Addressing Dementia Syndromes in Native American Communities

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Disclosures and Disclaimer

• No industry disclosures to report.

• The opinions expressed in this talk are the presenters and do not represent policy or position of the Indian Health Service (IHS) or the Center for Medicare and Medicaid Services (CMS).

• The presenter does have high degree of confidence, based in available evidence, that a capable platform of primary care integrated with community-based services and supported by accessible specialty services is the foundation of a health system capable of providing better patient care and improved health outcomes at lower cost.
To address these **Objectives**...

- Discuss cultural and health system factors in the development and delivery of services for individuals with dementia syndromes in American Indian and Alaska Native communities.
- Discuss strategies to adapt language for communication about dementia syndromes in American Indian and Alaska Native communities.

- **We will....**

  - Briefly review the orientation to the Indian Health system: Indian Health Service, Tribal, and Urban Indian Health programs.

  - Integrate a review of the published literature and clinical experience to suggest a practical approach to care of American Indians and Alaska Natives (AI/AN) with dementia syndromes (Alzheimer’s disease and related dementias).
Study the world, then study the literature

Advice for PhD Students
attributed to
Richard Thaler, PhD
2017 Nobel Laureate in Economics
“Now, at times, she thinks that Dad is out fishing and will be home soon. In some ways, this is good, because she does not always have to know that he is gone, and continuously have to suffer the pain that loss can bring after a lifetime like theirs together.

But there are many times that she is totally lucent and knows that he is not with her, but is waiting for her to be with him when her times comes too. We have as a family kept Nana in her home, in the surroundings most familiar to her.

There, every day she is close to all of her family who love her and accept her, wherever she may be mentally. She knows that she is home, and that she is safe and loved, despite her confusion.”

Introduction to the IHS

- Comprehensive health service delivery system
- Serves 2.2 million American Indians and Alaska Natives
- Serves 567 federally recognized tribes
- Twelve Areas and Headquarters
- FY 2017 appropriations - $5.0 billion

<table>
<thead>
<tr>
<th></th>
<th>Hospitals</th>
<th>Health Centers</th>
<th>Alaska Village Clinics</th>
<th>Health Stations</th>
</tr>
</thead>
<tbody>
<tr>
<td>IHS</td>
<td>26</td>
<td>59</td>
<td>N/A</td>
<td>32</td>
</tr>
<tr>
<td>Tribal</td>
<td>19</td>
<td>284</td>
<td>163</td>
<td>79</td>
</tr>
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</table>

IHS Mission: To raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level.
IHS Areas
Long –Term Services and Supports

Sec 124 (1621d) of the *Indian Health Care Improvement Act* within the *Patient Protection and Affordable Care Act*:

Other Authority for Provision of Services, Shared Services for Long-Term Care

The Secretary, acting through the Service, Indian tribes, and tribal organizations, may provide funding under this Act...for the following services:

1. Hospice Care
2. Assisted living services
3. Long-term care services
4. Home- and community-based services

But...no new funds authorized specifically for these services
Epidemiology of Dementia in Indian Country
Prevalence and Incidence of Dementia in American Indians and Alaska Natives

“Reliable data on the prevalence or incidence of dementia among populations who identify themselves as American Indian or Alaska Native in the United States are nonexistent.”

“...only a few researchers have attempted to study cognitive status among small samples of American Indian elders, none of which provided prevalence or incidence estimates”

- Mehta and Yeo Epub 2016

Kaiser Permanente Northern California
Dementia Incidence Rates 2000-2013

• KNPC members enrolled and 60 years and older as of 1/1/96

• KNPC seniors (65 years and older) are similar to general population of seniors in Northern CA: hx chronic conditions, lifestyle factors, and patterns of racial inequality (CHIS data)

• No dementia diagnosis as of 1/1/2000
• Incident cases between 1/1/2000 and 12/31/2013.

Not a population-based study
Self-identified AI/AN

Incidence among self-identified American Indians and Alaska Natives is second only to incidence among African-Americans.

<table>
<thead>
<tr>
<th>Race / Ethnicity</th>
<th>Age-adjusted Incidence Rate/1000 person-years (95% CI)</th>
<th>Hazard Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>African-American</td>
<td>26.60 (25.83-27.37)</td>
<td>1.73 - 1.65</td>
</tr>
<tr>
<td>American Indian / Alaska Native</td>
<td>22.18 (20.85-23.52)</td>
<td>1.32 - 1.43</td>
</tr>
<tr>
<td>Latino</td>
<td>19.59 (18.97–20.20)</td>
<td>1.24 – 1.29</td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>19.63 (14.51–24.75)</td>
<td>1.23 – 1.28</td>
</tr>
<tr>
<td>White</td>
<td>19.35 (19.16–19.54)</td>
<td>1.22 – 1.25</td>
</tr>
<tr>
<td>Asian-American</td>
<td>15.24 (14.73-15.74)</td>
<td>1.00 (reference)</td>
</tr>
</tbody>
</table>


- Aggregate data from Alberta Health and Wellness
- Physician-treated dementia
- Age-adjusted Prevalence

First Nations: 7.5/1000 (95% CI: 6.6-8.5)
Non First Nations: 5.6 (95% CI: 5.5-5.6)

Disproportionately younger and male in First Nations

*The emergence of dementia as a health concern among First Nations populations in Alberta, Canada.*
Trends in Indian Health 2014

Population-based risk factors

<table>
<thead>
<tr>
<th>Condition</th>
<th>Ratio: AI/AN to U.S. All Races</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>2.5</td>
</tr>
<tr>
<td>Unintentional injury</td>
<td>2.5</td>
</tr>
<tr>
<td>Nephritis, nephrotic syndrome</td>
<td>1.5</td>
</tr>
<tr>
<td>Chronic liver disease and cirrhosis</td>
<td>4.8</td>
</tr>
<tr>
<td>Cerebrovascular Diseases (stroke)</td>
<td>1.0</td>
</tr>
<tr>
<td>Hypertensive disease</td>
<td>1.0</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>0.7</td>
</tr>
</tbody>
</table>

https://www.ihs.gov/newsroom/factsheets/disparities/
In every region of IHS there are persons with dementia diagnoses.
“While reliable prevalence or incidence data on Alzheimer’s disease or other types of dementia in the American Indian and Alaska Native population are not currently available, we do know that in every Tribal community there are individuals with dementia and caregivers struggling to support them.”

BEFORE THE SPECIAL COMMITTEE ON AGING UNITED STATES SENATE
FIELD HEARING ON ALZHEIMER’S DISEASE:
A BIG SKY APPROACH TO A NATIONAL CHALLENGE BILLINGS, MT

Making the Diagnosis
From the literature

• A small series of articles about the use of video tele-conferencing (VTE) to support specialty diagnosis of dementia on the Choctaw and Cherokee Nations of Oklahoma (UT in Dallas) – in a research context.
  • Feasible, reliable – “...once cultural barriers are dealt with...”.
  • Didn’t overcome the major deterrent to clinic visits: transportation.

• A handful of articles, going back ~30 years, evaluating use of existing instruments in AI/AN elders
  • “...concluded that the examination of the possible effects of ethnicity, socioeconomic status, type/character of education, and language on MMSE and DRS-2 performance is essential in understanding cognitive test performance and developing culturally appropriate norms.”


• A relatively large literature on the comparative performance of a variety of instruments in a variety of populations.
Commonly used standard assessment instruments are affected by education level, language, sensory deficits, and normed to the dominant culture.

**Mini-Cog**
- Sensitivity for dementia: 76-99%
- Specificity: 89-93%

**Montreal Cognitive Assessment (MoCA)**
- Sensitivity: 90% for MCI, 100% for dementia
- Specificity: 87%

**St. Louis University Mental Status (SLUMS)**
- Sensitivity: 92% for MCI, 100% for dementia
- Specificity: 81%

Use them, but use them with judgment. Consider that they may be less specific in the AI/AN population than indicated in the published literature.
Experience of Dementia
What’s in the Literature?

Small set of studies over the past 20 years exploring AI/AN and First Nations conception of cognition and dementia

• Focus groups, talking circle, and structured interviews of elders and caregivers with capture of emergent themes.

Themes included:

• Normality of cognitive changes with aging.
• Change in culture linked to changes in health, including dementia
• Culturally based constructs for cognitive impairment and symptoms attributed to dementia.
• Preservation of the role and function of the elder.
What’s in the Literature?

Caregiving

• Small set of surveys, focus groups, and interviews over the past 20 years addressing attitudes toward caregiving and language of caregiving, effect of caregiving on the caregiver and cultural and geographic factors associated with caregiving.

Themes

• Caregiving as a role with expressed value in many Tribal communities.
• Impact of caregiving on HRQOL
• Avoidance of the language of burden
Let’s pull this together
KAER Toolkit
Gerontological Society of America (GSA)

• Approach and Tools for Primary Care Providers

• Developed by the GSA Workgroup on Cognitive Impairment Detection and Earlier Diagnosis

• Addressing the heterogeneity of population and disease.

or search for GSA KAER
KAER Toolkit

• **Kickstart the cognition conversation**
  - Talk about brain health
  - Observe for signs, symptoms of cognitive impairment
  - Listen for older adult and family concerns about cognition

• **Assess for Cognitive Impairment**
  - Brief cognitive test
  - Other structured assessments to detect cognitive impairment

• **Evaluate for Dementia**
  - Conduct or refer for diagnostic evaluation
  - Talk about the diagnosis

• **Refer for Community Resources**
  - Community resources and other resources
The KAER Approach in Indian Country

Kickstart the cognition conversation

• Talk about “brain health” in the context of the whole person and healthy life.
  o What’s good for the heart is good for the head.
  o Physical activity, health diet, healthy blood pressure, healthy sugar

• Look for signs, symptoms of cognitive impairment in function and management of health conditions.
  o Decreased involvement in community, family, or cultural activities, religious participation
  o Change in weight.
  o Difficulty managing chronic conditions.
  o Less likely to be asked directly about memory or cognition directly

• Focus on behaviors and function with family
  o Common - getting lost in familiar places, asking after someone who is gone, forgetting names of close family.
  o Watch for misattribution – he’s been “mean” or “stubborn” or ”mad”
  o Be alert to a tendency to minimize impairment and preserve elder competence.
The KAER Approach in Indian Country

Assess for Cognitive Impairment

• Incorporate a brief cognitive test into regular practice
  o Most experience is with the Mini-Cog.
  o Use words with emotional valence in normal life

• Assess function
  o ADLs, IADLs
  o Sometimes difficult to tease out why an elder may have relinquished a function to other family members.

• Assess for depression, anxiety

• Assess capabilities in self-management of chronic conditions
The KAER Approach in Indian Country

Evaluate for Dementia

• Use structured assessment tools
  - Experience with MOCA and SLUMS.
  - Modification of story in SLUMS for cultural relevance
  - Use norms carefully in making the diagnosis with attention to:
    - impact of culture and language, and education level
    - hearing, vision, test anxiety and discomfort

• Take time in making the diagnosis
  - Be willing to re-examine
  - Use evidence of cognitive impairment AND functional impairment
  - Be willing to reassess over time.
  - But MAKE A CALL each time, one way or the other – and reassess over time.

• Talk about the diagnosis with the elder and family
  - With language that acknowledge the continued important role of the elder in the life of family, community, and Tribe
The KAER Approach in Indian Country

Refer for Community Resources

• Tribal Senior Center (Title VI) and Senior Center caregiver programs
• Non-Tribal Services in the area
• Alzheimer’s Association
• VA resources if an eligible veteran

• Identify (and document) family and other support

• Refer or provide caregiver support
  o Evidence based programs (e.g. REACH, NYUCI)
  o REACH into Indian Country is now available in 50 Tribal communities through Public Health Nursing and Senior Center staff
Beyond KAER in Indian Country

• Offer treatment, with discussion of risks / benefits
  o Caregiver support services if available
  o Medication
    ▪ Engage family and patient in assessing utility.
    ▪ Assess baseline with patient and family before starting (function and behavioral symptoms), and discontinue if no improvement over baseline

• Offer referral for assessment for research trials, if available.
  o Be aware and sensitive to concerns about research and exploitation
  o Be clear and honest about potential value (or lack thereof) for the patient.
Beyond KAER in Indian Country

• Address preferences for care
  o Conversation about “the kind of care you want and where you want it”.
  o “If you can’t speak for yourself, who speaks for you” (healthcare proxy).

• Regular, scheduled assessment
  o Function, behavioral symptoms
  o Depression, anxiety
  o Caregiving system and caregiver(s) health and function
  o Medication review
Selected Additional References


• Lanting, S., Crossley, M., Morgan, D., Cammer, A. *Aboriginal Experiences of Aging and Dementia in a Context of Sociocultural Change: Qualitative Analysis of Key Informant Group Interviews with Aboriginal Seniors*


