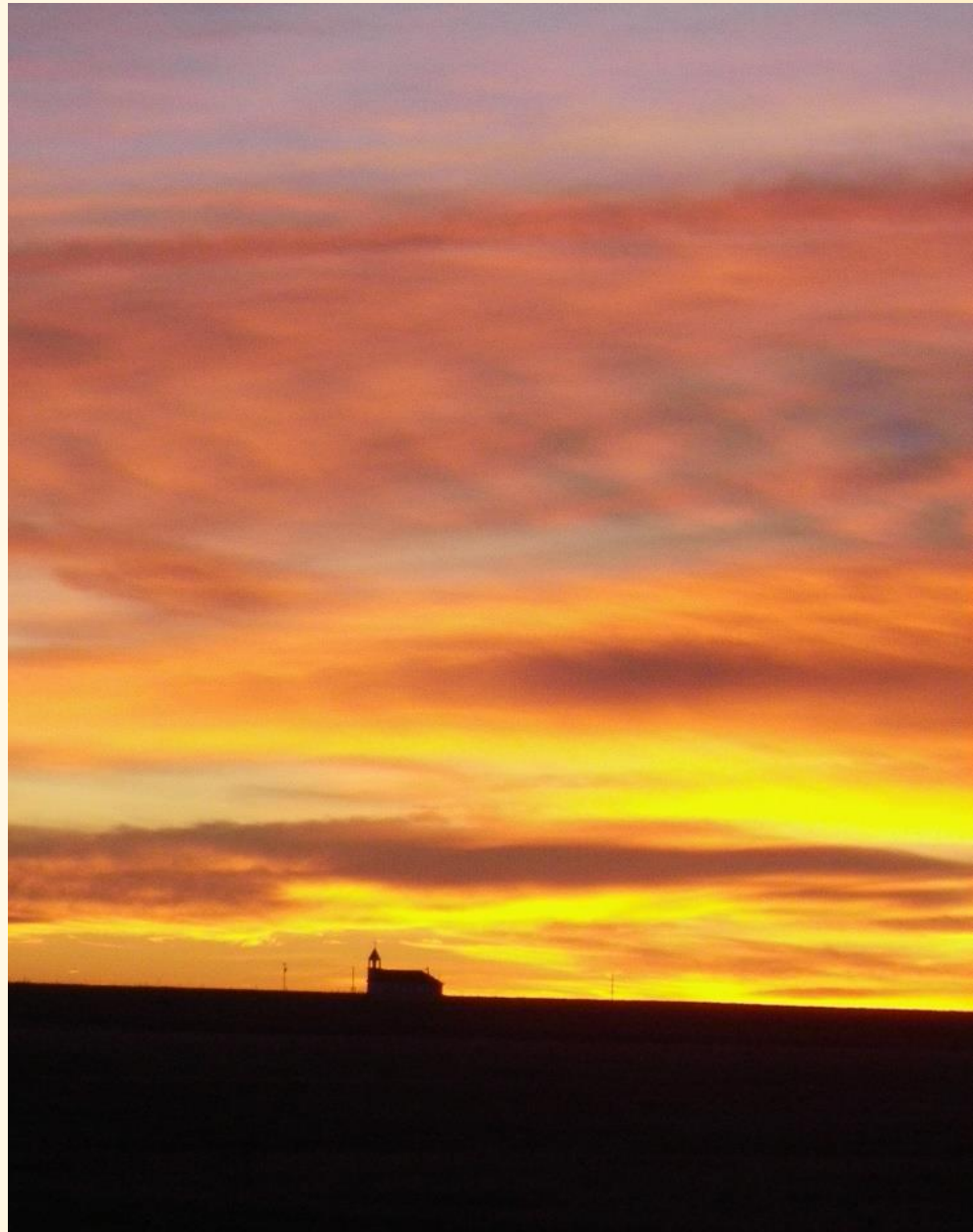
Conclusion



- Palliative & hospice care is possible if program design is done in collaboration WITH the community, incorporating the NCP *Clinical Practice Guidelines*.¹⁵
- Wakanki Ewastepikte — “Care for Our Elders”
 - An elder driven advance directive education program.

Questions

“I will always have
Tunkashila with me.
That’s all I need.
When I die, I don’t
want nobody fighting
or nothing, you know,
because everything is
already taken care
of.”



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