HTTPS://MEMORYKEEPERSMDT.COM

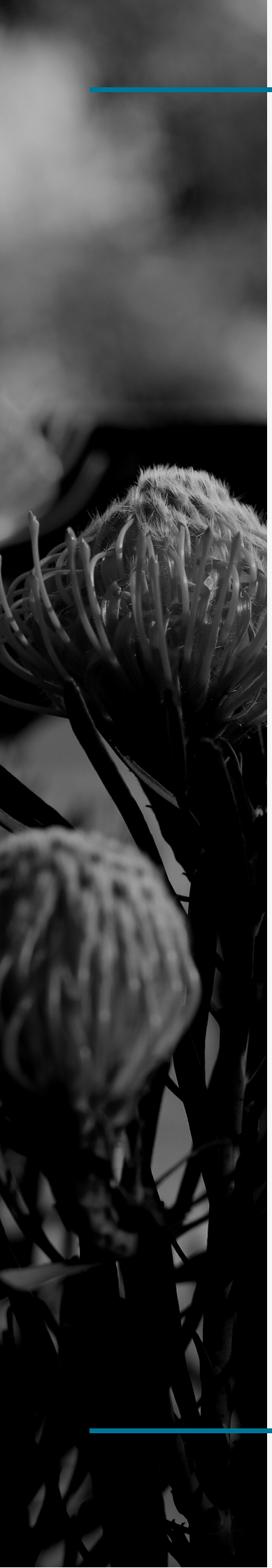
MAY 2022

Miskwaagamiiwi-zaaga'igan - Red Lake Nation

Community Report presented to the Tribal Council members April 12th, 2022

PREPARED AND PRESENTED BY

INDIGENOUS CULTURAL UNDERSTANDINGS OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS – RESEARCH AND ENGAGEMENT (ICARE)



BY:

University of Minnesota Medical School, Duluth Campus,
Memory Keepers Medical Discovery Team

Kristen Jacklin, PhD
Melissa Blind, PhD (Cree, George Gordon's First Nation)
Dana Ketcher, PhD, MPH
January Johnson, 3rd year BSW student (Red Lake Nation)
Annamarie Hill, MA (Red Lake Nation)

Red Lake Tribal Health Director

Oran Beaulieu, BS (Red Lake Nation)

Red Lake Community Lead

Ozaawaanakwadok, Susan L Ninham, BS, MS, EdS (Red Lake Nation)

Community Advisory Council members

Karen Holstein-Bedeau, BA (Red Lake Nation)
Eileen Miller, RN (Red Lake Nation)
Tina Roybal, AA (Red Lake Nation)
Alexis Mason, EMT (Red Lake Nation)
Nancy Richards, Accounts Payable Specialist (Red Lake Nation)
Darlene Johnson, LPN (Red Lake Nation)

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

This project was a collaborative effort that could not have been completed without the participation of the Red Lake Nation (Tribal Resolution No. 232-18) and the contributions of many people. We extend sincere thanks to the Red Lake Tribal Council, and all of the individuals and organizations in Red Lake who contributed their time and expertise to this research.

Chi Miigwech to our Community Advisory Council Members:

- Karen Bedeau
- Eileen Miller
- Tina Roybal
- Alexis Mason
- Nancy Richards
- Darlene Johnson

Special thank you to Susan Johnson who retired from the advisory council in 2021 and the Late William May and Late Richard Gibbs.

The ICARE project in Red Lake is overseen by Oran Beaulieu, Tribal Health Director, and Susan Ninham, Administrative Officer, for Red Lake Comprehensive Health Services. January Johnson is the community-based researcher for this project.

This research was generously supported by the National Institute on Aging (1R56AG062307-01, PI: Jacklin).

ABBREVIATIONS

ADRD: Alzheimer's Disease and Related Dementias
AI/FN: American Indian/First Nations
AI/NA: American Indian/Native American
A/P: Administrators/providers
CAB: Community Advisory Board
CAC: Community Advisory Council
CBPR: Community-Based Participatory Research
CBR: Community-Based Researcher
IHS: Indian Health Services
KII: Key Informant Interviews
KTE: Knowledge/Translation Exchange
PLWD: Persons Living with Dementia
SDOH: Social Determinants of Health
SFG: Sequential Focus Groups
TKK: Traditional Knowledge Keepers

EXECUTIVE SUMMARY

…I think it's because we take the attitude that of...we're not serving people that walk in the door, we're serving family. I mean, that's our family that's coming in. We're all brothers and sisters of the tribe. And it's a much more compassionate care being provided, especially for our Elders. We were raised and lived knowing that we respect our Elders. (RL AD03)

BOOZHOO!

The ICARE Project R56 grant (2018-2021), funded by the National Institute of Health (NIH), National Institutes on Aging (NIA), builds upon research conducted by Dr. Jacklin in Canada and has expanded the previous research to include the Tribal Nations surrounding the Great Lakes region, including the: Red Lake Nation, MN, Grand Portage Band of Chippewas, MN, Oneida Nation, WI, and seven First Nations in Manitoulin Island, ON. This grant focused on building and continuing community-based partnerships with Tribal Nations and First Nations, collecting preliminary data on dementia service needs in American Indian/Indigenous populations, and applying for additional funding through an NIH R01 five-year grant.

The following outlines the research activities that took place in partnership with Red Lake Nation.

On December 11, 2018, the Red Lake Nation Tribal Council approved the Red Lake Nation's research partnership with Dr. Kristen Jacklin and the Memory Keepers Medical Discovery Team (MK-MDT) through the ICARE Project R56 grant (Resolution No. 232-18).

During the first year of the grant, we worked closely with Susan Ninham, Administrator Comprehensive Health Services and Red Lake Research Project Lead, to establish a Community Advisory Council (CAC) to help guide all aspects of the research process. The CAC ensures that research activities are culturally safe for participants and ensure that findings are reflective of the community and its culture and members. The group has met 13 times since it was established in 2019.

We also hired a community researcher, January Johnson, who is employed full-time in this role by the University of Minnesota Medical School, Duluth Campus. January has completed extensive training for her role, including training modules developed by the research team, and attending webinars on health and tribal research, as well as Alzheimer's and Dementia education sessions. In addition to her role as a community researcher, January has taken the lead in writing updates within the ICARE project newsletters and has produced her own podcast to further community education and awareness on ADRD. This podcast can be found at: https://www.youtube.com/watch?v=nwA3OoJhmuo

The R56 project collected preliminary data through community-level data on demographics, health status, health services, and social determinants of health. Additionally, we conducted:

- Key informant interviews with Traditional Knowledge Keepers (n=5), Administrators (n=5), and Providers (n=3), and
- Sequential Focus Groups with health care providers for older Indigenous adults (n=3, 5 sessions).

The data in the following report, which draws from these interviews, has been de-identified to protect the identity of the participants.

Research updates were presented through community newsletters. The newsletters are produced twice a year and are distributed through the Elderly Nutrition Program. The research team also presented to the Red Lake Tribal Council in December 2019. A Tribal Resolution to continue the research relationship for an additional five years, through seeking additional NIH support, was granted on February 11, 2020 (Resolution No. 24-2020). An update was also presented to the Tribal Council in March 2021.

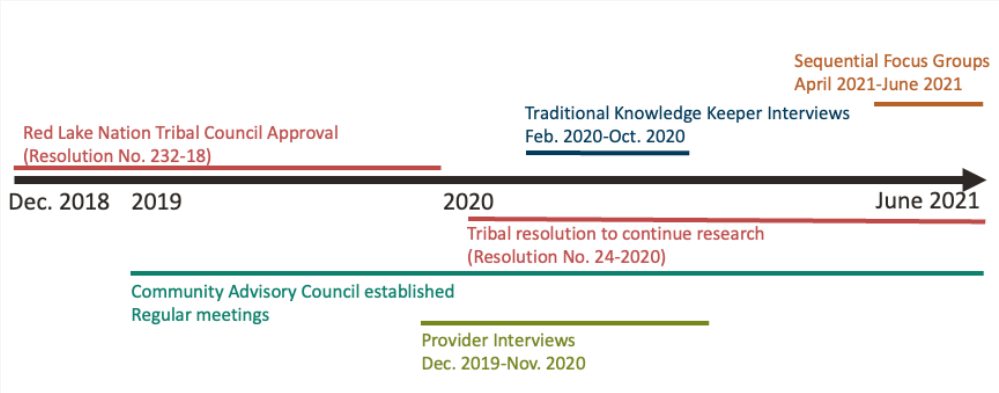


Figure 1. Timeline of research activities in Red Lake Nation.

This executive summary outlines the major findings from the R56 preliminary data detailed in the Red Lake community report and centers on these main areas:

- Dementia: Cultural and community understandings
- Caregiving: Cultural and community understandings
- Alzheimer's Disease and Related Dementias (ADRDs) in the community
- Services and barriers to care for people living with dementia and their caregivers
- Recommendations to improve dementia care

The next phase of the research will continue to build on research activities conducted during Phase 1 - the R56 funding period. We will continue our research partnership with Red Lake Nation, MN, Grand Portage Band of Chippewas, MN, Oneida Nation, WI, and the seven First Nations on Manitoulin Island, ON. The five years of NIH R01 funding allows us to create a foundational, culturally-grounded database of American Indian and Anishinaabe lived experience of ADRD that can be used to examine and inform the creation of culturally appropriate and safe approaches to improve dementia diagnostics, care, and outreach. In order to do this, we will conduct interviews with the following groups of participants:

- Healthy/non-symptomatic older adults (5 men and 5 women)
- People with dementia in the mild and moderate stages and their caregivers (10 dyads in the mild or early stages and 10 dyads in the moderate or mid stages of dementia)
- Caregivers to people with dementia in the late stages (10 participants)

The Red Lake Community Advisory Council will continue to guide all aspects of the research and January Johnson will continue her role as the community researcher.

KEY FINDINGS

PRELIMINARY FINDINGS FROM PHASE 1 OF THIS STUDY:

- **Dementia: Cultural and community understandings**
  - Circle of life: Participants described how dementia and/or memory loss is not necessarily viewed as an illness but rather a normal, expected part of the circle of life and the aging process. One Traditional Knowledge Keeper noted that in the past a person with living with dementia (PLWD) might be described as bagandizi (being absentminded) or giiwanaadizi (acting funny or different) in the Ojibwe language.
  - Importance of cultural adaptation and integration: Participants familiar with the Dementia Friends program detailed how, in describing memory loss and dementia to Native American/American Indian populations, they incorporated the environment (the flow of a river) and the four seasons/four stages of life. Participants also described how the Seven Grandfather Teachings, especially honesty, could be incorporated into caregiving.
  - Responses to ADRD: Participants described how there may be some stigma associated with brain disorders, causing community members to be reluctant to speak about problems or seek help. Participants also noted that community members may use humor as a coping mechanism in response to dealing with ADRDs, and to help them heal.
- **Caregiving: Cultural and community understandings**
  - Family caregiving: All participants identified family as incredibly important in taking care of a person living with dementia. Active family involvement was identified as important in keeping loved ones at home for as long as possible. It was acknowledged that caregiving can be stressful and complicated by family dynamics.
  - Community caregiving: Elders and those dealing with illness were described as taken care of by community members. Participants also described how they felt community members are better served if they are able to stay in Red Lake, as they will be supported by their “brothers and sisters of the tribe” with access to pow wows, smudging, drumming, and other traditions.
- **Alzheimer’s Disease and Related Dementias (ADRDs) in the community**
  - Risk factors: Participants identified the impact of chronic disease (e.g., diabetes, cardiovascular disease), health behaviors (e.g., substance use, lack of physical activity), and brain injuries/head trauma on the development of dementia.

Participants also acknowledged that since people are living longer, there is a need for more prevention and education efforts. Administrators made a connection between stress (related to poverty, homelessness, etc.), workplace hazards (such as secondhand smoke) and pre-existing conditions (e.g., diabetes) as important considerations for the Red Lake population they serve.

  - Signs and symptoms: Common signs and symptoms identified by participants included behavior changes, memory loss, telling the same stories repeatedly, and/or noticing that someone responds in a “wrong way”.
  - Diagnosis: Many times, it is a family member who brings their concerns about a loved one to a provider’s attention. However, the process around screening, receiving cognitive assessments, and referrals as described by participants was unclear and complicated.
  - Prevention, treatment & delay: Keeping active both mentally and physically was reported as important in keeping one’s mind healthy, in addition to taking part in spiritual activities such as drumming, singing, and/or smudging or using medicines such as tobacco, sage, cedar, and/or sweetgrass. Participants did not speak about any active outreach or community education about the prevention and delay of ADRDs.
- **Services and barriers to care for people living with dementia and their caregivers**
  - Services and programs: While administrators and providers detailed numerous facilities, services, and programs for people living with dementia and their caregivers, participants in the Sequential Focus Groups were not as knowledgeable about what was available. Overall, participants identified services such as a long-term care facility, community nursing, evidence-based classes for caregivers, and an Elderly Nutrition Program (ENP). Many of the programs and services offered to people living with dementia and their caregivers have been greatly reduced with COVID-19.
  - Barriers and challenges: Participants noted various financial, geographic, and resource/education barriers in Red Lake. Funding challenges have led to a loss of positions and staffing challenges. Many participants noted they would like to see more dementia resources on the reservation. Access to specialized services, such as neurologists, are located off reservation requiring travel. Finally, participants noted there may be reluctance of community members to discuss dementia, maybe partly due to a hesitancy to listen to non-Native providers.
- **Recommendations to improve dementia care**
  - Resources: Participants identified several resources they would like to see available to the community. Respite care and adult day services were cited as very important and needed aspects of dementia care. The Community Advisory Council echoed the importance of having respite options. Other suggestions were ADRD community education, caregiving support and education, and to have Elder advocates.

COMMENTS FROM THE COMMUNITY ADVISORY COUNCIL

A draft of this report was given to the Community Advisory Council in early January 2022. The CAC members provided feedback and comments on the draft at the February 2, 2022 meeting. The CAC found grammatical errors that needed to be fixed, in addition to clarification and correction of certain services available in the community. These updates were made throughout. The CAC was very supportive of the recommendations section found at the end of this report (pg. 34). The CAC was given another month to provide further edits or feedback to be integrated into the final report before presenting the report the Red Lake Tribal Council on April 12, 2022.

INTRODUCTION

The focus of much of the research conducted at Memory Keepers-Medical Discovery team is to improve the lives of persons living with dementia (PLWD) by examining the impact of dementia across the disease trajectory on Indigenous PLWD, families and communities. The origin of the name, “Memory Keepers” Medical Discovery Team is significant. In many American Indian cultures, respected adults and elders of the tribe are responsible for preserving sacred medicine bundles, songs, and stories. In this spirit, the research to preserve brain health will enable American Indian and First Nation communities to continue to benefit from the wisdom of their older adults and elders far into the future.

BACKGROUND

This report is based on research conducted from 2018-2021. The project was originally funded for a two-year period (2018-2020) with a 1 year no cost extension (2021), and was funded by the National Institute of Aging (1R56AG062307-01, PI: Jacklin). The aim of this research was to establish research partnerships with four diverse American Indian and First Nation communities (AI/FN; Figure 2):

1. Miskwaagamiiwi-zaaga'igan - Red Lake Nation (Minnesota [MN])
2. Kitchi-Onigaming - Grand Portage Band of Lake Superior Chippewa (MN)
3. Oneida Nation (Wisconsin [WI])
4. Seven First Nations on Manitoulin Island (Ontario [ON], Canada), including Wiikwemkoong Unceded Reserve, M'Chigeeng First Nation, Sheguiandah First Nation, Sheshegwaning First Nation, Wauwauskinga First Nation, Zhiibaahaasing First Nation, Aundeck Omni Kaning First Nation

Establishing these relationships allowed us to collect and analyze ethnographic data about the impacts of dementia along the disease trajectory in diverse community contexts. Ethnographic data encompass a wide range of data collection through observation, interviews, and focus groups and help to better describe a particular community.Our hypothesis was that Indigenous cultural understandings of Alzheimer’s Disease and Related Dementias (ADRDs), along with community-specific circumstances, shape the ADRD illness experience significantly enough to create distinct impacts in this group warranting culturally tailored approaches to diagnosis and care.

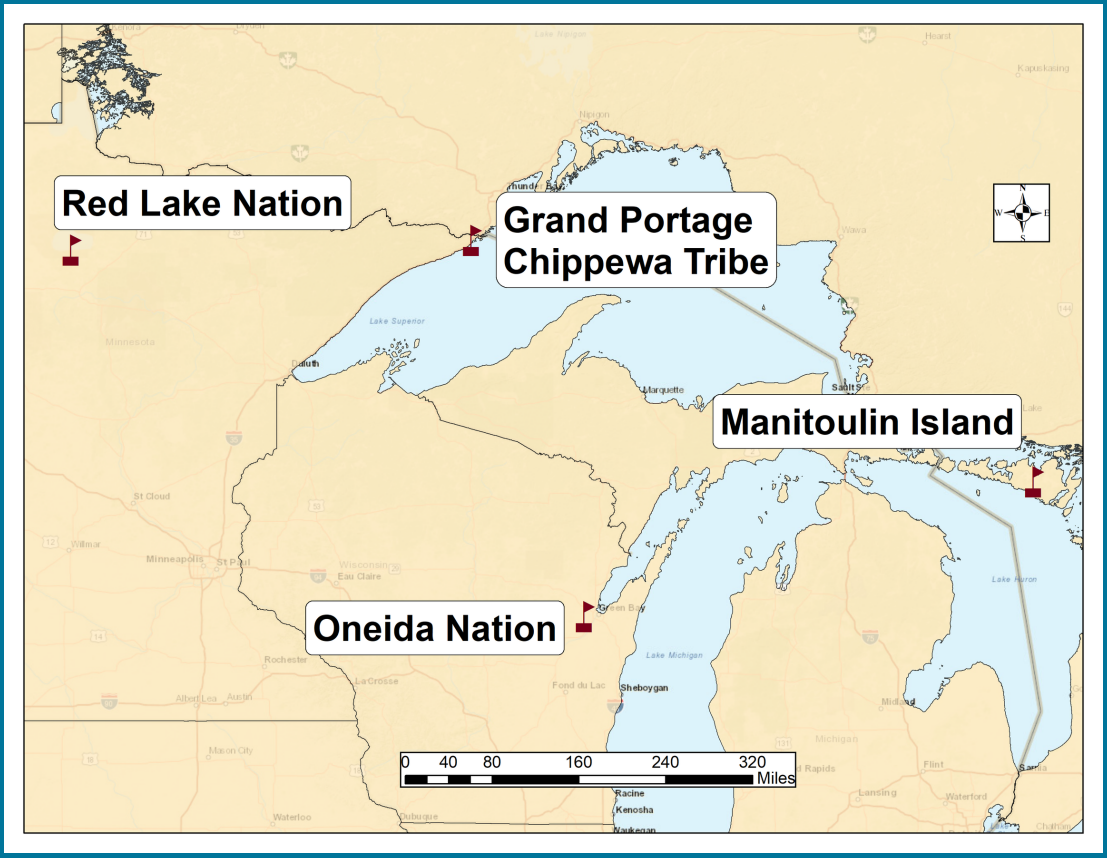


Figure 2. Map of study locations

Given the scope and breadth of Indigenous cultures in North America, this project aimed to understand dementia knowledge, beliefs and experiences of Indigenous peoples living in each specific, distinct region. We took this approach with the understanding that these different areas and cultures are affected by differing geographies, policies and economies. Through this approach, we hope to better understand the adaptability and scalability of our findings to other Indigenous communities in North America.

The specific aims of this three-year project included:

1. Implement a community engagement strategy in four diverse AI/FN communities to establish Tribal Resolutions supporting a research strategy examining the impact of ADRD on families, caregivers, PLWD and communities.
    - We will establish Community Advisory Boards (CABs) at each research site to represent community interests in the research and to assist with recruitment.
2. Generate preliminary data on community-level social determinants of health (SDOH), demographics, health status, and health service use at each site to assist in the development of a feasible and representative sampling strategy and research protocol

for qualitative interviews with community-dwelling people with mild and moderate dementia and their caregivers to be proposed in an R01.

3. Conduct key informant interviews (KIIs) and sequential focus groups (SFGs) to (a) gain an understanding of cultural and community level factors influencing the impact of ADRD across the disease trajectory in the diverse AI/FN communities; and (b) clarify AI/FN specific ADRD considerations for diagnosis and staging to identify appropriate methods to appropriately stage future interview participants.
4. Use the preliminary data and community-engaged research infrastructure developed during the R56 ICARE funding to support a R01 5-year grant proposal.

RED LAKE NATION: COMMUNITY PROFILE

GEOGRAPHY AND HISTORY

Miskwaagamiiwi-zaaga'igan (Red Lake Nation), located in northern Minnesota, is a sovereign Ojibwe Nation and one of only two "closed" reservations in the United States. The Red Lake reservation is the largest land-based closed reservation consisting of approximately 800,000 acres (Figure 3). Roughly half of the original acreage, including Upper Red Lake has been lost through years of broken treaty promises and encroachment by white settlers. The term "closed" means the current reservation held intact or in common and in trust by the membership with no private property parcels interspersed throughout the internal boundary. This closed or intact outcome means that individual tribal members do not have the legal right to sell their land to outsiders for personal and financial gain. The trust land status is a mass of land that is solely held in common or trust by its members/citizens and under tribal control and is not for sale by its members.

Indian Tribes have always been considered separate, sovereign nations as proven by treaty making and stated in Article 1, Section 8, Clause 3, of the Constitution (commerce clause). Red Lake exercises its right to self-govern the people and works on a government-to-government basis with the federal and state governments. Red Lake membership is the second largest member tribe in the state of Minnesota, next to White Earth. The Red Lake Tribal Council is the largest governing body of tribal elected officials in the state of Minnesota, consisting of eleven elected tribal leaders. A Chairman, Secretary, and Treasurer along with two representatives from each district make up the sole governing body of the entire Tribal Nation. The council also includes a council of Hereditary Chiefs which is unique in today's Tribal Governance structure, although, the historical tradition of the Ojibwe people. Four communities which are distinct voting districts inside of the Red Lake reservation include:

1. Red Lake
2. Little Rock
3. Redby
4. Ponemah

The Red Lake Nation is one of seven federally-recognized sovereign Ojibwe Nations in Minnesota. However, Red Lake is not a member of the Minnesota Chippewa Tribe (MCT), which is comprised of the Bois Forte, Fond du Lac, Grand Portage, Leech Lake, Mille Lacs, and White Earth reservations. MCT is a federally recognized tribal government that, through

unified leadership, promotes and protects the member Bands while providing quality services and technical assistance to the reservation governments and tribal people (Minnesota Chippewa Tribe, n.d.).

Figure 3. Map of Red Lake Nation and surrounding area

The reservation land covers 636,954 acres surrounding and including lower Red Lake with additional land holdings in the Northwest Angle totaling 156,900 acres (Minnesota House of Representatives - Research Department, 2017; Minnesota Indian Affairs Council, 2019). Red Lake reservation land in the Northwest Angle includes most of the inland with the exception of the lakeshore property, which is divided into private property parcels.

POPULATION

According to the Red Lake Enrollment Department, there are 16,179 enrolled members with 6,990 people residing on the reservation in 2022 (Table 1). Males consist of 48.9% with a 51.1% female population. Age 20-34 compose the greatest segment of the population at 25.3 percent (Table 2). The population 55 and older comprise about 22% of the population.

Table 1. Red Lake population totals.

Tribal Enrollment	Tribal Population on Reservation	Total Reserve Population (Estimated)	Age 55+ Total Population %	Age 65+ Total Population %	Male	Female
16,179	43.2%	6,990	15.6%	6.6%	48.9%	51.1%

Table 2. Red Lake age cohorts.

Age 0-9	Age 10-19	Age 20-34	Age 35-44	Age 45-54	Age 55 and Over	Age 65 and Over
15.1%	18.9%	25.3%	14.6%	10.3%	15.6%	6.6%

The ACS of 2018 reported median household income at $35,919 with an overall poverty rate of 34.2 percent (U.S. Census Bureau, 2019). More than 20 percent of all households earn less than $15,000 per year (Table 3). Household income breakdowns are presented below.

Table 3. Red Lake household income.

Total Households	<$10 K	$10,000 to $14,999	$15,000 to $24,999	$25,000 to $34,999	$35,000 to $49,999	$50,000 to $74,999	$75,000 to $99,999	$100,000 to $149,999	$150,000 to $199,999	$200,000 or more
1,457	11.8%	9.9%	12.6%	13.7%	23.8%	13.5%	7.5%	6.4%	0.5%	0.4%

EMPLOYMENT

The Red Lake Nation owns and operates three gaming, hotel and conference center facilities known as the Seven Clans Enterprises, which are located in Red Lake, Warroad, and Thief River Falls. An unofficial count reported by a Red Lake official cites a total Tribal Gaming enterprise employment of approximately 1,000 employees with the following approximate breakdown: 200 in Red Lake with 90% tribal employees; approximately 500 in Thief River falls with a 60 percent tribal employee base; and 300 in Warroad with approximately 15% tribal employees. In addition, employing entities include the Tribal government, Red Lake Elementary, Middle, and High School, a Catholic Mission School, Red Lake Hospital, Comprehensive Health Services, Red Lake Criminal justice system (e.g., courts, detention, public safety), a Tribal College, Family and Children Services (e.g., Vulnerable Adults Unit, Foster Care, Child Protection Services, Children's Mental Health, Long-term Care Services, Indian child welfare ACT unit), and Oshkiimaajitahdah (e.g., Community action program, Career Development Services, Adult Basic Education and General Education Development Program, Giniw waakaa'igan- Red lake Vocational Rehabilitation, Temporary Assistance for Needy Families, Supplemental Nutrition Assistance Program, Ganawendindiwag Cultural Program, Agricultural Program, MNsure, Grant Writing, Institutes of Technology, Automotive Training Center, Red Lake Nation Child Development Center, Child Care Assistance Program, Emergency Adult Services, and Wiisiniiwigamig Café and Catering).

Table 4. Red Lake employment information.

Industry	Percentage of Residents Employed
Education, Health & Social Services	42.8%
Arts, Entertainment, Recreation, Accommodation & Food Service	22.2%
Retail Trade	7.6%

All on-reservation industries and employees, with the exception of school district employees, are governed and controlled ultimately by the Red Lake Tribal government. Red Lake employs many non-members from outside of the reservation as well. An exact count is not available.

Unemployment is very high on the reservation. Although the 2018 ACS reports a figure of roughly 25.4%, on-reservation figures reported on by tribal leaders, employers and advocates for economic development and jobs quote an astronomical unemployment rate well above 50%. This more realistic percentage contains an estimation of individuals considered chronically unemployed or who have fallen off the national framework for gathering unemployment statistics, which is a figure, obtained through counting only the individuals actively collecting unemployment benefits.

HEALTH INSURANCE AND COVERAGE

In 2018, 72.5% of the population had health insurance coverage. 17.1% had private coverage, while 57.6% had public coverage. 26.7% had no insurance coverage which is significantly higher than the state of Minnesota average of 4.7% (U.S. Census Bureau, 2019).

On the statewide level, Red Lake Tribal members are eligible to apply for both Medical Assistance (MA), and the MinnesotaCare Program. These are both health care programs for low-income individuals and families (Minnesota Department of Human Services, 2016; Red Lake Nation, 2019b). MA is the state of Minnesota's Medicaid program for low-income individuals (at or below 138% of the Federal Poverty Guidelines (FPG)), while MinnesotaCare also serves low-income individuals who may not meet MA's income limits and guidelines (Income levels at or below 200% of FPG). Most members receive their health care through a health plan or fee for service basis. Eligibility for both programs is based upon income and assets. These programs serve the general population; however, American Indians have certain provisions related to exemption from premiums and asset eligibility, and maintain the ability to use the programs in conjunction with Indian Health Services (Minnesota Department of Human Services, 2016, 2020; Red Lake Nation, 2019b; U.S. Census Bureau, 2019).

HEALTH SERVICES

On-reservation health services include an Indian Health Services (IHS) Hospital and a Comprehensive Health Program. The Red Lake Nation IHS Hospital is a full-service, critical access hospital offering both outpatient and inpatient care and services. The hospital operates 24-hour emergency care, prenatal, well child, diabetes, women's health, diabetic foot clinics, immunizations, and general care (Indian Health Service, n.d.).

The Comprehensive Health Program provides the following:

- Emergency Medical Ambulance services,
- Elderly transportation services,
- Community health nursing services,
- An off-site clinic in Ponemah,
- Physician services,
- Pharmacy services,
- Physical and occupational services,
- Homecare Services
- Hospital support staff,
- Dietary and nutrition services,
- Medication Management
- Mental health and social services,
- Adult dental program (limited services available),
- School-based dental program,
- Optometry,
- Special diabetes program for Indians (SDPI),
- Ship Program (Statewide Health Improvement Program), and
- Nursing Home Services

The nearest off-reservation medical facility and hospital is the Sanford Health Care Facility in Bemidji, Minnesota, and is a 30-minute drive from Red Lake. Sanford Health out of Bemidji, Minnesota, manages a dialysis station on Red Lake (Indian Health Service, n.d.; Red Lake Nation, 2019a; Sandford Health, 2021).

The Red Lake Nation offers a variety of Elderly Health care and support services and includes:

- Jourdain/Perpich Extended Care Center: Built in 1989, the facility is named after the former Tribal Chairman Roger Jourdain and the former Governor Rudy Perpich. The Joudain/Perpich Extended Care Center is a 47-bed Minnesota Department of Health licensed nursing home facility designed to service the elderly and disabled population of Red Lake. All residents are members of the Red Lake Nation, or members or descendants of federally-recognized tribes. The facility is conveniently attached to the Red Lake hospital, providing critical, on-sight care when necessary. The facility does not have a memory care unit but does provide care for people with dementia. The criteria for dementia care are limited and they are not equipped to accept individuals with dementia who wander, are in need of a bracelet alarm system, or exhibit aggressive behaviors.
- Elderly Nutrition Program (ENP): The ENP delivers and serves a meal to the elderly and handicapped daily from 10 am to 1 pm. Food is delivered daily to in-bound residents and a meal is served daily at the center. The ENP also provides other services such as transportation to and from Bemidji on Wednesdays, distribution of a monthly $40 casino card, a $10 meal voucher, and a yearly annual Christmas holiday dinner and celebration.

- Nutrition Services for elderly in Red Lake Hospital, Jourdain/Perpich Extended Care Center, the Ponemah Health Center, and in various elderly nutrition sites.
- Access to all services: Elderly residents of Red Lake also have access to all other health services provided by Comprehensive Health.

The following is a list of Memory Care Secure Unit facilities found off reservation in nearby towns:

- Eldercare of Bemidji/Havenwood Care Center (Bemidji, MN): Independent living, assisted living, rehabilitative care, skill nursing care, memory care; approximately 30 miles away
- Good Samaritan Society (Blackduck, MN): Special care unit with a secure environment; approximately 45 miles
- Sanford Health Trillium (Bemidji, MN): Secure unit memory care; approximately 30 miles away
- Cornerstone Memory Care (Bagley, MN): Memory Care Skilled Care secure unit; approximately 55 miles away

The following is a list of supportive programs and services:

- Northwoods Caregivers (Bemidji, MN): Servicing the local and surrounding areas including the Red Lake nation, provides transportation, respite, homemaking, in home nursing, medication support services, and other support services. A key component of their services includes education and awareness of ADRD and evidence-based support classes for caregivers.
- Elder Services provided by the Minnesota Indian Area Office on Aging, although an MCT tribal program, extends services to Red Lake Nation members
- Dancing Sky Area Agency on Aging: Elderly services provided in 21-counties in Northwest and West Central Minnesota. Service area includes the Red Lake Reservation, located in Beltrami and Clearwater counties.
- Wisdom Steps: Founded in 1999 through an initiative with the Department of Human Services, Minnesota Board on Aging. Wisdom Steps operates to this day with the mission “to foster community partnerships and coordinate resources to provide for the increased advocacy, health education, health screenings and healthy living activities and offers an incentive plan to encourage participation in prevention health programs that will improve the health of American Indian Elders.” Wisdom Steps represents the entire American Indian elder population of the state of Minnesota, including the Red Lake Nation.

METHODS

COMMUNITY-BASED AND INDIGENOUS APPROACHES

Community-based participatory research (CBPR) and Indigenous methodologies are central to this project. While “community” in CBPR can include communities of interest or organizational cultures, for the purpose of our research we define community as distinct geographic and cultural groups; that is, as AI/FN communities residing on federally recognized tribal lands or reservations in Canada and the United States. In our approach Indigenous people (as represented by AI/FN community or organizational leadership) are involved in, and have control over, the research that affects them, so that our research promotes data sovereignty. In CBPR researchers, community members and knowledge users collaborate at all stages of the research and there is reciprocal, iterative capacity building for team members. Participation includes defining research questions, determining appropriate methodologies, interpreting data, reviewing conclusions, and participating in dissemination. This reciprocal process enhances the rigor of the study design and analysis by ensuring the research is culturally appropriate and relevant to communities. Research should have direct or indirect practical benefits to the participants and their communities and should support capacity building at the local level.

We utilize *Indigenous Knowledge/Methodologies* and a *Two-Eyed Seeing* approach. This approach is designed to reflect Indigenous cultural diversity, as well as intra-cultural variability influenced by historical forces of colonialism, geographical factors such as the degree of rurality of communities, and political factors such as health policy and identity related to accessing health benefits. Indigenous methodologies are prioritized in our work and community-based models of care embedded. This is done by incorporating Indigenous ways of knowing, privileging Indigenous stories and voices as a culturally informed interpretation process, building relationships, following Indigenous protocols and being accountable to the communities by adhering to the 4Rs of research involving Indigenous peoples: respect, reciprocity, relevance, and responsibility.

To ensure that Indigenous knowledge is prioritized, we adopted a Two-Eyed Seeing approach. Mi’kmaw Elder Albert Marshall explained that Two-Eyed Seeing was a gift where we learn to see from one eye with the strengths of Indigenous knowledge and ways of knowing, and from the other eye with the strengths of Western knowledge and ways of knowing. An explicit Two-Eyed Seeing approach addresses the power imbalance between the two knowledge systems and places Indigenous and Western Knowledge on equal ground. Elders (respected knowledge keepers), community partners and Indigenous academics are included in our work to ensure Indigenous knowledge approaches are equally valued and ensure effective integrated Knowledge Translation/Exchange (KTE) activities.

COMMUNITY ADVISORY COUNCIL

Previous to this research, we established community advisory groups in Ontario and Wisconsin. In Ontario, the community advisory group is comprised of 10 members and includes Indigenous Knowledge Keepers who are fluent Anishinaabe language speakers, formal and informal caregivers to people with dementia, community members, and health care

providers. The Wisconsin community advisory group consists of six members representing Elder Services, Oneida Nation Commission on Aging, and Great Lakes Native American Elder Association.

In Red Lake Nation, we worked closely with the Comprehensive Health Services Administrative Officer to establish a Community Advisory Council (CAC) in year one of the research. The CAC consists of respected members within the community able to provide guidance on research activities specific to the ICARE project. Members represent a variety of diverse backgrounds, including, but not limited to: health care staff working with seniors and individuals with dementia; caregivers and family members caring or who have cared for individuals with dementia; individuals representing traditional cultural backgrounds and/or language speakers familiar with dementia; and individuals with knowledge of or who represent the dementia community.

The research team works closely with the CAC at each site to review, negotiate and refine the methods, including interview questions, and identifying participants. The CAC is also involved in the analysis and dissemination of results, which will yield opportunities for co-authorship if desired. The research team meets with each CAC at least quarterly to ensure community perspectives and understandings are prominent throughout the project.

COMMUNITY-BASED RESEARCHERS

We work with the leadership and community advisory councils in each location to hire local community-based researchers (CBRs) to assist with all aspects of the research. The CBRs do not require a background in research, but are hired for their expertise and knowledge of their community. The CBR plays a key role in building and facilitating relationships and acts as a liaison between the research team, Indigenous partner organizations, and communities. Key responsibilities include: working with leadership to obtain Tribal Council Resolutions and Motions of Support to conduct the research; provide regular project updates to Health Directors and Leadership; coordinate and facilitate CAC meetings; all aspects of data collection, including recruitment, conducting interviews, focus groups, as well as assisting with analysis and dissemination; and attending community events and answering any questions related to the research.

For the ICARE project, we developed an extensive four-part training module, where CBRs were introduced to the project (module 1), Community Based Research Practices (module 2), Administration and Related Research Duties (module 3), and Qualitative Research Practices (module 4). The training was supported by the ICARE coordinator, Dr. Melissa Blind (Cree), and senior CBR, Karen Pitawanakwat (Anishinaabe kwe). Karen Pitawanakwat, from Wiikwemkoong Unceded Territory, has worked as a registered nurse for over 25 years and has over 13 years' experience as a CBR.

The CBR for Red Lake Nation is January Johnson. January was hired for the ICARE project in October 2019 on a part time basis and became a full-time CBR in June 2020 and a full-time University of Minnesota employee conducting community-based research in December 2021.

KEY-INFORMANT INTERVIEWS (KIIS) AND SEQUENTIAL FOCUS GROUPS (SFGS)

Across all sites data was drawn from the following sources: (1) KIIs with Traditional Knowledge Keepers (TKKs), Providers and Administrators, and (2) Sequential Focus Groups. KIIs were selected in consultation with CAC members and key community stakeholders for their expertise in different aspects of prevention, diagnosis, and care for people with ADRD. KIIs were conducted either in-person or remotely, depending on the needs of the participant and COVID restrictions. Interviews lasted between thirty minutes and two hours. Each participant received a $75 honorarium for their participation. Key informants included Administrators, Physicians, Nurse Practitioners, and Specialists, as well as Traditional Knowledge Keepers.

Table 5. Key Informant Interview information across all study sites

Location	Traditional Knowledge Keepers	Admin	Providers (physicians, nurse practitioners, specialists, social workers)	Total
Ontario	3	5	5	13
Wisconsin	6	5	2	13
Grand Portage	5	5	5	15
Red Lake	**5**	**5**	**3 (2 full interviews, 1 emailed response – not included for analysis)**	**13**
Total	19	20	15	54

The focus group methodology brings together groups of knowledgeable individuals who have shared experiences, lifestyle or interests. We conducted a recently described innovative Sequential Focus Group method successfully implemented in Indigenous communities in Canada. Sequential Focus Groups involve “a series of semi-structured interviews with a consistent small group of people coming together to gain deep insight into a topic by exploring questions about an issue with each other and a group facilitator over an established period of time” (Jacklin et al., 2016). An advantage of the Sequential Focus Group method is the process of daily debriefing and “member-checking” of our initial analysis at the start of each Sequential Focus Group meeting. The Sequential Focus Group documents the care pathways of diverse Indigenous people with dementia (PLWD) by talking with providers, and individuals who identify as personal support/care workers, staff that work with older adults and PLWD whether in their homes, or in independent living facilities, or long-term care facilities in order to get their understanding of dementia during the early, moderate and late stages of the disease.

For this project, Sequential Focus Groups were held with health care staff, formal caregivers, and program managers and staff that work with Indigenous seniors across each site. Each site held between 4-5 sessions, with each session lasting between 30-90 minutes.

The Sequential Focus Groups allowed the research team to gain deeper insight on the mild, moderate, and late stages of dementia with a small and consistent group of people. Across all sites we had 17 participants (3 men, 14 women). Each participant received a $75 honorarium for each session they attended. All participants provided informed consent prior to being interviewed. All interviews after March 2020 were conducted virtually to adhere to COVID-related safety precautions.

Table 6. Sequential Focus Group information across all study sites

Location	Grand Portage	Ontario	Wisconsin	Red Lake	Total
Time frame	December 2020 – January 2021	March 2021 May 2021	April 2021	**April 2021 – June 2021**	Dec 2020 – June 2021
sessions	4	5	4	**5**	14 sessions
participants	5	5	4	**3**	17 participants

DATA ANALYSIS

Interviews were recorded and then transcribed word for word. Those transcriptions were taken back to the original participant and checked for accuracy. The experiences that participants shared were sorted into categories and coded according to a theme – for example, a theme would be Caregiving for Persons Living with Dementia, and a subtheme would be Cultural Understandings of Caregiving. This process allows us to search across interviews for particular topics or experiences and shows us the topics most people agreed upon or there were common experiences. The way sections of the interviews were coded were doubled checked by our research team using a process called double coding and inter-coder reliability. The research team would meet frequently to discuss the themes in the data and analyze the meaning. We created tables with each theme, what it means and quotes from the transcripts that provided examples.

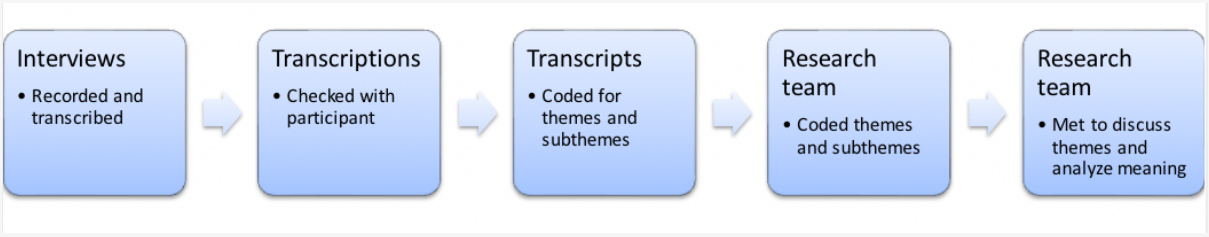


Figure 4. Data analysis procedure.

LIMITATIONS

COVID-19 introduced many difficulties throughout the recruitment, data gathering, and data analysis phases. For instance, recruitment of physicians and providers stopped November 12, 2020 due to competing community priorities. A couple interviews were not completed or the follow ups were not conducted, or translation was not completed, due to numerous time constraints, staff who had to take leave, and COVID related issues. In another instance, a recording failed and did not capture any of the interview. Related to data analysis, transcript

verification took longer than initially anticipated. Specific to Red Lake, a provider interview was attempted over email, but was not included for analysis due to lack of data.

RED LAKE PARTICIPANTS

Data reported here is from research conducted in Red Lake, specifically. A local community-based researcher (CBR; January Johnson) worked closely with the community advisory members, health care managers and administrators in Red Lake to identify and recruit participants. The advisory members and Susan Ninham (comprehensive health administrator) generated a list of names for potential key informants at a community advisory meeting. We also asked participants to recommend anyone else that we should be talking with about dementia in AI/FN populations in this community/region. A description of the general roles of the participants is outlined below.

Table 7. Participant group type from Red Lake study site

Participant Group (n)	General role participant
Traditional Knowledge Keepers (5)	• Elders • Knowledge Keepers • Language specialists
Administrators (5)	• Health Services Administrator • Director • Coordinator • Educational Specialist • Program Manager
Providers (2)	• Social worker • Physician
Sequential Focus Group (3)	• Former CNA, 8 years • Community health tech, EMT, in health field 31 years • Outreach worker, worked in health care for 13 years

The Traditional Knowledge Keeper interviews took place between February 2020-October 2020. Administrator interviews took place between November 2019-July 2020. Provider interviews took place between December 2019-November 2020. Red Lake Sequential Focus Groups occurred between April 2021-June 2021 and took place over the course of 5 sessions.

Figure 5. Timeline of participant interviews.

FINDINGS

We have organized the preliminary findings from our analysis into five large categories which will be further explored in the funded R01 project. Each of these have subthemes that represent topics that emerged as important considerations for Red Lake.

DEMENTIA: CULTURAL AND COMMUNITY UNDERSTANDINGS

Participants provided feedback that greatly improved our understanding of dementia in the community and cultural context, especially the importance of culturally relevant explanations and understandings in health. Many participants interpret dementia through a "circle of life" lens, where dementia is not necessarily seen as problematic but as a natural stage of life. This was also reflected in an example of an explanation of dementia which has been culturally adapted for Native American populations. Finally, in understanding and coping with dementia, participants described how stigma and humor come into play.

CIRCLE OF LIFE

Some Traditional Knowledge Keepers described how dementia and/or memory loss wasn't necessarily viewed as an illness but rather a normal, expected part of the circle of life and the aging process. One Traditional Knowledge Keeper noted that in Ojibwe a person living with dementia (PLWD) might be described as bagandizi (being absentminded) or giiwanaadizi (acting funny or different). Some Traditional Knowledge Keepers mentioned that "personality changes" were expected to happen as people age, and was attributed to the circle of life:

> "…*they talk about that circle of life, when you start out as a baby, you know, they got to take care of you. They got to feed you, they got to carry you around, you can't walk, and they got to make you food to eat, they got to put it right there for you and, and figure out, as you're growing, you got to figure it out. All your, your growing and, and there's, there's, there's, I think there's four stages I'm not ... I'm not an expert in that, but I do uh, what I do know, there's four stages and they, they just go in that circle, and or people understood, you know, how it is being a baby. They understood what, they, what they needed to do to take care of that baby, and uh, in the uh, adolescent this time went on, the, the teenager, with ceremonies that uh, they would do you know, for teens. They would, and they would have ceremonies. They, pass, rites of passage, they call them, where they would uh ... And I remember my mother talking about the, the, her uh, about something like that, she would talk about that, they would not let them use a plate um, because they were on their moon time. You know, they, so they had to have their own, their own plate and fork and spoon and cup and everything on the side, because they told them, they, they needed to use that one until they were done. Then they could go back to use, using regular, you know, regular plates and dishes with everybody else. Cups. She said, she told me that, and they would keep them in a in a bedroom. They couldn't come out, they would have to stay in and look after themselves, and, and when, as, as they got older, there were ceremonies that they had to go through, but then when, when uh, that circle, when they get into that [inaudible] you start coming on like they start getting not even remembering things and like that, you know, that's uh, um, they understood that. You know, they accepted it.*

They didn't, they didn't say, "Oh, don't go over there. They're, they're talking out of their head." You know? And they just understood them. They were just, oh. That's okay. They, no, it's not a big, it's not ... I don't know how to say it out, it wasn't a uh, it wasn't wrong that they were sometimes they would, they would forget things and sometimes they would say things uh, that uh, they were, they were, they, that old, that older people start saying, you know? (TKK-01)

Similar to Traditional Knowledge Keepers, administrators/providers also recognized the importance of the circle of life. They described how, culturally and historically, memory problems might be more likely to be attributed to normal aging or life experience (AI/NA view) rather than needing a diagnosis (biomedical, Western view) of ADRDs. The cyclical view of life was described by an administrator:

"…we cycle through life that we are born you know, that when we are born, we are born um, where we need to have somebody nurture us in growth with and to take care of us, all the things we need and then as we, as we go through life you know, we're still getting, we should still be getting that guidance and stuff you know, um, through life until we reach that level of maturity you know, where now things are changing with us, physically and mentally and we are now on the other side of life. That mid-point you know. And, and so we're in a natural process of aging." (AD-02)

CULTURALLY ADAPTING STORIES TO DESCRIBE DEMENTIA

Finally, one administrator detailed how the Dementia Friends program had worked to culturally adapt a story about memory loss and dementia for NA/AI populations by describing it as a river and incorporating the four seasons. "The River Story" (found here: Dementia Friends: The River (a Story about Dementia) first connects the four seasons with the four stages of life, as well as to the flow of a river. In a person's Elder stage (winter), dementia is described as a blizzard, causing fierce winds, making a person unable to hear and see because of the blinding snow (more information about adapting the story can be found here: https://www.dementiafriendsusa.org/sites/default/files/documents/Dementia%20Friends%20Tools%20and%20Resources%20Flyer.pdf).

STIGMA

Administrators described how they perceived stigma associated with all brain disorders (e.g., epilepsy, memory loss), not just dementia. However, they felt that with more education, people became more comfortable discussing ADRDs:

"There has been shame in identifying or recognizing or even acknowledging that you have some type of brain disorder that, you know, my... I remember hearing my parents and my grandparents, my aunts using a negative descriptor of community members who were experiencing any kind of brain disorder. And it was for epilepsy, for, you know, loss of memory. Those two are the primary two areas that I remember them using the, that negative terminology about. And for epilepsy, they used to call it the fits. For memory, it was, it wasn't dementia or Alzheimer's, they would just say that it was of old age." (AD-01)

Another provider felt that all populations, not just AI/NA groups, did not fully understand aging and memory changes until they had confronted it personally or received more education.

IMPORTANCE OF HUMOR

Administrators also pointed out that sometimes when a “weakness” is identified, AI/NA people will resort to humor, rather than being “gloomy about it”. This was echoed by a Sequential Focus Group participant, who noted:

> ““I noticed like in another, um, in another race, it probably wouldn't be as humorous or whatever, like, like we tend to make it, you know? (laughs) It's like he likes to make jokes about it and stuff, but yeah, and I think that's how, that's how we've been talking about it lately.” (SFG-01)

This Sequential Focus Group later noted that using humor was a part of the healing process, a way to cope with the situation.

CAREGIVING: CULTURAL AND COMMUNITY UNDERSTANDINGS

Caregiving is essential in understanding how persons living with dementia are living their lives. In this section, participants gave examples of, and describe the importance of, both family and community caregiving. They also connected aspects of caregiving to traditional knowledge such as the Seven Grandfather Teachings.

FAMILY CAREGIVING

Family caregivers were understood by all participants as immensely important in taking care of a PLWD. Administrators/providers specifically identified how important family members are. A Sequential Focus Group member described family caregiving as such:

> *“…one of my grandsons that lives with me, and his mom... um, he's now pro. But when I became sick, or have surgeries and all, he would help me and that was from like eight years old, and it, it was just a natural thing to be... so that's probably the way they see it, they don't see it as caregiving, you know, it's just a, a norm to be helping the family, the elders, the older people in their homes. They don't see it as being a job or, you know, they just help take care of their grandparents, great grandparents who's ever ill, I guess.” (SFG-03)*

Administrators/providers also recognize that there are family dynamics and relationships that can be hard to negotiate, but they felt that active family involvement is important in keeping a loved one at home for as long as possible.

> *“I think just the strong family connections that people have. Um, not everybody but, you know, many families have large extended family and, and they're close and nieces and nephews, and aunts and uncles and grandchildren are all involved with the care often. Some of 'em, so it's not always, but yet that, that's a huge strength in the community that families are...have strong bonds and care for each other.” (PR-01)*

"I mean, there's a great amount of love that, you know, again, with [a] small population, a subset population that we're talking about within my practice, it's the amount of love that their family has for them. And that's huge. They're not just going to send mom, dad, grandma, grandpa into a home and say, 'Good luck'. I meant, they're there, they want to be active, they want to help. I think they want their family member to still feel that they have some sort of independence still…I think it's a huge advantage that they have that much engagement [in] that patient's care." (PR-02)

Sequential Focus Group participants also identified stressful situations that family caregivers may face:

"Well, I do have a friend. She's recently opened up to me about her grandpa, he's like in the beginning stages, then, just recently got diagnosed. And I know she's dealing with a lot of stress, you know, because you forget a lot of things and um, I don't know, nobody really comes over from the family, and I know she wishes that she had help, but um, you know, being that how he is everybody kinda just don't go over there anymore, you know. She thinks it would be helpful though if there was more family that came around on every day and helped, or you know just at least came to visit, but um...Like around where I lived there's a lot of drug use. There's families that kind of... however the ones that are using they just tell them, 'You know, can you stay away?' People with dementia get taken advantage of, you know, cause they don't remember things and they're just really vulnerable." (SFG-03)

"I don't wanna say it was a burden because I was glad I got to spend the time I got to spend with my grandpa and stuff, but it, it was hard, you know? It was hard for, it was hard for the one family member to be there... (SFG-01)

COMMUNITY CAREGIVING

Traditional Knowledge Keepers noted that in the past, if someone in the community was dealing with dementia or any other illness, community members would step up to help. Traditional Knowledge Keepers described the omnipresent nature of community caregiving:

"Any illnesses that comes about in any of the communities around here, everybody, most people will know and they all just kind of look after them, right?" (TKK-01)

Traditional Knowledge Keepers also mentioned that elders especially are looked out for, with younger members bringing them food or pushing their wheelchair. Yet a Sequential Focus Group participant identified a potential weakness in this system, saying:

"I guess people who have been at home being taken care of by family, I think that, um, like that program that [another participant] worked with, which is like community health type of nurse. But, um, they don't really, we know they're not there every day and maybe just like once a week. So, I guess the family gets exhausted, you know, taking care of their loved one, making things worse." (SFG-04)

This is tied to the cultural understanding that aging is a natural process (discussed earlier) which requires help from other people and is supported by the idea of respecting elders and serving people of the tribe as your own family ("brothers and sisters of the tribe"). As a result, it is felt that it is better for tribe members to stay in the community so they are better taken care of, as many doctors are not "Red Lakers" and might not provide the same level of compassion as a tribal member would. Similarly, traditions (such as pow wows, smudging, drumming, traditional games, Ojibwe language class) were also seen to be upheld in the community:

> *"Um, like from my experience, like, the non-Native workers were kinda like, like I would call all the elders, grandma and grandpa and that's just, you know, I believe, it's out of respect. But they wouldn't give it, you know, I'd be like come on grandma, come on grandpa, let's go to bed, you know, like putting them to bed and stuff and they were like, 'Why do you keep calling them grandma?', like, 'I just heard you call like five ladies grandma today', like (laughs). Because, you know, and I'd have to explain and it is kinda different in a Native, you know, with Natives than it is with non-Natives to be caring for them. They are all our grandpas and we treat them [with respect]." (SFG-04)*

THE SEVEN GRANDFATHER TEACHINGS

In the final Sequential Focus Group, members spoke about the importance of being honest with PLWD during caregiving. One member gave the following example about his grandfather:

> *"He would sit there and wait for my dad to come to work every day. And he would forget that he was gone and he used to be sitting there watching out the window. And I'd have to say, 'Grandpa, he's not going to be, he's not going to be here, you know, cause he's passed away now.' And that would hurt him all over again. But I couldn't let him think that he was gonna show up for work you know. So there's instances like that too where you've gotta be honest with the resident about occurrences that happened in his life or their life that they may have forgotten happened or, you know. (SFG-05)*

The Sequential Focus Group was asked by the moderator if they thought this could be connected back to the Seven Grandfather teachings about honesty, which the Sequential Focus Group agreed it could. They also highlight how important honesty in caregiving for a PLWD was for their mental health.

ADRDS IN THE COMMUNITY: RISK FACTORS, SYMPTOMS, PREVENTION

This project sought to understand how Alzheimer's disease and associated dementias are viewed in the community. In this section, participants outline what they perceive are risk factors and signs and symptoms of dementia, as well as how it is diagnosed, prevented, and treated.

RISK FACTORS

Administrators and providers both mentioned the impact of chronic disease (e.g., diabetes, cardiovascular disease), health behaviors (e.g., substance use, lack of physical activity), and brain injuries/head trauma on the development of dementia. These ideas were also reflected

by some of the Traditional Knowledge Keepers, who pointed to genetics, vascular issues, brain injuries, diet, and substance abuse as potential impacts for developing ADRDs. Providers described seeing brain injuries more often in males than females, mostly due to accidents resulting from risky behaviors. Administrators connected homelessness and overall health inequalities among AI/NA to these risk factors. Providers were also concerned with knowing the specific type of dementia a person had in case there was a genetic component, in order to give family members information on how to reduce their risk factors/behaviors. Administrators acknowledged that since people are living longer, there is a need for more prevention and education efforts. Administrators made a connection between stress (related to poverty, homelessness, etc.), workplace hazards (such as secondhand smoke) and pre-existing conditions (e.g., diabetes) as important considerations for the Red Lake population they serve.

SIGNS AND SYMPTOMS

Participants mentioned similar signs and symptoms when it came to ADRDs. Administrators/providers described seeing behavior changes (e.g., anger) and memory loss (e.g., forgetting appointments, medication, needing help with certain tasks) as primary indicators that someone's cognitive status may be changing. One provider described a typical discussion regarding cognitive decline with patients:

> *"Well, first and foremost, we talked. It's a great history taking. Its, uhm, what are your concerns with this? I mean, if they bring it up, then either they're truly concerned about it, or they just want to make sure they don't have it. Um, so, I think, the first thing I do is get a good history from them. Um, what are their concerns? What are the events that caused them to think this?" (PR-02)*

A Sequential Focus Group participant described later stage symptoms when sharing the situation which caused them to move their loved one into a facility:

> *"Like my grandpa used to get pretty combative, but it wasn't... Like in the early stages, like, he would remember me because I was there, like, um, daily and stuff, but like with my aunties, like they weren't there as often. So when they would try to go over there and boss him around and stuff, like, yeah he would get mean. But, like, when we decided to finally, um, bring him to the nursing home, it was because he was forgetting to eat, he was forgetting to eat, he was forgetting to wash up and, you know, and, and we'd ask him, you know, 'Did you, did you eat today, or...' And he would say, 'Yeah.' But then, you know, I would notice like the dishes or whatever would still be clean, that I did the day before and he was just forgetting to eat, you know, and thinking that he did." (SFG-01)*

Traditional Knowledge Keepers mentioned experiencing loved ones telling the same stories over and over, or people forgetting where they parked their car, or visiting people in the nursing home and they mistake them for someone else. They noticed that loved ones might be responding the "wrong way" to their questions or visiting people in the middle of the night.

DIAGNOSIS

Participants mentioned various ways in a which a loved one may get a diagnosis of an ADRD. Providers mentioned that often it is a family member who brings their concerns to the attention of the provider, who can then work with specialist to work towards a diagnosis. However, between the administrators and providers, the process of screening, receiving cognitive assessments, and eventual referrals, seemed to be unclear and complicated. Administrators mentioned several different providers who could make dementia diagnoses, including primary physicians, behavioral health, nursing staff, Social Services, psychiatrists, social workers, and mental health professionals. Providers mentioned working with psychiatry, psychology, or neurology to obtain a diagnosis. While the diagnosis/referral pathway was unclear, both administrators/providers agreed that accurate, early assessments are necessary to build appropriate care plans for a PLWD and their caregiver(s). Providers felt that an earlier diagnosis can help families provide better care, emotionally adjust, and helps prepare everyone for the future.

PREVENTION, TREATMENT & DELAY

In discussing the prevention and delay of ADRDs, Traditional Knowledge Keepers discussed how keeping active – both mentally and physically – could help keep one's mind healthy. Mental activities, such as conversing and interacting with family or community members, are good to keep social isolation at bay. Physical activity was described as a way to both connect to the environment and as a way to connect the brain with physical movements and tasks.

> *"To keep your mind active, maybe even learn something new that requires using both your brain and also using your hands, you know…what you have in your brain is also being transferred to your hands, whether its cooking or doing some kind of craft." (TKK-03)*

> *"I believe that if you lead an active life, that in itself will be able to help prevent or slow that process [memory loss/dementia]. Like myself, I got a brain injury, and I got memory issues. But I'm always doing something, I'm always cutting wood or setting up something or doing something. Try to stay busy all day." (TKK-04)*

Other Traditional Knowledge Keepers mentioned the importance of spiritual activities such as drumming, singing, praying, smudging, as well as using medicines such as tobacco, sage, sweetgrass, and taking cedar baths to help keep the mind healthy. Wild game was described as medicinal since game are eating medicinal plants and roots. The importance of being in balance was also discussed.

> *"I would think that you'd have to work with your spirit. You know? You gotta get everything in balance. Your four parts. Your mind, your emotions, your physical, and your spiritual. You gotta eat, you gotta exercise, you gotta rest, you gotta sit and do your prayer. You've gotta live that way and then, then everything will even out. And I, that's what I believe. And then the spirits will help you." (TKK-04)*

Traditional Knowledge Keepers also mentioned using swamp tea, baruk, and even CBD oil to help keep the mind healthy.

In relation to prevention and delay of ADRDs, administrators described an informational brochure which included healthy brain tips (e.g., healthy diet, being physically active, etc.) available for the community. Neither administrators/providers nor Sequential Focus Groups spoke about prevention efforts associated with ADRDs, other than an informational brochure described in the administrators/providers group. Besides this brochure, active outreach/community education about the prevention/delay of ADRDs was not discussed. Providers also stressed the need for loved ones and family members to understand that life is different after an ADRD diagnosis, but it is “not the end of your life”.

In relation to treatment of ADRDs, both administrators/providers discussed the role of traditional healers. Administrators seemed to be much more connected to traditional healers, as they were aware of specific individuals who could provide spiritual care. Providers, on the other hand, were aware of traditional healers but did not (professionally) refer to them.

SERVICES AND BARRIERS TO CARE FOR A PLWD AND THEIR CAREGIVER(S)

While administrators and providers described many available facilities, services, and programs for persons living with dementia and their caregivers, participants in the Sequential Focus Groups did not seem to be aware of these services and programs. This is a potential challenge to those seeking support, along with described financial and programing cuts, geographical issues, and a need for specialized dementia training and education for all community members.

SERVICES AND PROGRAMS FOR CAREGIVERS AND PLWD

Administrators/providers detailed numerous available facilities, services, and programs for PLWD and their caregivers. For example, within the community there is a long-term care facility, the Indian Health Service to provide diagnostic services, and help/services for elders and people with disabilities (e.g., homemaking, transportation, respite, medication management, etc.) through individuals such as a community nurse. Additionally, individual and group support is available for caregivers including evidence-based classes (e.g., Powerful Tools for Caregivers, REACH) and awareness (e.g., Dementia Friends, conference on dementia education). Providers identified the importance of family in providing support to a PLWD and identified ways to pay family caregivers as “providers for clients”. Administrators/providers also identified that language translation, either through family members or formal services, were readily available. This is in contrast to Sequential Focus Groups, who identified that translation can be a problem (especially with younger generations).

In contrast, Sequential Focus Groups were not as knowledgeable about available services or facilities, identifying the nursing home, dementia education workshops, and Google as resources. One participant told a story about her friend:

"I know she goes to like... well if she has, like you know, have questions about it or, you know, wants to know... it's like if anything new starts happening with her grandpa, she's just goes to Google a lot is the only thing that she ever tells me, she just... she's kind of a bookworm to associate like, maybe she... I know she does most of the work online too, so it's probably mainly just Google and, you know, reading up on it on websites and stuff, but there's nothing in the community that she uses that I know of besides her doctor." (SFG-03)

While there seems to be services available, administrators rely on "word of mouth" and informal relationships to disseminate information and get people access to services. This could be both a benefit and deficit to receiving care/services, since the reliance on relationships can be helpful for those with the right connections, and potentially harmful for those outside the necessary connections.

BARRIERS AND CHALLENGES

Other barriers were also identified, including financial (e.g., budget cuts, staffing shortages, ability of families to pay for services), geographical, and a general need for specific training on dementia resources/education. Sequential Focus Groups stated that there were not many services for PLWD and their caregivers available in the community. When asked about barriers or challenges faced by the AI/NA population, one provider said:

"Probably the first thing I think of is the lack of resources on the reservation, for education and, and like you know, even our services. I think we could be meeting a lot more people and having more clients if we were bigger and had more people and more resources. We could still be growing right now, but we're kinda plateaued with the staff that we have right now, but, I mean even dementia education, if there was more resources, it would help the community." (PR-01)

Administrators/providers noted that funding challenges led to a loss of positions (e.g., activity coordinators, community outreach) and general staffing challenges, especially nurses and mental health providers. As a result, there is a reliance on volunteers who may not have the appropriate dementia training or knowledge.

As for how the community feels about dementia, administrators/providers both felt that there was some reluctance among the Red Lake population to discuss dementia. Part of this reluctance might be "stubbornness" or "resistance" on the part of the loved one. For instance:

*"**Participant 1:** A barrier to them is just not wanting to and trying to get them to, to go. (laughs)*
***Participant 2:** That's true.*
***Participant 1:** It's hard, especially when, you know, they're adults and, yeah, that, that's hard.*

Participant 2: *Well, my mom, um, she was, what, 80... Well, sh- she was 83 when she passed, but, um, she passed from COVID. And, uh, but all the time when we... before she wound up in a nursing home, um, she says, "Well, I don't have to listen. I'm 80-something years old. I can do what I want." And we said, "Okay."*
Participant 1: *(laughs)*
Participant 2: *So we would just do what mom says. (laughs)*
Participant 1: *Yeah. It's hard. Sometimes they just don't know what's good for them, you know? And even, especially if they got dementia and they know they... they know they're adults. (laughs)*
Participant 2: *Yeah, yeah. They won't let you forget that. (laughs)" (SFG 01)*

Another potential barrier identified by a Sequential Focus Group was a reluctance to listen to non-Native providers:

> *"…with the few elders that I worked with, like, they hated to, um, listen to the white nurses or, you know, the non-Native caregivers. And they would, like, kinda mock them, you know (laughs), when they would tell them to try to take care of them and stuff and so that was- that was another, like, barrier or, you know, for their care and stuff because they were stubborn when it came to having to take advice from a non-Native. And so then we'd have to go there and tell them what to do. The same thing that the White nurse or, you know, whatever White doctor tell them and they would listen to us because we were Natives and it was. So that's kind of a barrier too, you know, like they hated to take advice from a non-Native. And I know that." (SFG-01)*

RECOMMENDATIONS TO IMPROVE DEMENTIA CARE

Administrators discussed wanting more ADRD community education, caregiving support and education (including adult day services), and elder advocates. Sequential Focus Groups also wanted to see more education for the community on signs and symptoms for dementia, and education especially for younger people who are living in multigenerational homes. Specifically, administrators wanted to see a public service campaign that explained about services available to people/caregivers of those with ADRDs, as well as more education on dementia, such as signs/symptoms for families to lookout for or how to care for someone with dementia.

Administrators also noted the importance for respite care/adult day services, but that similar operations (such as one in Cass Lake) had closed because community members were not bringing in their family members. Providers mentioned wanting to see more prevention efforts for high-risk health behaviors that contribute to ADRDs, and to get access to services that currently do not exist in the community (e.g., assisted living, memory care) or to expand service options (e.g., respite care providers). One provider stated:

> *"Respite is a big, needed service, and the other huge need that we have is for assisted living options here in the Red Lake nation. There are none. There are no options for assisted living or memory care. [T]he nursing home that we have here, they don't take people with memory prob[lems]...with dementia that might wander away cause they're not a locked facility. Or they have behavior issues 'cause they're not specifically a*

memory care facility. They don't have a unit even...one thing we really need is a unit... And Respite Care services for caregivers." (RL-PR-01)

The lack of respite for family caregivers was echoed in the Sequential Focus Groups, with a participant stating:

"I know, um, when they're in the community, at home or whatever, um, I think it's just, you know, family relying on family." (SFG-04)

The Sequential Focus Group participants also mentioned they would like to see some sort of community center or adult daycare available for the elders to visit during the day, which could also provide respite for caregivers. They felt it would be better attended if there was an option available in each community.

Lastly, one administrator felt that there was a need for elder advocates within the community. They said they wanted elder advocate spanning all elder issues, not just ADRDs:

"Not only for individuals with dementia, but for all our elders, we need people out there advocating for them. I try to do it sitting at this desk, but with all the other responsibilities, I feel like my attempts are diluted. So, I think if we, If I could get a volunteer in each of the communities with the Senior Companion Program right now, I would change their title. Rather than senior companion, I would make them elder advocates and I'd have them sit at the Elderly Nutrition Program every day to hear any concerns that our elders have, and I would pay them to do it. So we can get elderly advocates out in the community." (RL-AD-03)

Administrators mentioned that elder advocates would be beneficial in the various Red Lake communities, at Indian Health Services, and on the Tribal Council.

Sequential Focus Groups and Traditional Knowledge Keepers had suggestions for care teams, caregivers, and providers associated with PLWD. Traditional Knowledge Keepers encouraged family caregivers and HCPs to treat people with dementia with compassion, respect, and with spiritual care. One Traditional Knowledge Keeper suggested for caregivers especially that:

"…caring for someone with dementia, I would, you know, just tell them to, you know, keep them safe and, you know, use your tobacco and pray, and ask the spirits to help, and guide and help you to know what to do." (TKK-04)

Sequential Focus Group participants wanted to see the same people taking care of PLWD in order to develop a bond and alleviate potential problems.

"That could probably be one of the recommendations for like, for caregivers to like, um, be repetitive in the care for people with dementia. Like, you know, like instead of just having any old buddy in there. Because you really do gotta to know the, the people that you're caring for in order to give them the right care, the proper care, you know." (SFG-05)

Understanding the loved one's likes and dislikes was important to pass along to formal caregivers in order to keep a loved one happy. For instance, a Sequential Focus Group participant noted:

> *"Like, like say one resident didn't like her hair pinned up, but you know, they come to work and found out that, you know, somebody pinned her hair up. And, you know, she was sitting there looking all crabby and they didn't understand why. It was because their hair was pinned up a certain way, (laughs) you know. Just little things like that can... You know, some of things like that, that's what I, you know, think about when I would see somebody with late, late-stage dementia. And it would, it, it, little things like that would make their day better, you know? That's just from experience, you know?" (SFG-05)*

Similar to the idea of a cohesive and consistent care team was the importance of communication. Sequential Focus Groups also stressed the importance of communication for everyone associated with providing care to a PLWD. For instance, starting with education and knowledge for the family so that they better understand the disease and the situation. They also suggested that family meetings would be beneficial once a PLWD is in a facility, so everyone is on the same page.

SUMMARY

This report covers research conducted from 2018-2021. One of the aims of this research was to establish research partnerships with four diverse American Indian and First Nation communities in Minnesota, Wisconsin, and Canada, in order to collect and analyze ethnographic data about the impacts of dementia. In conducting this research, we used several approaches to make sure communities were involved with, and had control over, any research that affects them. This included utilizing the following approaches: community-based participatory research, two-eyed seeing, and Indigenous knowledge and methodologies. In Red Lake, a total of 13 Key Informant Interviews were conducted along with 5 Sequential Focus Groups with 3 participants. The preliminary findings reported above will be explored in the next phase of research and is currently ongoing.

REFERENCES

Indian Health Service. (n.d.). Red Lake Hospital. Retrieved from https://www.ihs.gov/Bemidji/healthcarefacilities/redlake/

Jacklin, K., Ly, A., Calam, B., Green, M., Walker, L., & Crowshoe, L. (2016). An innovative sequential focus group method for investigating diabetes care experiences with Indigenous peoples in Canada. *International Journal of Qualitative Methods,* 15(1), 1609406916674965.

Minnesota Chippewa Tribe. (n.d.). Mission Statement. Retrieved from https://www.mnchippewatribe.org/

Minnesota Department of Human Services. (2016). Medical Assistance. Retrieved from https://mn.gov/dhs/people-we-serve/adults/health-care/health-care-programs/programs-and-services/medical-assistance.jsp

Minnesota Department of Human Services. (2020). MinnesotaCare. Retrieved from https://mn.gov/dhs/people-we-serve/adults/health-care/health-care-programs/programs-and-services/minnesotacare.jsp

Minnesota House of Representatives - Research Department. (2017). *American Indians, Tribes, and State Government*.Retrieved from https://www.house.leg.state.mn.us/hrd/pubs/indiangb.pdf

Minnesota Indian Affairs Council. (2019). *Red Lake Nation.* Retrieved from https://mn.gov/indianaffairs/redlake-iac.html

Red Lake Nation. (2019a). Comprehensive Health. Retrieved from https://www.redlakenation.org/comprehensive-health/

Red Lake Nation. (2019b). Elderly Nutrition Program. Retrieved from https://www.redlakenation.org/elderly-nutrition-program/

Sandford Health. (2021). Sanford Dialysis Red Lake. Retrieved from https://www.sanfordhealth.org/locations/sanford-dialysis-red-lake

U.S. Census Bureau. (2019). My Tribal Area: Powered by the American Community Survey (ACS) 2014-2018. Retrieved from https://www.census.gov/tribal