Making Sense of Dementia, a Disease That Makes No Sense

June 24, 2026

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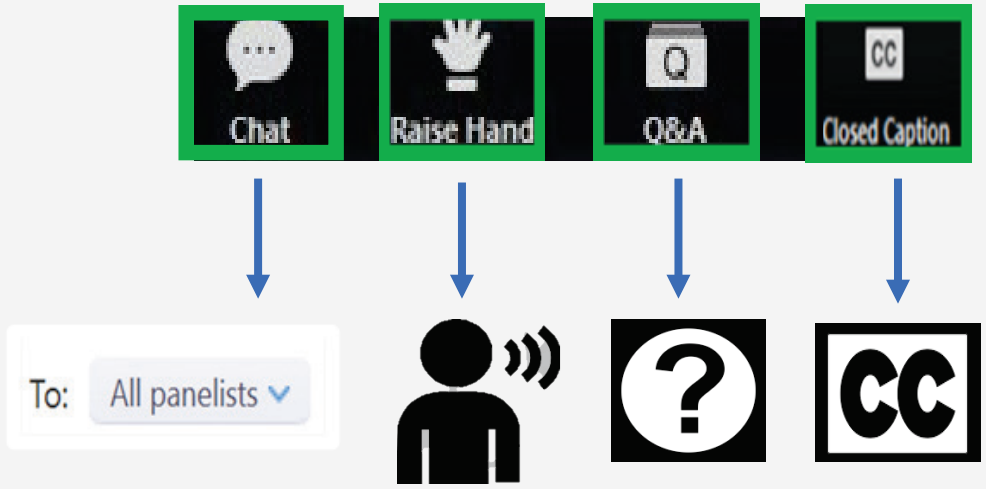

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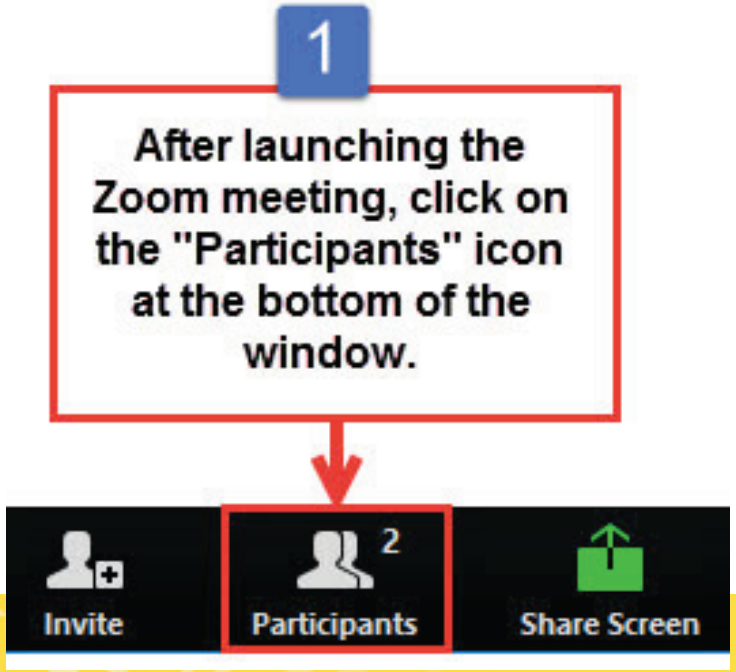

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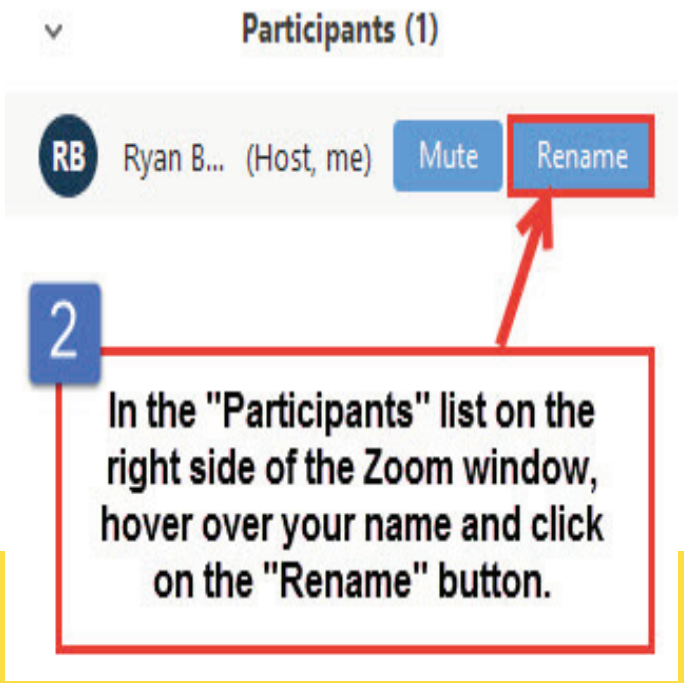

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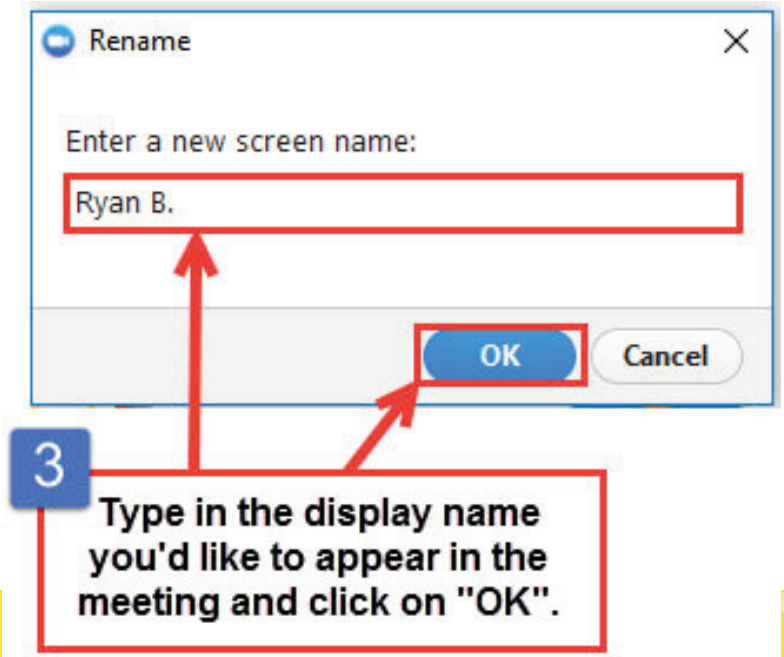

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Today's Presenter

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Webinar Objectives

- Review Arthur Kleinman's explanatory model of illness
- List three reasons for integrating culture into caregiver programs and services
- Describe the goal and purpose of the Savvy Caregiver program

Making Sense of Dementia, a Disease That Makes no Sense

Jordan P. Lewis, PhD, MSW
Aleut, Sugpiaq; Naknek Native Village

June 24, 2026

About Me

- Aleut, Sugpiaq
- Commercial fishing background
- Raised among elders in my family and community
  - Great-grandparents, late Paul and Anna Chukan
  - Grandparents, late Gordon and Anisha McCormick; Alden and Muriel Lewis
  - Elders in village of Naknek

Naknek, Alaska

Cannon Beach, Oregon

Prevalence of ADRD Among AI/ANs

- By 2050, one new case of Alzheimer's disease and related dementias (ADRD) will develop every 33 seconds.
  - Approximately 1 million new cases per year
- The American Indian and Alaska Native (AI/AN) population age 65 years and older has nearly tripled since 1976, from 4.8% to 14.1%.
- Tribal health systems and families are ill-prepared to address the challenges associated with dementia.
- There is an increasing urgency to articulate AI/AN views of ADRD.

Cultural Understanding of Dementia

- Provides insight so healthcare providers can integrate cultural beliefs into treatment
- Improves the processes of care for families
- Enables AI/AN people to better comprehend and adhere to early, critical stages of treatment

Setting the Stage

- Symptoms of ADRD typically are not viewed as a disease or illness that needs immediate attention.
- Differences between the family's and medical community's understandings of dementia can result in miscommunication and delays in seeking a diagnosis and or care.
- Without formal diagnosis, families cannot access support services (i.e., respite, home health, medical treatments).

Kleinman’s Explanatory Model of Illness

- Kleinman’s explanatory model of illness (1978): Patients and healthcare providers may have different conceptual understandings of nature of illness, its cause, and treatments.
  - Exploring and understanding illness narratives can promote healing.
- The model has been applied to a range of diseases and disorders, including diabetes, chronic heart disease, and dementia.
- The model has been applied to various racial and ethnic groups.

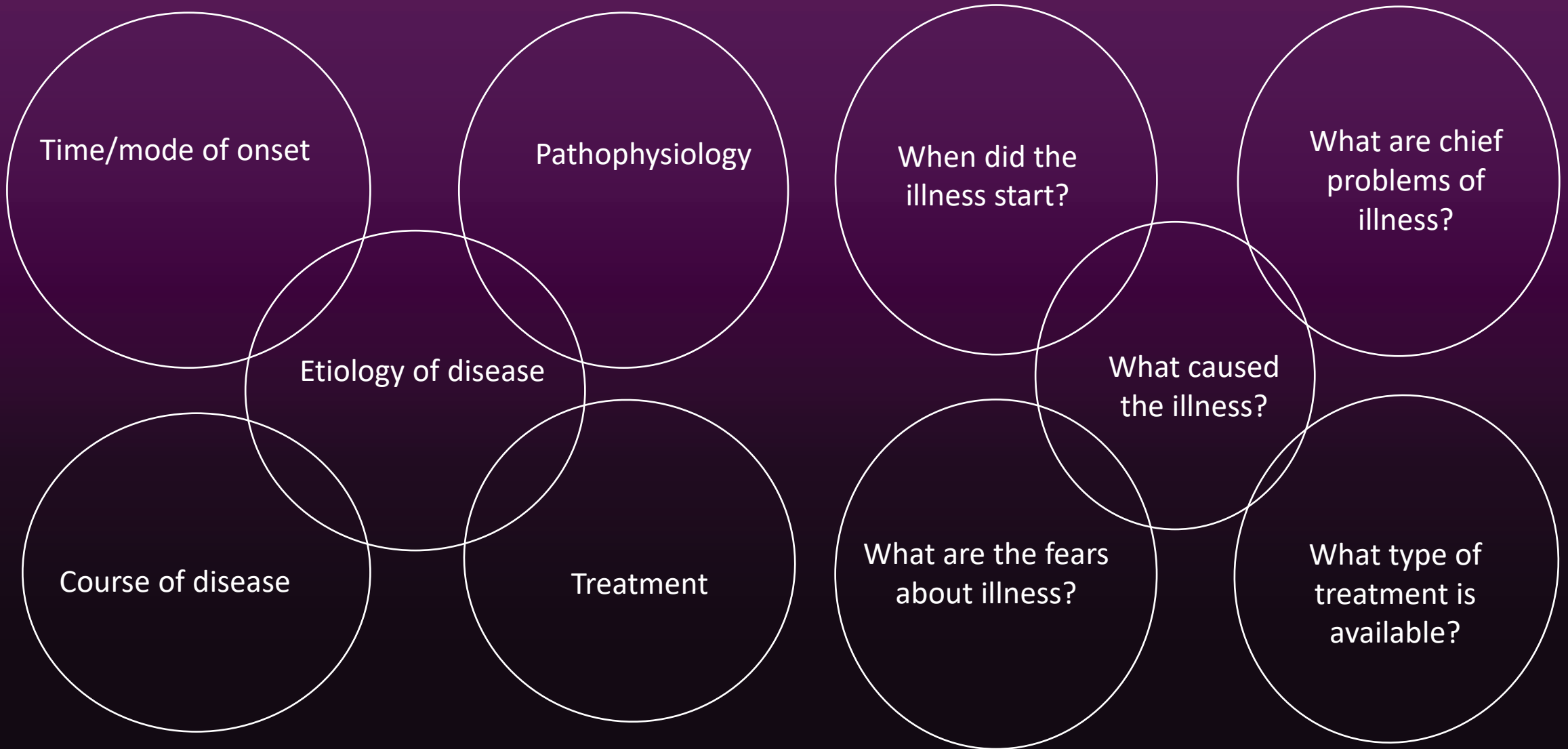
Caregiver Demographics

Providing care for:	
Spouse	60%
Parent	10%
Grandparent	25%
Other	5%
Rural	38%
Gender	
Female	86%
Male	14%
Age	53
Education	
Some high school	10%
High school graduate	19%
Some college	29%
College graduate	29%
Graduate school	14%

Provider Demographics

Gender	
Female	83%%
Male	17%%
Mean age	55
Mean years living in community	25
Mean years treating ADRD	15
Rural residence	33%
Profession	
Nurse	33%
Social Service Provider	33%
Physician (MD)	25%
CHA	1%

Kleinman's Explanatory Model



Explanatory Model Findings

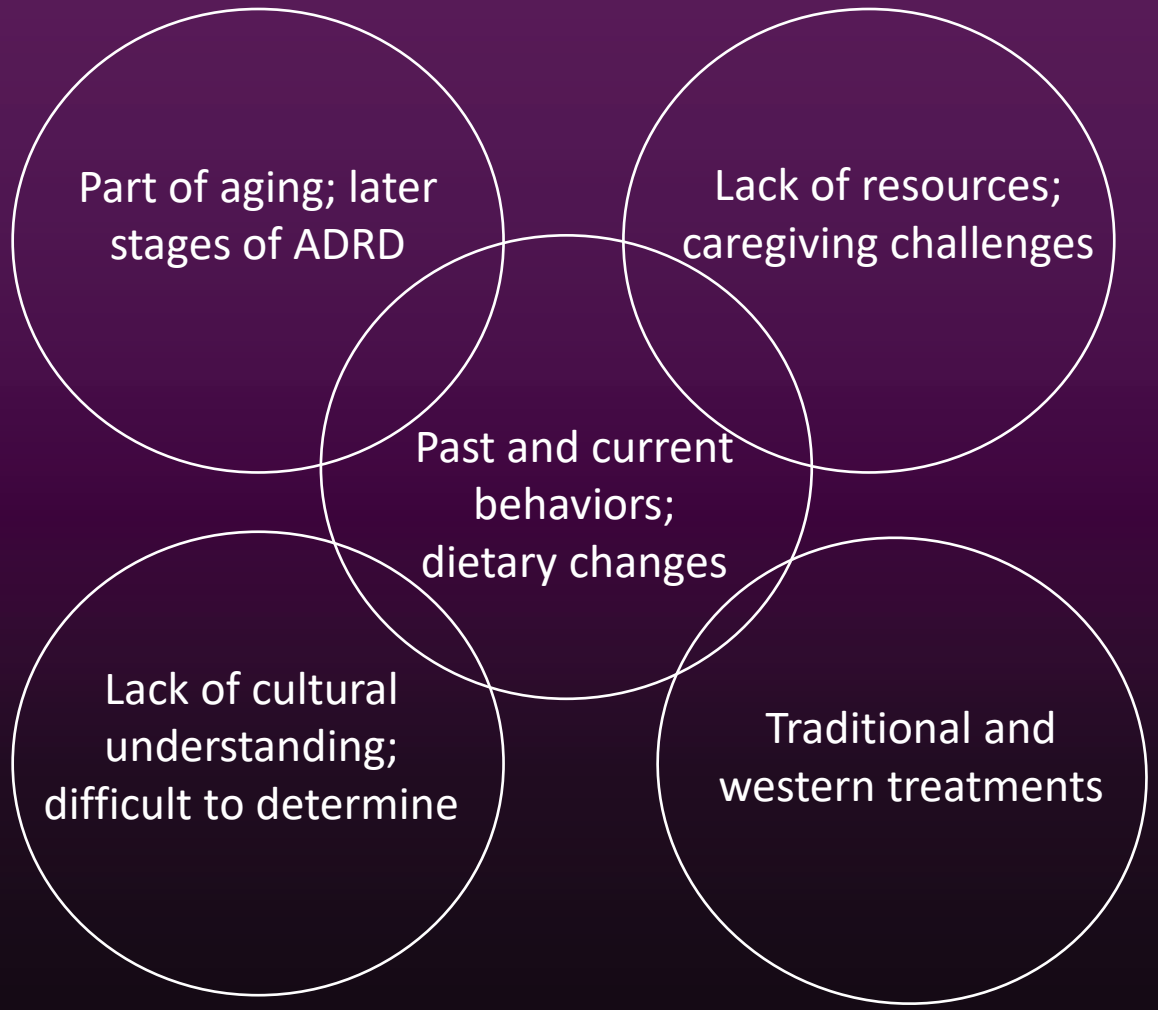


Figure 1: Provider's Explanatory Model

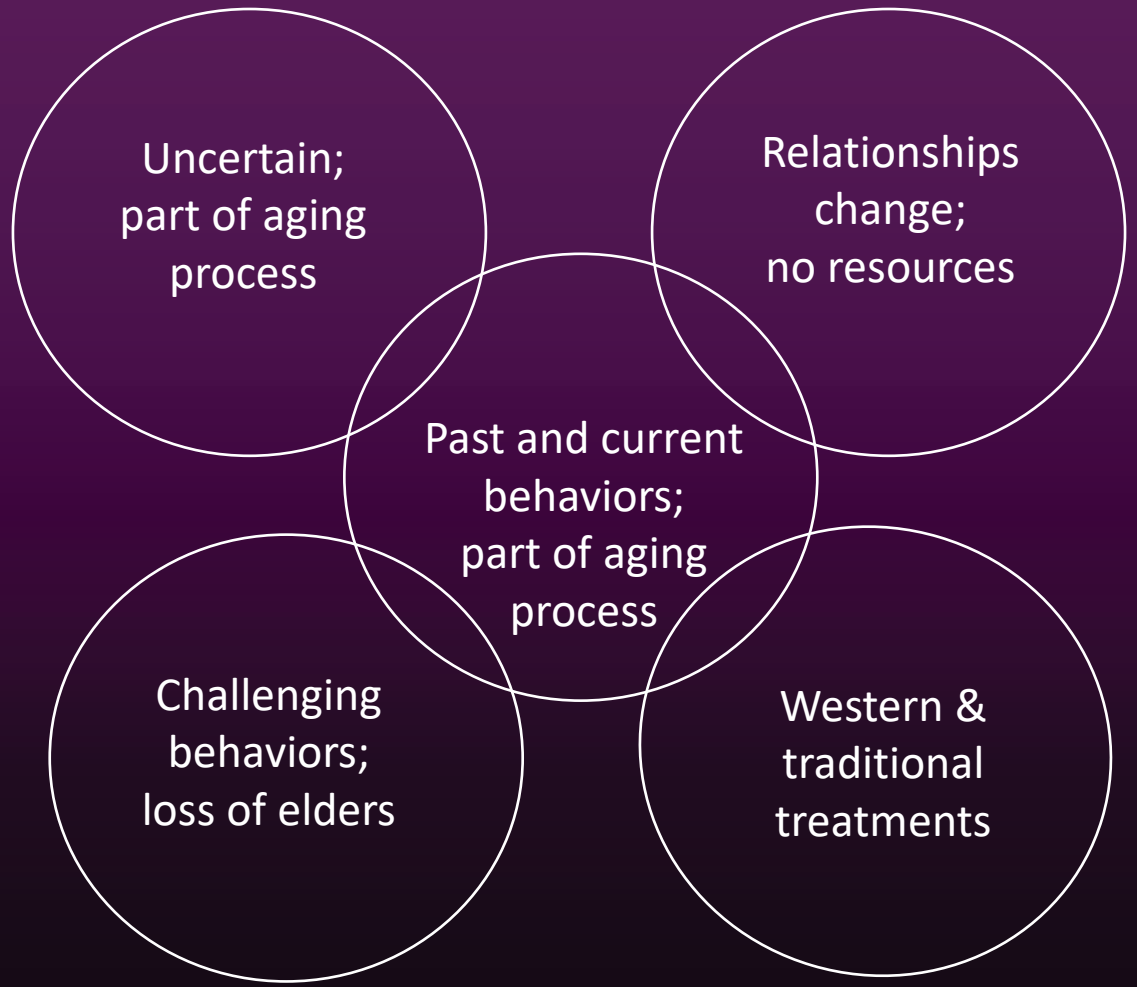


Figure 2: Caregiver's Explanatory Model

Explanatory Model Findings (cont.)

	CAREGIVERS		PROVIDERS
ADRD ONSET	Uncertain	ADRD ONSET	Part of aging
	Part of aging		Later stages of ADRD
ADRD CAUSES	Past & current behaviors	ADRD CAUSES	Past & current behaviors
	Part of aging		Dietary changes
ADRD PROBLEMS	Relationships change	ADRD PROBLEMS	Lack of resources
	Lack of resources		Caregiver challenges
ADRD TREATMENTS	Western treatments	ADRD TREATMENTS	Traditional healing
	Traditional healing		Western treatments
ADRD FEARS	Challenging behaviors	ADRD COURSE	Cultural understanding lacking
	Loss of Elders		Difficult to determine

Findings: Caregiver Onset

- Subtle cognitive changes were noticed, but uncertain of specific date when changes occurred.
  - *”Probably five years ago. Four or five years ago.”*

- Caregivers used noticeable changes to guess the year they believed ADRD symptoms started.
  - *“I just started to notice over a month’s time that things were changed with her. She couldn’t remember where she put things. And just her logic in discussions was not right. It was changing.”*

Findings: Caregiver Problems

- Lack of knowledge re: ADRD process and what to expect led to challenges.
  - *”What troubles me most is that I am trying to make sense of a disease that has no explanation and it’s something that you cannot make sense of.”*
- Personality changes in family member were unexpected and led to family staying away.
  - *“They just stay away. And that’s the first thing they do, when a family gets dementia. The other family, they find out about it and they just stay away – why stick around when she doesn’t remember them.”*

Findings: Caregiver Problems (cont.)

- Role shifting was problematic for younger caregivers.
  - *“And it was an odd conversation because I’m used to always being the daughter and taking direction from him. The roles flipped, which is real odd for me, telling him what to do.”*

- Lack of accessible education and training resources was problematic for caregivers and educating family members.
  - *“I tried to explain it to my family when he was first diagnosed with dementia. They’re really good at denying stuff. It’s like this is not going away. This is not going to get better. This is what we are facing and I am going to need your help, but nobody.”*

Findings: Caregiver Blessings

- There were unexpected blessings for caregivers.
  - *“I wouldn’t have traded it for anything. I was like, I am at peace with what I was able to – the time I spent, and my 32-year-old, she was pretty young, she was in junior high. She said that was probably the best time in her life that she got to spend with her grandma. She said, ‘Thank God we had Grandma.’”*

Findings: Caregiver Perspective on Causes of Dementia

- Lifestyle choices were primary cause, including alcohol, being sedentary, unresolved trauma, and poor diet.
  - "*Maybe drinking, drugs, alcohol. Elders tell me they drank when they were young and maybe that had something to do with it, but I don't know.*"
  - *"I would think if they weren't physically active. They're just sitting there and not talking or visiting too would affect dementia."*
  - *"I think trauma and just constantly being on edge all of the time."*
- Some caregivers had no answer or idea on the cause.
  - "*I don't think there is a clear yes or no answer, but part of old age.*"

Findings: Caregiver Fears

- Loss of elders and their knowledge was the primary fear discussed.
  - *“It’s a sad thing to see. You always want them to have their wits about them to the very end. That wisdom that they had way back when they were young and what they know.”*
  - *“Not being able to hear all they know deep within them. The wisdom and knowledge they picked up through the years with the grandmas and grandpas back in the early 1900s, 1800s, and not remembering.”*

Findings: Caregiver Perspective on Treatments

- Treatments focused on holistic approaches, treating the entire person, and not just ADRD symptoms or delaying disease progression.
  - *"I'd like to have her [provider] review the rest of his health other than the Alzheimer's to make sure that he's up to date with the meds he's taking and talk about other issues that have been bothering him [husband with ADRD]."*
- Traditional treatments were also used for mental and behavioral health symptoms.
  - *"I had him going to a naturopath, for different supplements and things and different things that help, natural things to help him calm down."*
  - *"We found that music soothed him so much."*

Findings: Provider Perspective on Onset

- Difficult to determine approximate date of onset for patients who came to the clinic during the later stages of ADRD.
  - "*Some people accept it as a natural part of aging and they're not too worried about it until the person becomes such a care burden for the spouse, the family, that they bring the person to medical attention, and it's pretty late in the disease.*"
- Patients and families did not understand ADRD and associated changes until it was too late.
  - *"I think a lot of them don't really understand it a lot until pretty much it comes down to they have it [ADRD]."*

Findings: Provider Perspective on Problems

- Lack of resources across the state was the most discussed problem.
  - "*And sometimes they're very isolated. There was this guy I always felt like there was nothing that I was able to assist with. We tried different things. We couldn't hire respite workers to go in. I was pulling out my hair. It was almost like I dreaded calling him because I couldn't – I didn't feel I could help with him anything.*"
- Providers saw how lack of resources exacerbated family roles and relationships.
  - *"It's a tough job to care for somebody with dementia. Families cannot do it. You can't be a parent or grandparent and take care of something with dementia too."*

Findings: Provider Perspective on Causes of Dementia

- Perceived causes of ADRD included dietary changes and being sedentary
  - *"But I think with the change in the diet and high blood pressure, and those kinds of things, adds to dementia."*
  - "*And we're talking about the 60-year-olds, they're not as active as the elders used to be. I think that's why we're seeing higher numbers of dementia as well."*
- Also discussed vascular and heart disease among patients
  - *"It seems like the cardiovascular risk factors are big correlates with dementing processes. So, it's unsurprising that many of my patients with either AD, or vascular dementia, have comorbidities, high blood pressure, diabetes, and so on."*

Findings: Provider Perspective on Course

- Despite scientific training, providers were much less knowledgeable when discussing and understanding cultural aspects of dementia.
  - "*Certainly providers know about it, but it's hard to determine – a lot of things are cultural. If you don't have exposure to those ideas and concepts – you don't know if this individual is having problems, or this is how, as a whole, people [Alaska Natives], think about certain things.*"

Findings: Provider Treatments

- Included both western and traditional treatments, focused on physical activity and dietary changes.
  - *“Sticking to Native foods, as opposed to exposing themselves to some of the westernized, bad-for-you, foods. Berry picking and traditional mushroom picking and some of the grasses that are known to be good herbal remedies.”*
- Traditional healing was also prioritized.
  - *“If people are feeling like they’re not thinking right and they’re in the earlier stages of having unclear thinking, it can be really helpful for them to use traditional healing techniques. Helping them to remember what’s important in their life and to help them re-engage in their community, creating more structure, prioritizing, and creating that circle of healing in their own life.”*

Findings: Summary

- AI/AN people's understanding of dementia is like that of other racial and ethnic minority groups.
  - Natural part of aging, seek support later in disease process, need more resources and supports for family and providers, blend of western and traditional healing
- Providers have concerns regarding lack of resources, cultural understandings, and engagement earlier in disease process.
- The focus on blessings was not commonly found in literature.
- Not answering questions may be culturally motivated and stem from the belief that discussing disease may bring disease upon their family.

Implications

- State, local, and tribal health organizations need to develop rural outreach and support groups for caregivers.
  - Reduce isolation, increase knowledge base of disease process
- Training and education must reflect AI/AN understanding of dementia.
  - Need for culturally responsive screening tools for memory loss
- Caregiver programs, support groups, and education need to be culturally responsive.

AI/AN Caregivers and Savvy Caregiver Program Cultural Enhancement

Pushing the Boundaries of Caregiving Trainings

Indigenizing caregiving to be inclusive, culturally safe, and appropriate

AI/AN Caregiver Demographics

- AI/AN elders live in multigenerational households
- Bulk of caregiving duties is provided by informal caregivers
  - Family, fictive kin, relatives, neighbors, community members
- Geographic distances, lack of services, mobility and safety
  - Challenges in accessing care for multiple chronic conditions
  - Fragmented healthcare services in rural and Indigenous communities

Biggest Lesson Learned

AI/AN caregivers learn best from peers

Current Needs for AI/AN Caregivers

- Respite programs
  - Mental and physical health support
- Financial support
- Training and education programs that look like you
- Practical, hands-on training for ”in the moment” needs
- Programs and services to work with multiple caregivers (not just dyad)
- Invited to be part of the healthcare team

What You Can Do

- Adapt caregiver training and education programs to:
  - Integrate cultural values
  - Reflect traditional practices and beliefs
  - Take culturally safe approaches to care and support
  - Build upon strengths and current care practices of caregivers

The Savvy Caregiver Program

- 6-week class for family caregivers
- Classes teach knowledge and skills to improve quality of life for their family member, as well as for themselves
  - Focus on contented involvement
- Course topics include:
  - Information on dementia
  - Knowledge of how dementia affects the person
  - Ideas for setting up daily care and activities for success
  - Strategies for figuring out what behaviors mean and how to respond
  - Tools for decision-making

Savvy Caregiver for Tribal Nations "Savvy Caregiver Peer Program"

- Spend time with caregivers and community members
- Address current needs and gaps in caregiver supports, training, and education
- Familiarize community with Savvy Caregiver
- Build upon current strengths
  - Peers
  - Sense of community
  - Informal networks

Savvy Caregiver Peer Program

- Enhancing, not adapting, the Savvy Caregiver Program (SCP) to meet caregiver needs
- Class participants will have a peer to assist with translating course material into daily life
- Peer mentors return “soul” of caregiving into the SCP
- Peer mentors have sense of purpose, meaningful engagement
- Sustainability – use of community members to culturally enhance SCP

Big Picture Reflections

- Dementia caregiver trainings focus on Evidence-Based Practices (EBP)
  - Community needs to be at the forefront, not science
- The ”spirit” and “soul” of AI/AN people is missing from the trainings
- Need to think outside the box; caregiver dyads are not always common
- Caregivers and community need to be engaged in development of trainings, education, interventions

Thank you for your time!
Any questions?

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Acknowledgments

- We would like to thank each caregiver who shared their time, stories, humor, tears, and recommendations to improve supports for other caregivers.
- We would like to thank the Alzheimer's Resource of Alaska, Aleutian Pribilof Islands Association, Bristol Bay Area Health Corporation, Denali Center in Fairbanks, and Fairbanks Native Association for their support and guidance of this study.

This project was funded by:

- WWAMI AIAN CTRC pilot study award (PI: Lewis, J.P.). Sub-award #: G248-17-W6223 (NIH NIGMS)
- Native Elder Research Center, UC Denver, pilot study award (PI: Lewis, J.P.). Sub-award #: FY17.001.023 (NIH, NIA)

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