

What is ACCORDS?

Adult and Child Center for Outcomes Research and Delivery Science

ACCORDS is a ‘one-stop shop’ for pragmatic research:

- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally

ACCORDS Upcoming Events – mark your calendars!

| | |
|-----------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| January | <ul style="list-style-type: none">• January 15 – D&I Science Graduate Certificate application launch• January 28 – ACCORDS/CCTSI Community Engagement Forum – <i>Engaging Community in Data Analysis and Interpretation</i> |
| May 20-21, 2026 | <p>Colorado Pragmatic Research in Health Conference <i>Pragmatic Research: Methods, Tools, and Technology for Rapidly Changing Contexts</i></p> <p>Registration is live! Visit cprhcon.com for more info.</p> <p><u>*New to COPRH Con*</u> Pre-conference workshops:</p> <ul style="list-style-type: none">• Pragmatic Research Planning• Planning for a Competitive Career Development Award: A Roadmap for Health Services Researchers• Mixed Methods Design & Integration Training for Health Services Research• Design for Innovation: Practical Use of User-Centered Design• AI Essentials for Health Services Researchers: Balancing Increased Productivity with Responsible Use• Elevating Research Project Management Practice• Dissemination in the Age of AI: Design Tools at Your Fingertip |

ACCORDS Grand Rounds



Draping the Star Quilt: Developing a Palliative Care Community Health Worker Intervention in American Indian Reservation Communities

Bethany-Rose Daubman, MD
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Program at Massachusetts
General Hospital

Draping the Star Quilt: Lessons Learned from an American Indian Palliative Care (PC) Community Health Worker Program

Bethany-Rose (BR) Daubman, MD

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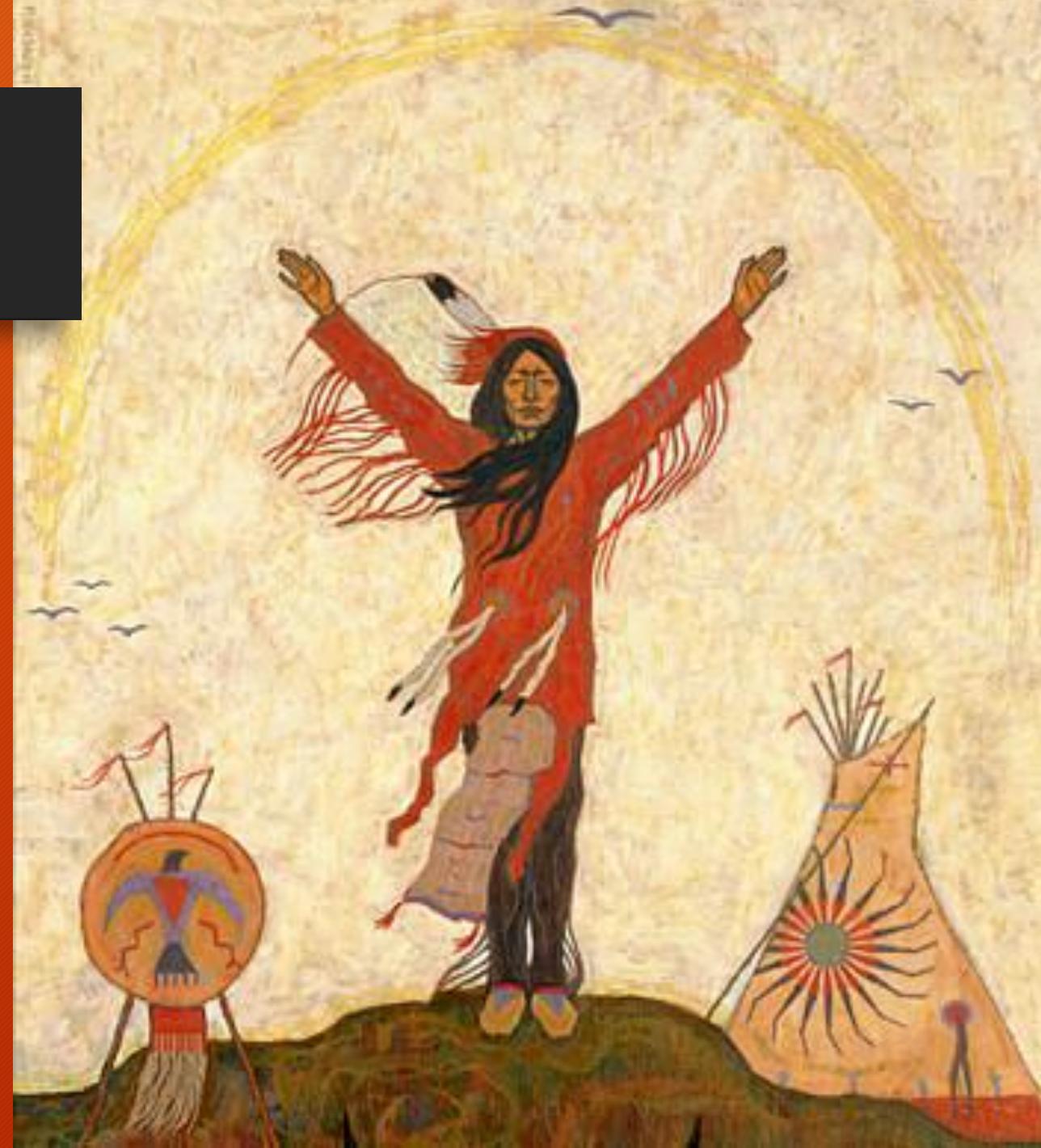
Objectives

Use a case-based example to discuss how community-based participatory research can be a powerful tool to advance care in disenfranchised communities

Consider inclusion of a wider team than is traditionally represented in research/clinical care when developing care in disenfranchised communities such as American Indians

Acknowledgements

- Paige Fast Wolf
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- Mary J. Isaacson, PhD, RN, RHNC, CHPN, FPCN
- JR LaPlante, JD
- Sara Purvis, MPH



Two things to note...

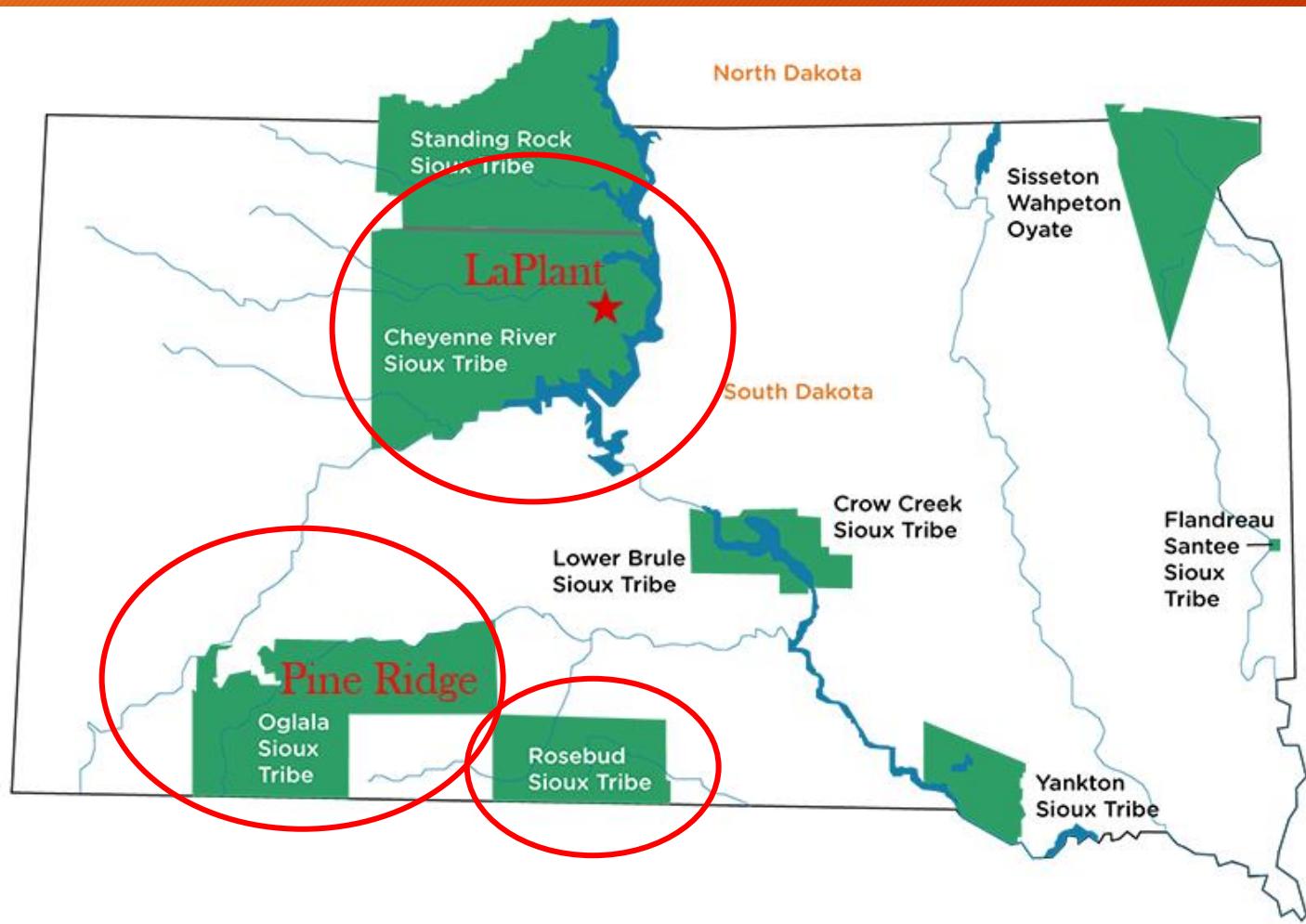
- Definition of palliative care
- Stories vs data



Lakota artist Derek "Focus" Smith

Lakota Nation





Palliative Care Access

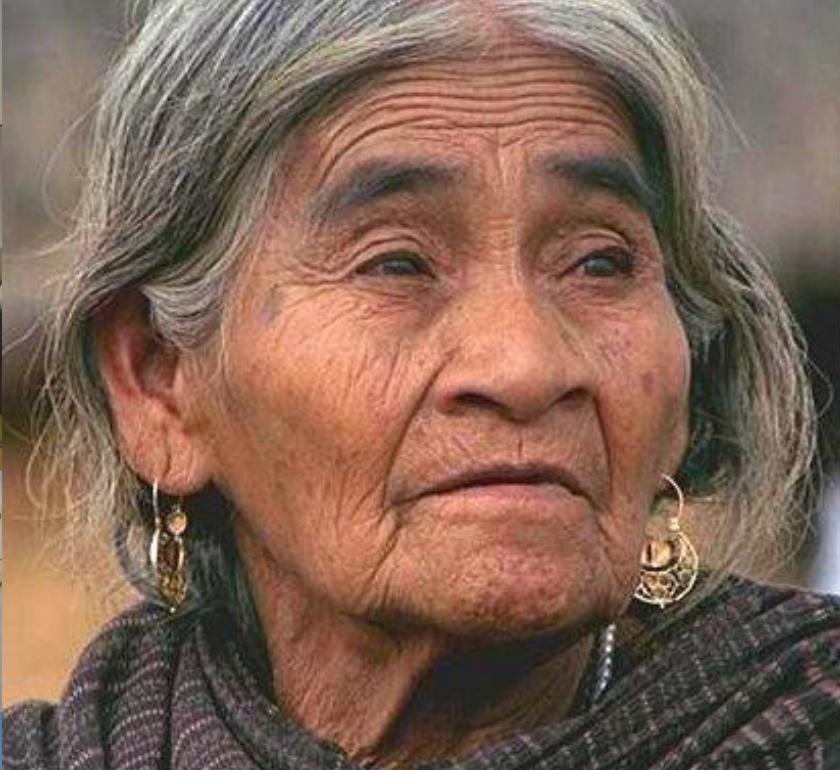
- Does it exist?
- Is it accessible?
- Is it culturally responsive?



American Indian Health Outcomes

- Higher rates of many cancers
 - Diagnosed at more advanced stages
 - Higher mortality rates
- Greater incidence of heart, kidney, and liver disease
- Less access to high-quality care
- Geographic challenges to accessing care
- Poverty
- Lack of culturally responsive healthcare
- Historical and ongoing trauma









Exploring Palliative Care Program Implementation for American Indian and Alaska Natives throughout the US

Table 2. Interviewee Role, Palliative Care Delivery Model, and Entity Involved in Palliative Care Program Administration

| Interviewee role | PC delivery models ^a | Entity involved in PC ^a |
|------------------------------------|---------------------------------|---------------------------------------------|
| Physician (<i>n</i> = 7) | HBC (<i>n</i> = 5) | Tribally owned hospital/org (<i>n</i> = 6) |
| Administrator (<i>n</i> = 3) | IS (<i>n</i> = 4) | IHS hospital (<i>n</i> = 3) |
| Social worker (<i>n</i> = 1) | OC (<i>n</i> = 2) | Nontribal PC agency (<i>n</i> = 1) |
| Nurse practitioner (<i>n</i> = 1) | HS (<i>n</i> = 2) | Academic medical center (<i>n</i> = 1) |

^a Several of the nine programs utilized more than one model and entity to deliver PC services; numbers do not add up to nine.

HBC, home-based care; HS, hospice; IHS, Indian Health Service; IS, inpatient services; OC, outpatient clinic; PC, palliative care.

Exploring Palliative Care Program Implementation for American Indian and Alaska Natives throughout the US

- **Facilitators of implementation included:**

- a high tension for change
- effort of champions
- use of existing resources
- engaging community
- consideration of cultural values
- and the presence of Native staff

- **Barriers to sustainability included:**

- administrative leadership support
- dependence on champions
- and high cost

| Program aggregate | Innovation characteristics | | | Outer setting | Inner setting | | | |
|-----------------------|----------------------------|----------------------------|------------------------------|---------------|--------------------|----------------------------|-------------------|-----------------------|
| | Cost | Culturally tailored design | Knowledge of needs+resources | | Tension for change | Compatibility with culture | Relative priority | Leadership engagement |
| Sustained (n = 5) | + | ++ | ++ | ++ | ++ | ++ | ++ | ++ |
| Not sustained (n = 4) | - | ++ | ++ | ++ | ++ | ++ | -- | -- |



Exploring Factors Influencing Palliative Care Access for Great Plains American Indians

- Qualitative study interviewing 38 individuals working at 5 regional cancer centers (specialty clinicians) and 3 IHS service units (primary clinicians) in the Great Plains
- Broad themes identified included:
 - Healthcare system operations
 - Geography
 - Workforce elements
 - Historical trauma and racism



R01 Talking Circles and Interviews

Daubman BR, Duran T, Johnson G, Soltoff A, Purvis SJ, LaPlante LJR, Jackson S, Petereit D, Tobey M, Armstrong K, Isaacson MJ. "Are They Just Experimenting With All of Us?" Cultural Considerations for Clinicians Caring for Seriously Ill Great Plains American Indians. *Am J Hosp Palliat Care*. 2025 Mar 14:10499091251327404.

Isaacson MJ, Duran T, Johnson GR, Soltoff A, Jackson SM, Purvis SJ, Sargent M, LaPlante JR, Petereit DG, Armstrong K, Daubman BR. Great Plains American Indians' Perspectives on Patient and Family Needs Throughout the Cancer Journey. *Oncol Nurs Forum*. 2023 Apr 21;50(3):279-289.

Isaacson MJ, Duran T, Johnson G, Soltoff A, Jackson S, Petereit D, Armstrong K, Daubman BR. "Calling the Spirit Back:" Spiritual Needs Among Great Plains American Indians. *J Pain Symptom Manage*. 2022 May 23:S0885-3924(22)00718-7.

Daubman BR, Duran T, Johnson G, Soltoff A, Purvis S, Sargent M, LaPlante JR, Petereit D, Armstrong K, Isaacson MJ. "You Can't Record That!" Engaging American Indian Traditional Healers in Qualitative Research. *J Pain Symptom Manage*. 2023 Jan 20:S0885-3924(23)00033-7.



Overarching Themes

- Native-led
- Involving accompaniment for both patient and caregiver
- Adapted to fit the needs of each reservation
- Incorporating traditional spiritual practices

"Lakota Women" by Linda Haukaas



JR LaPlante, JD R01 Co-Investigator



Community-Based Participatory Research Focus

- Interviews with American Indian/Alaska Native PC Leaders Nationally
- IHS and Specialty Provider Interviews
- Talking Circles
- Traditional Healer Interviews
- Tribal Leader Interviews
- Lakota Community Advisory Boards
- Meeting with Community Health Workers (CHWs)
- Developing a CHW PC Training Curriculum
- CHW PC Clinical Trial





Palliative Care: the
origin

PALLIARE (LATIN): “TO CLOAK”

Strength in Partnerships

- Interdisciplinary R01 team (clinicians and researchers)
- Native and non-Native partners
- Community Advisory Boards
- Tribal leaders
- Traditional healers
- A judge



Adding to the team....

- Community Health Workers, or **Wawokiya** Health Advocates

Wa- something good, natural, and pure

Wo- doing something collectively

Ki- with

Ya- a journey



Ledger art by Evans Flammond, Sr.

Wawokiya Health Advocate Training Modalities

Virtual Modules

In-Person 2 Day Training

Shadowing Interdisciplinary Team in Palliative Care Clinic

Team Debrief

Weekly Case Conferences/Check-ins

Everyone
Teaches,
Everyone
Learns

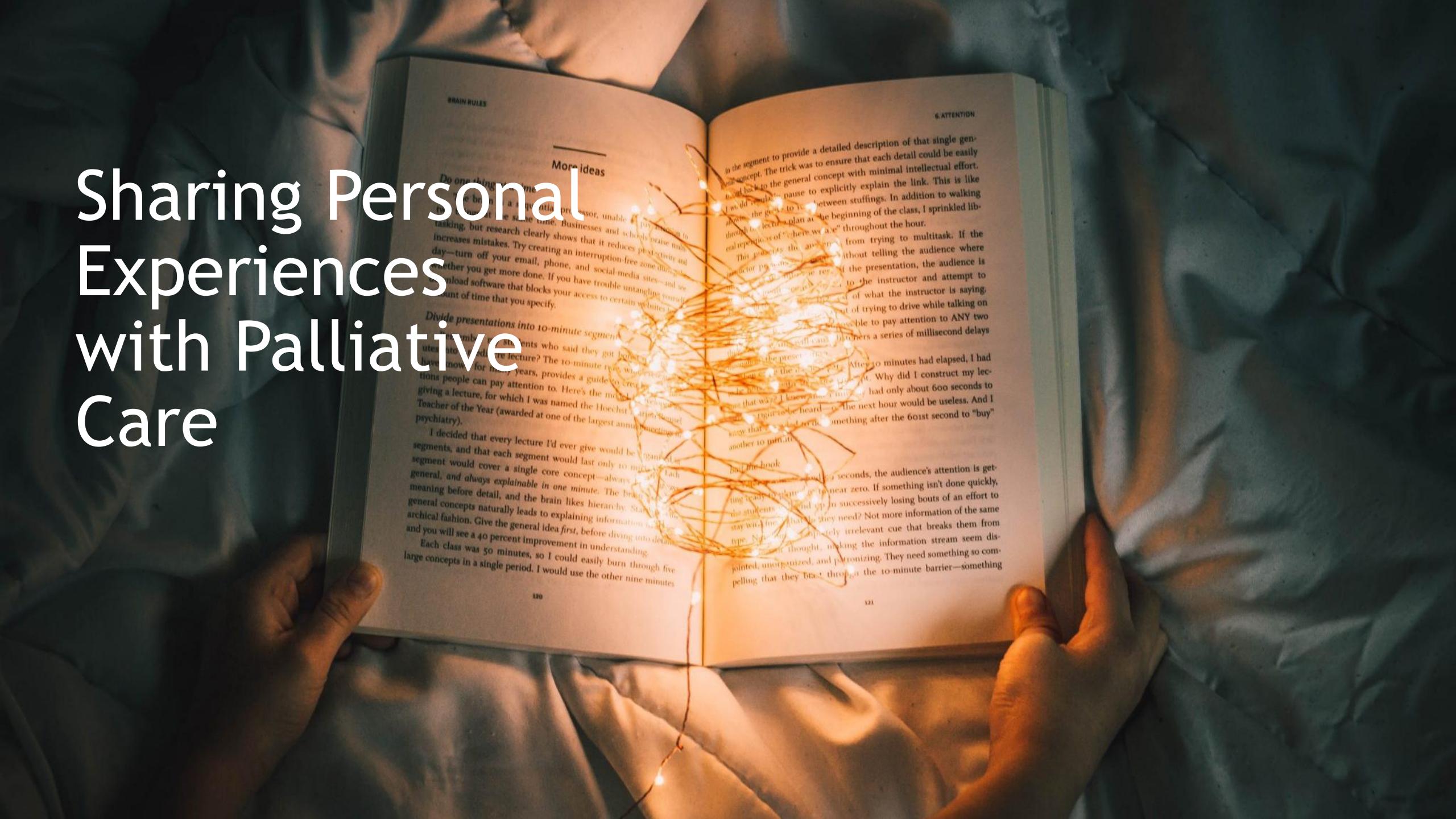


Acknowledging Wakhuza

Art by Genevieve Bluebird



Sharing Personal Experiences with Palliative Care



Virtual Modules

7 modules, completed asynchronously

Roughly based on:

- Clinical Practice Guidelines for Quality Palliative Care
(Ed4) <https://www.nationalcoalitionhpc.org/ncp/>
- Pallium India CHW training program

Everyone Teaches, Everyone Learns:

- Lakota elder co-teachers as well as MD and RN educators
- Reflection Questions and Case Exercises after each module

Module 1: What is Palliative Care?

Module 2:
Community Participation in Palliative Care & Role of the WHA

Module 3: Physical Needs in Palliative Care

Module 4: Emotional Needs in Palliative Care

Module 5: Spiritual & Religious Needs in Palliative Care

Module 6: Social Needs in Palliative Care

Module 7: Safety in the WHA Visits

Community Advisory
Board Member
Angela Stover
Introducing
Palliative Care



2 Day In-Person Workshop

Presentations, including co-teaching from Lakota elders via video

Group discussion

Role-play scenarios

Prayer

Flexibility in responding to community member's needs





Next Steps in Training



Refresher Trainings



Team Debrief after Clinical Shadowing



Weekly Case Conferences/Check-ins



**Wawokiya Health
Advocate:
Paige Fast Wolf**

Exploring Sustainability and Burnout in Palliative Care Wawokiya Health Advocates



Exploring Sustainability and Burnout in Wawokiya Health Advocates

Weekly interdisciplinary calls with additional training

Offers of joint visits

Offers of referral to specialty palliative care

Surveys on burnout

Creative scheduling

Brainstorming solutions together

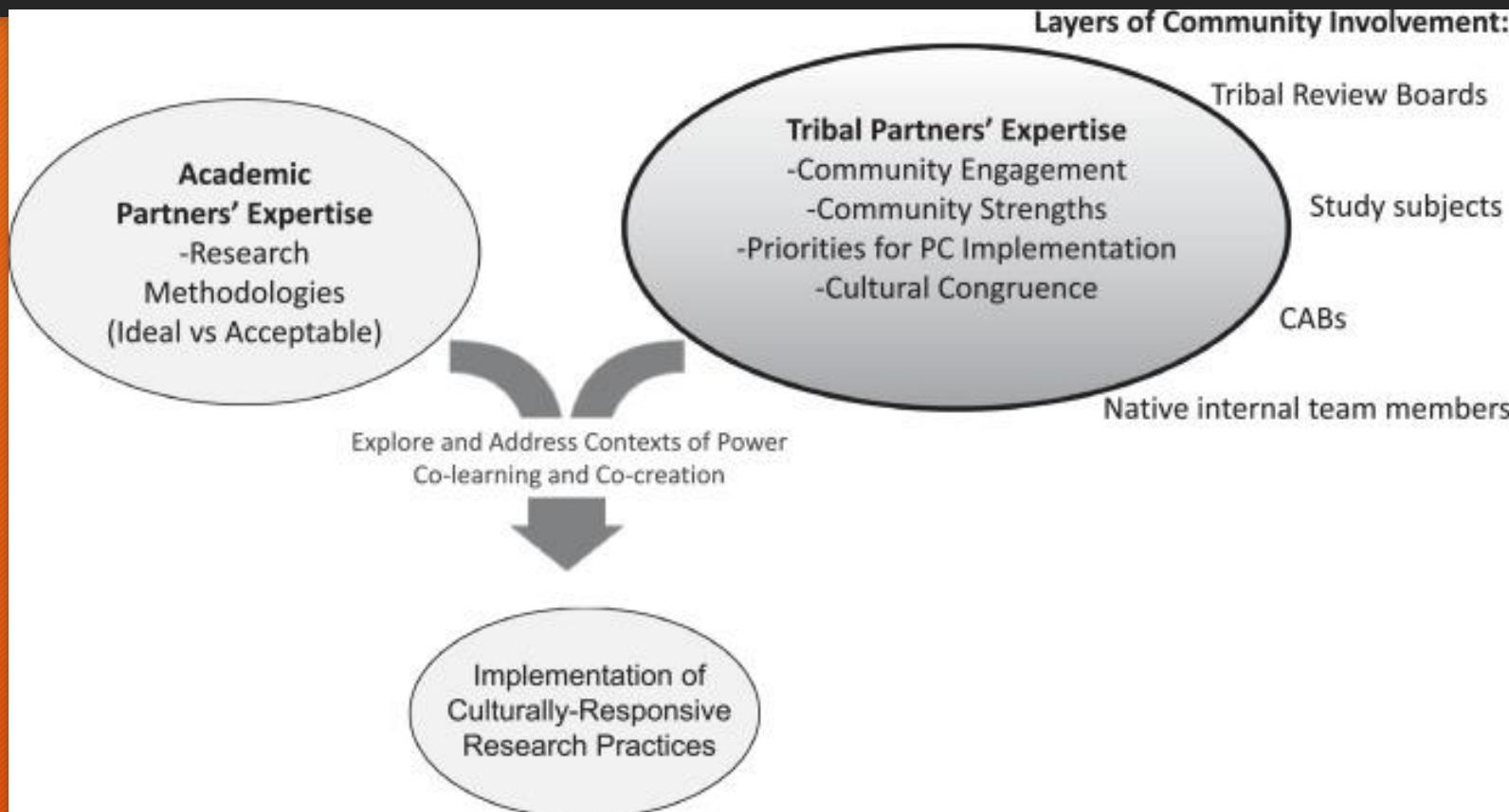


Heal the Healers retreat

- Suggested by one of our Wawokiya Health Advocates
- Led by a Tribal leader who is a social worker and a Tribal elder
- Exploration of traditional healing practices, self-care, grief and bereavement practices



Research processes development model for Tribal-academic research partnerships



Patient Interviews at Study Conclusion



Has [WHA] been helpful
to you?

Yes-7, No-0



Has [WHA] been helpful
to your family?

Yes- 6, No-1



How helpful? (Likert
scale: Very unhelpful,
somewhat unhelpful,
neutral, somewhat
helpful, very helpful)

All said Very
Helpful

Patient Interviews at Study Conclusion

Has [WHA] been able to connect you to any resources/people?

Yes-6, No-1

Were you connected to any resources that were not helpful?

No- 6, Yes-1

How satisfied have you been with your visits? (Likert scale: Very unsatisfied, somewhat unsatisfied, neutral, somewhat satisfied, very satisfied)

All said Very Satisfied

Themes from the interviews with representative quotes



Wawokiyas helping with Resources

- “I mean, she’s not knowledgeable medically, but she’s knowledgeable with, like you said, trying to find resources for us. She’s knowledgeable with IHS, the Tribe’s help or stuff like that.”
- “..she’s helping me with my house, so that’s very helpful. Because I don’t have a job. So, the added help that she helped get for my money and for mileage and stuff, that helps my family as well because my parents were the ones who were paying for everything before.”
- “Even the gift certificates that I get from doing these surveys have really helped, especially in a time where we didn’t have no gas money or maybe it came in a time where I didn’t know how I was going to get supper that night. So, I mean, it has really helped in that way as well.”

Wawokiyas helping with Advocacy and Education

- “She just sat us down, explained things to them about cancer patients.”
- “Yes, it was ‘cause they didn’t understand why I was always full of anxiety and stuff like that.”
- “She called the hospital for me one day.”

Wawokiyas helping with Accompaniment

- “sometimes she’s the only person I see all day beyond my grandson... I’m pretty much a shut in because of my blood from the surgeries. It’s good to see her. She’s a nice person.”
- “.. it’s good to talk about things too. You don’t really have anybody to talk to about that kind of stuff.”
- “She listens whenever I’m having a bad day or if I don’t have anybody to talk to, she – she just checks on me. She would just call and is always asking if I’m okay and if I need anything that she can help me with.”

Sub-theme: Emotional Support from Unexpected Sources- Study Paperwork

- “..I was really, really impressed with the manner in which the language, the Lakota language was implemented into the paperwork that they gave me. The - like the information. There was a lot of Lakota language incorporated into that. For me, it was really comforting and really special to see that. **It made it feel more spiritual in a sense because I know it's sacred and you feel it when you hear it spoken.**
- When you're going through things like that you get a lot of medical terminologies, jargons thrown at you. Then to see this program and you open up that folder that they give you and **there's this paperwork in there and it's in Lakota but it's talking about your cancer.** It's like, “Man, this feels good.” You know? So, I really, really appreciated that...
- With that cultural component with our people and our ways is that we always share that compassion with one another and ..people whenever they're going through difficult times and that was really helpful.”



Relevance of Community Health Worker Sustainability Beyond Tribal Communities



LOCATION OF NATIVE AMERICAN RESERVATIONS, ALASKA NATIVE AREAS, AND HAWAIIAN HOME LANDS

CANADA

Washington

oregon

Montana

Idaho

Wyoming

++ Nevada

Utah

Colorado

California

Arizona

New Mexico

PACIFIC OCEAN

braska

Kansas

Oklahoma

Texas

MEXICO

Alaska

CANADA

A scale bar with two sets of markings. The top set, labeled 'm', shows 0, 150, and 300. The bottom set, labeled 'km', shows 0, 225, and 450. The scale is non-uniform, with larger increments between 0-150 and 150-300 compared to 0-225 and 225-450.

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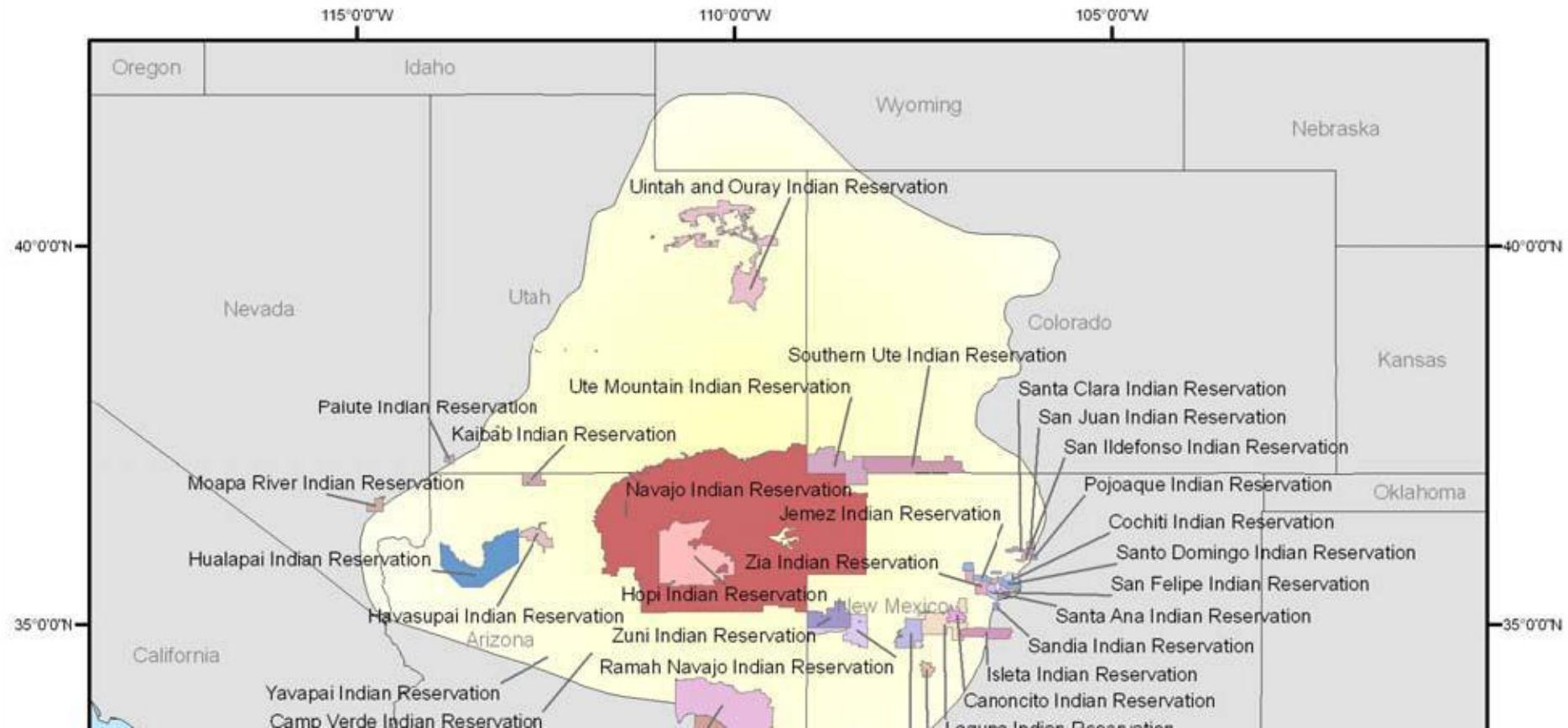
PACIFIC OCEAN

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CUBA 0 125 250 mi

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Native American Reservations Located on the Colorado Plateau



Draping the Star Quilt Together

- Community-based participatory research can be a powerful tool to advance palliative care in disenfranchised communities
- Consider inclusion of a wider team than is traditionally represented in research/clinical care when developing palliative care in disenfranchised communities



Wopila Tanka (Thank you)

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