“Going into a Community, We Need to Start from Where They’re At”—Caregiver and Advocate Perspectives

Zachary G. Baker, PhD
Land Acknowledgment

Today, the state of Minnesota is home to twelve federally and non-federally recognized indigenous nations, including five Dakota Nations and seven Ojibwe Nations. Those nations include the Prairie Island Indian Community, Shakopee Mdewakanton Indian Community, Lower Sioux Indian Community, Upper Sioux Community, Mendota Mdewakanton Tribal Community, Bois Forte Band of Chippewa, Red Lake Nation, Leech Lake Band of Ojibwe, Mille Lacs Band of Ojibwe, White Earth Nation, Fond du Lac Band of Ojibwe, and Grand Portage Band of Lake Superior Chippewa.

Supporting Dementia Caregivers After Death – Community Advisory Board
Road Map for Today

- General Themes
- American Indian – Specific Themes
- Alternative Terms

General Themes
- Dementia = Alzheimer’s
- Dementia -> Alzheimer’s
- Natural Part of Aging
American Indian - Specific Themes

• Two Members
• One Tribe on One Reservation
• Terms that focused on memory, crazy, or brain change
• Healthy Aging

Alternative Terms

• Memory Loss
• Brain Failure
• Brain Change
• Destigmatization
“I Didn’t Really Fully Understand Until I came into the States”: African Immigrants’ Introduction and Awareness of Dementia

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DISCLOSURE(S)

I have no commercial relationships to disclose

Funding

❖ University of Minnesota Program in Health Disparities

❖ Robert L. Kane Endowed Chair, University of Minnesota School of Public Health

❖ Johns Hopkins Alzheimer’s Disease Resource Center for Minority Aging Research (JHAD-RCMAR)

❖ The Minnesota Northstar GWEP is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). Additional funding for the Minnesota Northstar GWEP is provided by a gracious gift from the Otto Bremer Trust Foundation. The Minnesota Northstar GWEP is also supported by the University of Minnesota Office of Academic Clinical Affairs.
The Immigrant Memory Collaborative

❖ The African Immigrant Memory Loss Project

❖ The African Immigrant Dementia Education Project

The African Immigrant Memory Loss Project

❖ Develop culturally informed instruments, and use these instruments to collect data to identify dementia care needs, knowledge, and resources
The African Immigrant Dementia Project

❖ The goal of this project is to develop a culturally tailored dementia education program for the African immigrant community.

Methods

1. Have held 10 Project Advisory Board meetings
2. Conducted community conversations (n=6)
3. Surveys (n=177)
4. Key informant interviews (n=9) so far
Preliminary Findings

“No dementia relevant words in many African languages”

No word for dementia

No word/definition for caregiver

“About 6 or 7 years ago when I started doing this CNA, PSA job. Back home in Africa, I know some of our elders suffer this disease but it is not evident and not visible”

“Recognition of dementia as a medical problem typically occurs in a healthcare job in the U.S.”

“Just living in village settings you could tell that there are some that have issues but I didn’t really fully understand until I came into the states and was able to articulate it and call it memory loss instead of just being, as kids we would just say they are crazy or just lost their minds”
Preliminary Findings

“Stigma surrounding dementia affects care and caregiving”

“Stigma - [people] don’t want memory loss on their chart because people treat you differently with diagnoses. It takes [African immigrants] time to accept the diagnosis.”

“Lifting up that stigma that they did something wrong or that it is contagious you know there is always that fear that if you come around them you might get it. It is kind of outlandish but there is that risk”

Myth: dementia and mental health illnesses have spiritual causes

“So for me if I happen to have memory loss can they think of it as a medical issue as opposed to a curse.”

“She wants to tell me that my mom is crazy.” And then the news spread around, [like] a bomb.”
Implications

• Significant need for education about dementia in the African immigrant community

• Need for intervention to decrease stigma and other challenges that influence access to dementia care

• More research is needed:
  - To understand the incidence and prevalence of dementia
  - To explore caregiving challenges related to dementia and caregiving in African immigrants with memory loss and dementia

Thank you

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Communication of ADRD in Hispanic/Latin American Communities

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Long-term goal:
• to address effective recruitment of Hispanics/Latinos into aging and Alzheimer’s disease research

Aims:
• inspire & recruit community members (stakeholders) to become part of the recruitment infrastructure
• develop community-relevant awareness, education, and recruitment materials (products)
• support research infrastructure & facilitate inclusive enrollment in aging research (pilot grants)

There are a lot of people in the community who want to help and who are curious. All you have to do is ask.

Ned Norman, High Plains Research Network Community Advisory Council member
| NIH RCDC 2018 Report                                      | United States 2017: Leading Causes of Death in Hispanics/Latinos |
|----------------------------------------------------------|-------------------------------------------------------------------|
| **Total**                                                | **Cancer**                                                        |
| 2,660,047                                                |                                                                  |
| 1,209,266                                                |                                                                  |
| 822,859*                                                 |                                                                  |
| 165,533                                                  |                                                                  |
| 294,562                                                  |                                                                  |
| 203,113                                                  |                                                                  |
| 236,517                                                  |                                                                  |
| 486,706                                                  |                                                                  |
| 52,256                                                   |                                                                  |
| 171,644                                                  |                                                                  |
| **Median % H/L**                                         | **Heart Disease**                                                 |
| 6%                                                       |                                                                  |
| 6%                                                       |                                                                  |
| 10%                                                      |                                                                  |
| 6%                                                       |                                                                  |
| 10%                                                      |                                                                  |
| 5%                                                       |                                                                  |
| 14%                                                      |                                                                  |
| 6%                                                       |                                                                  |
| 6%                                                       |                                                                  |
| 11%                                                      |                                                                  |
| 6%                                                       |                                                                  |
|                                                            | **Accidents**                                                     |
|                                                            |                                                                  |
|                                                            | **Cerebrovascular**                                               |
|                                                            |                                                                  |
|                                                            | **Diabetes**                                                      |
|                                                            |                                                                  |
|                                                            | **Alzheimer’s**                                                   |
|                                                            |                                                                  |
|                                                            | **Liver**                                                         |
|                                                            |                                                                  |
|                                                            | **Lung**                                                          |
|                                                            |                                                                  |
|                                                            | **Suicide**                                                       |
|                                                            |                                                                  |
|                                                            | **Kidney**                                                        |

*Represents RCDC Category “Emergency Care”
No One-Size-Fits-All

Figure 5: English Proficiency Among Foreign-Born Latinx - 2017

Figure 7: Educational Attainment of Foreign-Born Latino Adults by Length of Residence in the U.S. - 2017
Culturally Responsive Language

- **Actively and consciously** considering beliefs, phrases, and customs that may be specific to H/Ls.
- Communication depends on target group.
  - Heritage Groups (e.g., Mexican, Cuban, Puerto Rican)
  - Socioeconomic Status (SES)
  - Age
  - Education

“Building trust, improving communication, and developing cultural competency are vital steps for inclusion. Including diverse voices from the community at each of these steps is vital for equity.”
Health literacy: The ability to *find, understand*, and *use* information to make health related decisions (NIH).

DEMENTIA ≠ DEMENCIA

**Boot Camp Translation**

- Process based on principals of community engagement (CE) and community-based participatory research (CBPR)
- Aims to “translate” medical jargon into community-relevant language
  - Disseminate these meaningful messages to the community
- Not a series of focus groups
- Not a training program for community health liaisons
- **Main questions BCT seeks to answer:**
  - **What** are the key messages (about this health topic) for my community?
  - **Who** in my community needs to hear these messages?
  - **How** do we best get these message to my community?
Communication of Health Topics

Ensure H/Ls exemplified both IN the materials and HOW the materials are presented.

Communication of Health Topics

• Pictures should reflect the community (physical features and culturally) and ones with people who are in closer proximity are more desirable.
Communication of Health Topics

• Shorter messages that are both easier and quicker to read.

*What is good for your heart, is good for your brain!*

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Culture, Health Care, and Trust

Interactions between H/L families and health services

- Migration history
- Cultural values
- Generation
- Education
- Acculturation
- Literacy
- Health
Intergenerational Information Transfer (IGI)

- **Transfer** of information to each subsequent generation.
- "**Brokering**: family members acting as linguistic and cultural intermediaries for their families with limited English proficiency and/or health literacy.

What does this mean for the health of H/L adults with dementia and their loved ones?

- **Family takes priority**: Family financial security > individual well-being
- **Duty towards parents**: Adult children closely involved in the needs of older family members
- **Diligence equals affection**: Caregiving is not described as "burden," but rather as "doing right" by family
- **"Yes, doctor"**: Health providers are highly respected and rarely questioned
- **There is no "I"**: The well-being of one strongly influences the well-being of the others
- **When in doubt, the best equipped speaks for the rest**: When a family member is unable to engage with the world as needed, whomever can step in must do so
Cultural needs of H/L families

- Systemic disparities
- Diversity and heterogeneity of the H/L population
Lessons Learned from Focus Groups and Community Outreach in the African American Community

Robbin Frazier, Associate Director of Equity and Community Engagement, UMN, School of Public Health
Multiple ADRD Collaborations and Funding Sources

- Alzheimer’s Association MN-ND
- Department of Health & Human Services
- Federally Qualified Healthcare Clinics and Health Systems
- Minnesota Board on Aging
- Minnesota Brain Aging Research Collaborative (M-BARC)
- State of MN Alzheimer’s Disease Working Group
- University of Minnesota School of Nursing

Objective

To **synthesize key themes and recommendations** identified in multiple projects designed to better understand the experience and implications of dementia for BIPOC and underserved communities

- Project #1 – DHS African American experiences with ADRD, two focus groups conducted by the Alzheimer’s Association MN-ND
- Project #2 – Minnesota Board on Aging ADRD multi-cultural community Listening sessions with FQHC patients and staff affiliated “Safety Net”

Appendix

- Project #1 – methodology and additional findings
- Project #2 – methodology
- Project #3 – MBA Legislative Report, update of State Alzheimer’s plan
What is the culturally acceptable way to refer to dementia?

“I understand what he’s saying about educating people on the correct terms (Alzheimer’s and Dementia) but using the terms with our elders is not okay with them. It’s not that it’s not okay with us… To tell them that they have it, they’re like ‘nah’. I just forget this and forget that every now and then. So it’s, more them (Elders) not wanting that label than it is us giving it to them.”

Focus Group Findings:
The culturally acceptable way to refer to dementia

✓ Lack of consensus on use of Alzheimer’s and dementia terminology.
✓ For some, it is disrespectful to “dumb down” the information.
✓ Others believe using the Alzheimer’s and Dementia labels will cause elders to reject these words and deny the problem.
✓ The terms frequently used in initial conversations and education events include memory loss, brain health, cognitive changes, changes in thinking/behavior
“In the African American community, we like to be portrayed as strong individuals. And we don’t share things so personal with other peoples because of the embarrassment. You got in trouble, if you shared anything with anybody out of your household.”

Focus Group Findings

Dementia discussions in the AA community?

✓ View themselves through the lens of the disease.
✓ Keep information within the family.
✓ Cultural legacy of silence.
✓ Emphasis on individual strength.
✓ Lack of cure makes talking about it unnecessary.
✓ Spirituality plays a large role.
“So it’s a lot of confusion, and fear, and that brings that denial. So just kind of let it go as long as you can, until you have to do something.”

“Trust goes all the way back to slavery. Trusting people other people other than your family, in the black community, like that’s big. To put our trust, and especially our health, in somebody else’s hands, it is a barrier that is hard to get over.”

What are your or your family/friends’ concerns about Alzheimer’s and dementia?

Focus Group Findings
Community’s concerns about Alzheimer’s, dementia, and memory loss?

✓ Stigma and historical trauma impact beliefs.
✓ Lack of trust in doctors - active listening and two-way conversations build trust
✓ Discomfort with disease terminology
✓ Action will likely not be taken before a crisis.
Recommendations

- Identify African American cultural values and beliefs and their implications for addressing dementia.

- Be aware of historical legacies and current trauma.

- Identify and address myths and misunderstandings.

- Educate community members and healthcare providers about the multiple benefits of early diagnosis along with community resources.

Recommendations

- Engage community in developing age-culturally-relevant messaging to break the stigma, shame, and silence

- Deliver community-based, culturally-sensitive education

- Use the existing community assets and structures to disseminate information.

- Give “real life” stories/examples of Alzheimer's.
Project #2 - MBA Community Dementia Listening Sessions

- **Background:** Minnesota Board on Aging - dementia grant for an equity-based research collaboration with the UMN, Alzheimer’s Association, MBARC and community partners

- **Purpose:** To better understand the experience of dementia among BIPOC and underserved communities, as well as their health care provider expectations for ADRD care, to inform provider and community outreach, messaging and referrals for services.

- **Methodology:**
  - Five community listening sessions community with cultural communities at greater risk for dementia and the tolls of dementia care
  - Conducted with community at “Safety Net” healthcare provider clinics and community gathering spaces for older adults

#2 Community listening sessions - Top 5 findings

Participants from diverse communities wanted doctor’s help:

- Provide me information and education about dementia
- Talk to me routinely about my brain health, memory, or cognitive changes
- Ask me routinely about changes in my memory
- Explain the difference between memory as part of normal aging vs. what I should be concerned about
- Help me find resources in my community to help with dementia-related needs
Thank you

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Appendix: Additional information and recommendations

• Project 1: Additional Information on the African American understanding of ADRD and barriers to diagnosis
  ➢ What does dementia mean?
  ➢ How are dementia and memory loss different?
  ➢ What is the difference between Alzheimer’s and dementia?

• Project 2: Five Multi-cultural Community Listening Sessions

• Project 3: Recommendations to State’s Alzheimer’s Disease Working Group from Cultural Responsiveness Committee
  ➢ Consideration of guiding values when conducting work
  ➢ Ask Equity Lens questions during your work
Project #1 - African American Experiences with ADRD

• **Background:**
  
  DHS qualitative research shows that African Americans are twice as likely as Whites to develop late-on-set Alzheimer’s disease, and less likely to have a diagnosis of their condition, resulting in less time for treatment and care planning.

• **Purpose:**
  
  Focus groups information about their experiences with ADRD will shape future educational programs for working with this population in community and aging services settings, and health care systems.

• **Methodology**
  
  Two African American focus groups 1) Persons with Dementia and their Care Partners/Givers 2) professionals working with older adults impacted by dementia

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Additional findings from Project #1
African American Experiences with ADRD
“Your brain functions in many different ways, and every piece of your brain has a certain function. There’s memory, decision making, or other situations… some of those duties and jobs kind of like malfunction and they’re breaking down.”

“Short and long terms … they can remember, some of them will remember back, and don’t remember today. You know, and some remember the little baby but don’t remember the daughter.”

**What does dementia mean?**

**Focus Group Findings:**

✓ Varying levels of understanding.
✓ Distinction between understanding of community members and understanding of professionals.
✓ Basic understanding: People with dementia are forgetful.
✓ Advanced understanding: Brain areas affected, which often leads to wandering.
How are dementia and memory loss different?

“... where you’re thinking about a movie, and you can’t think of that person’s name, and then 2:00 in the morning when you go to the bathroom, it’s like when the light bulb goes off, and now you remember. That’s age-related memory loss right there. It came back to you. But when you can’t remember it at all, or you know someone who’s close to you and you don’t even recognize them, then that’s a challenge.”

Focus Group Findings:
How are dementia and memory loss different?

✓ Varying levels of understanding.
✓ Distinction between understanding of community members and understanding of professionals.
✓ Basic understanding: People with dementia are forgetful.
✓ Advanced understanding: Brain areas affected, which often leads to wandering.
What is the difference between Alzheimer’s and dementia?

“I worked at a nursing home with Alzheimer’s and dementia and I, I never knew the difference. They never pointed out this one is Alzheimer’s. This one is dementia.”

“I think it’s kind of like cancer, but under the umbrella of cancer you have breast cancer, prostate cancer, you know, all, liver cancer, and so under the umbrella of dementia there’s Alzheimer’s and there’s Parkinson’s and there’s the other forms.”

Focus Group Findings
Understanding the Difference between Alzheimer’s and dementia

✓ Some participants, including professional staff, could not differentiate between Alzheimer’s and dementia.

✓ General belief that Alzheimer’s is more serious than dementia.

✓ Professionals described dementia as an umbrella concept.
“My experience taking care of my grandma, it can get kind of frustrating, I guess. It’s like having a child. It’s definitely a group effort. I mean, like my cousin lives with us too, and she helps. So, it’s like multiple people. But it’s still a lot to, take care of.”

Focus Group Findings
Share your experience with dementia

✓ “Shot Caller” role in family.
✓ “Family” can come in many forms.
✓ Elders are valued.
✓ Attempt to keep family members in the home.
✓ Fear and denial leading to isolation.
✓ Stigma, shame, and uncertainty lead to silence.
✓ Caregiving is both rewarding and frustrating.
What are the barriers to receiving a diagnosis?

“Right now, what you hear is that there’s nothing you can do. So why would you want a diagnosis of something that you can’t do anything about?”

Focus Group Findings
Barriers to receiving a diagnosis

✓ Lack of convenient access.
✓ Long wait for testing.
✓ Belief that lives change immediately upon receiving the diagnosis.
✓ No benefits to diagnosis.
Additional findings from Project #2
African American Experiences with ADRD

Project #2 Five Multi-cultural Community Listening Sessions

- People living with memory loss or dementia n=7
- Caregiver to a person with memory loss or dementia n=10
- People helping a family/ friends one or more everyday activities n=15
- People with a family/friends living with dementia or memory loss n= 17
- Professional working with people with dementia or memory loss n=11
- People generally healthy concerned about their memory n=21
- People with a generally healthy loved ones concerned about memory n=19
- People generally healthy n=45
Project #3  Minnesota Board on Aging Legislative Report update of the state Alzheimer’s plan

• **Background:** Preparing Minnesota for Alzheimer’s: the Budgetary, Social, and Personal Impacts.

• **Purpose:** The legislature directed the Minnesota Board on Aging (MBA) convened a 16-member Alzheimer’s Disease Working Group (ADWG) to review and revise the 2011 Alzheimer’s plan

• **Methodology:** The ADWG convened five committees to address key topics, the following topics, as determined by the Work Group. The Cultural Responsiveness committee was formed to reduce health disparities and improve access to high-quality dementia care
#3 Cultural Responsiveness Committee - Guiding Values

Recommendations to MN State Alzheimer’s Disease Working Group

Consider these guiding values when conducting work:

- Authenticity – meet people where they are
- Assets-based approach to equity and diversity
- Openness in discussions
  - Acknowledge the role that race, and racism play
  - Seek input from those who are not of that culture but deserve "a seat at the table" of decision-making.
  - Create opportunity for voices that have been hidden to participate in ideation and decision-making

#3 Cultural Responsiveness Committee - Equity Lens Recommendations

Recommendations to MN State Alzheimer’s Disease Working Group

Ask Equity Lens questions during your work:

- What groups are most impacted or marginalized in relation to this policy/program/issue?
- Who is most effected by the policy/issue program? Who is included/excluded from this policy/program/issue?
- What are the biomedical and public health barriers?
- Who is at the table for decision making related to this topic? Who is missing?
Questions or comments? Contact info@mngero.org

Next Webinar: Wednesday, January 19
12N-1:30PM

Gray Matter: Understanding Substance Abuse Disorders in Older Adults with Kay King, NAMI Minnesota

Webinar Sponsors