Indigenous Cultural Understandings of Alzheimer's Disease and Related Dementias – Research and Engagement (ICARE)

Kitchi-Onigaming – Grand Portage Band of Lake Superior Chippewa.
Presented to Reservation Tribal Council October 19, 2022

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- Emma Carlson
- Rebecca Deschampe
- Mary Harrelson
- John Morrin
- Jennifer Sorenson
- Shirley Stevens
- Patty Winchell-Dahl

Collette Pederson is the community-based researcher for this project.

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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
CAG: Community Advisory Group
CBPR: Community-Based Participatory Research
CBR: Community-Based Researcher
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

People here just take care of their own. People do not go away. They will try and keep them here as long as possible and for the couple of people that I've worked with that have had Alzheimer's or early onset, trying to set up services and work with them, it was never they're going to the nursing home. It's, they're going to stay home. They're going to age here in place. We're going to keep them home here. This is where they're going to pass away. This is where they're going to stay. (TKK-02)

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: 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 Grand Portage Band of Chippewas.

On April 12, 2019, the Grand Portage Tribal Council approved the research partnership with Dr. Kristen Jacklin and the Memory Keepers Medical Discovery Team (MK-MDT) through the ICARE Project R56 (Resolution No. 06-19).

During the first year of the grant, we worked closely with former Tribal Health Director, Paula Schaefbauer, to hire a community-based researcher, Collette Pederson. Collette 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, Collette has taken the lead in writing updates within the ICARE project newsletters and building dementia through many community events, including a dementia awareness walk.

Collette was instrumental in helping establish a Community Advisory Group (CAG) to help guide all aspects of the research process. The CAG 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 20 times since it was established in 2019.

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=5), and

- Sequential Focus Groups with health care providers for older Indigenous adults (n=5, 4 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. An annual brief was submitted to the Grand Portage Reservation Tribal Council in February 2020. A Tribal Resolution to continue the research relationship for an additional five years, through seeking additional NIH support, was granted on February 10, 2020 (Resolution No. 05-20). In March 2021, an additional research brief was provided to the Grand Portage Reservation Tribal Council with updates on the research.

This executive summary outlines the major findings from the R56 preliminary data detailed in the Grand Portage 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
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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 Grand Portage Band of Chippewas, MN, Red Lake Nation, 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 Grand Portage Advisory Council will continue to guide all aspects of the research and Collette Pederson will continue her role as the community researcher.

Key Findings

Preliminary findings from Phase 1 of this study:

Dementia: Cultural and community understandings

- **Connection between mental and physical health:** Traditional Knowledge Keepers noted that while there was no known word or words in the Anishinaabe language to describe dementia, one Traditional Knowledge Keeper used the phrase *giiwashkwe niinindib*, "dizziness of the brain". This dizziness could be caused by many different ailments, including depression, as well as spiritual repercussions from not following traditional teachings or ways of life. The importance of physical and mental health was highlighted.

- **Dementia & stigma :** Administrators reported that people living with dementia may downplay early symptoms for various reasons. Sequential Focus Group participants felt that people may be reluctant to discuss ADRDs because “they’re no longer seen as a person”.
- **Aging :** What to expect in the aging process was described by one Traditional Knowledge Keeper using a story of the “four hills of humankind”. Many participants spoke about the importance of keeping an active body and mind to ensure healthy aging. This, on topof using sacred medicines, could ensure healthy aging and aging in place. Participants felt that the AI/NA population they serve was more tolerant to growing older, and that ADRDs may be assumed to be a natural part of the aging process.

Caregiving: Cultural and community understandings

- **Family caregiving** : Participants noted how important it was to keep family members at home, and in the community. While some participants felt that family did a good job of supporting one another, other participants noted that elders could use more support, and highlighted the strain that caregiving can have on people.
- **Community caregiving** : Participants made an explicit connection between cultural values and community caregiving, citing the importance of elder care, rurality, and sharing of resources. Grand Portage was described as a small, tight-knit community, which was cited as a strength in helping to identify ADRD and other health issues among individuals.
- **Formal caregiving:** This is caregiving provided by medical or social service providers. Participants noted the importance of cultural competency training and education for these providers. Additionally, participants described how important it is to check in on vulnerable people in their homes in order to provide access to services or visitations.

Alzheimer’s Disease and Related Dementias (ADRDs) in the community

- **Symptoms :** Participants noted that, most often, friends and/or family members identify issues of concern, particularly memory issues.
- **Risk factors :** Administrators and Providers identified a range of pre-existing conditions, chronic diseases, and health behaviors that they felt were risk factors for developing ADRDs. Sequential Focus Group members also identified what they felt were hereditary risks for developing ADRDs.
- **Diagnosis :** Provider interviewees described implementing routine cognitive screening at 75 years of age to help identify ADRD in earlier stages. When diagnosed earlier, Providers felt that patients and family members would be better prepared for the ADRD journey, and also potential lessen stigma.
- **Prevention, treatment & delay** : While participants noted that medications exist to decrease memory impairment progression, they also reported that having good community support for loved ones and family caregivers was more important. Traditional Knowledge Keepers described several ways that traditional healers could use to help treat ADRD and its progression, but Providers were less aware of traditional healers and how to connect patients to them.

Services and barriers to care for people living with dementia and their caregivers

- Barriers & challenges : Administrators were very attuned to new regulations for assisted living companies that they felt may cause funding challenges due to the need to adhere to the regulations. Participants also reported wanting to see more services provided for respite care, in-home care, and assisted living, within the community. Transportation and distance was highlighted as a barrier to services and specialties. Finally, participants reported that even for services provided in the community, long waiting lists make some services unavailable to community members.
- **Services & programs :** Participants detailed various services available to community members including: rides to medical appointments, respite care, volunteers for companionship, a caregiver support program, a transportation program, nurses for homecare and home health, and a nutrition program.

Recommendations to improve dementia care

- **Understanding available services** : Administrators reported they would like to better understand what services and supports are available from the tribe in order to work together more coherently.
- **Resources :** Participants described wanting to see more services that allow elders to age in place (e.g., in-home care, companion services), as well as respite options, and ADRD education/awareness throughout the community. Providers also described wanting an assisted living facility in Grand Portage, which would allow couples to move in together.

Comments from the Community Advisory Council

A draft of this report was given to the Community Advisory Council mid-March 2022. The CAC members provided feedback and comments on the draft at that meeting. The CAC was supportive of the recommendations section found at the end of this report.

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 sites (AI/FN; Figure 1):

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.

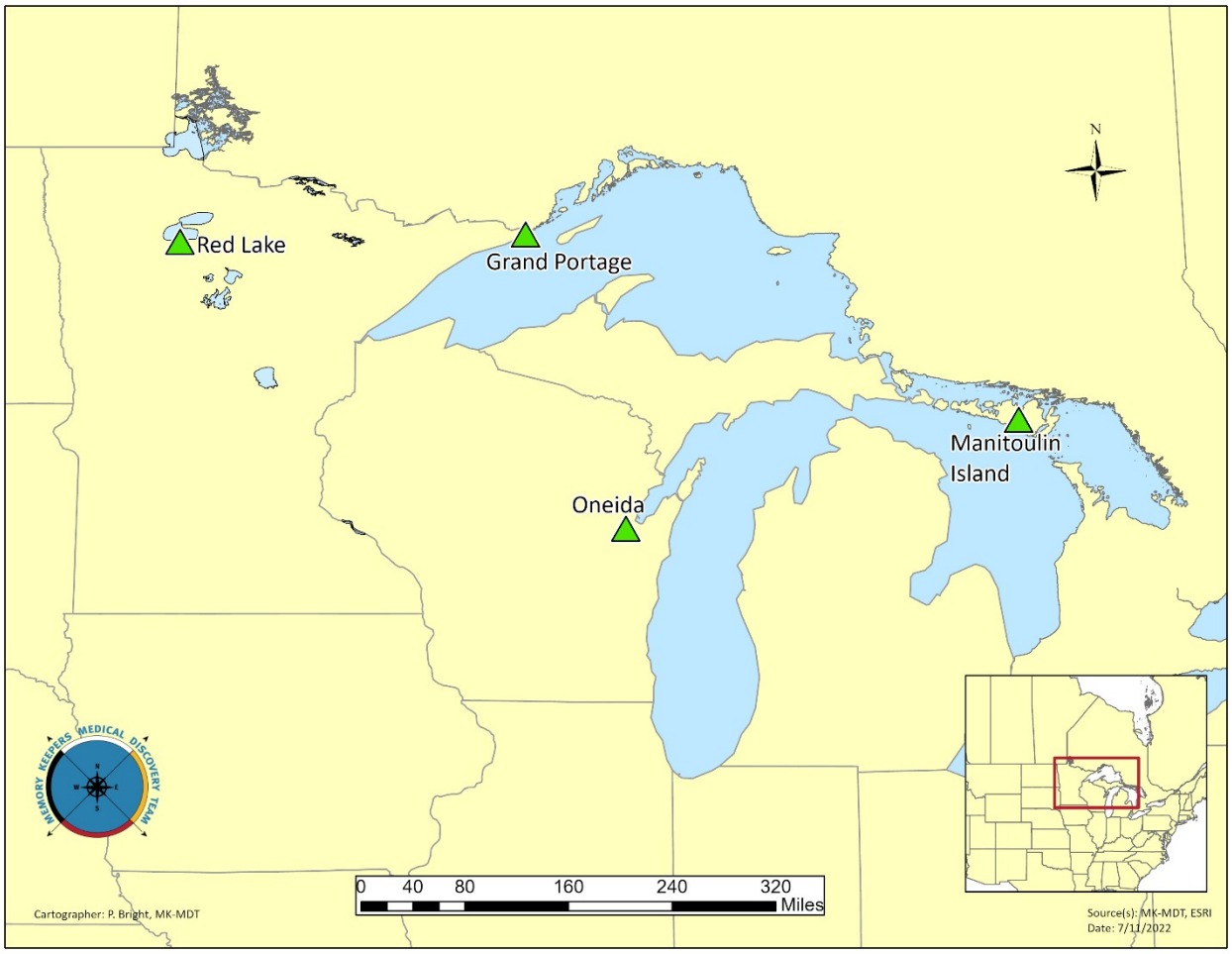

Figure 1. Map of study locations

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, histories, 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.

Kitchi-Onigaming – Grand Portage Band of Lake Superior Chippewa: Community Profile

The Kitchi-Onigaming or Grand Portage Band of Lake Superior Chippewa is located on the beautiful shores of Lake Superior in the far tip of northeastern Minnesota, next to the Canadian border (Grand Portage Band of Lake Superior Chippewa, n.d.). Grand Portage is approximately 36 miles northeast of Grand Marais, MN, and 37 miles southwest Thunder Bay, Ontario. Established in the 1854 Treaty, the reservation comprises approximately 39,517 acres of tribal trust land, 6,357 acres of individual tribal fee land, and 81.5 acres of government land. The name “Grand Portage” comes from the nine-mile overland portage necessary for transit from Lake Superior to the Pigeon River that was used during the fur trade.

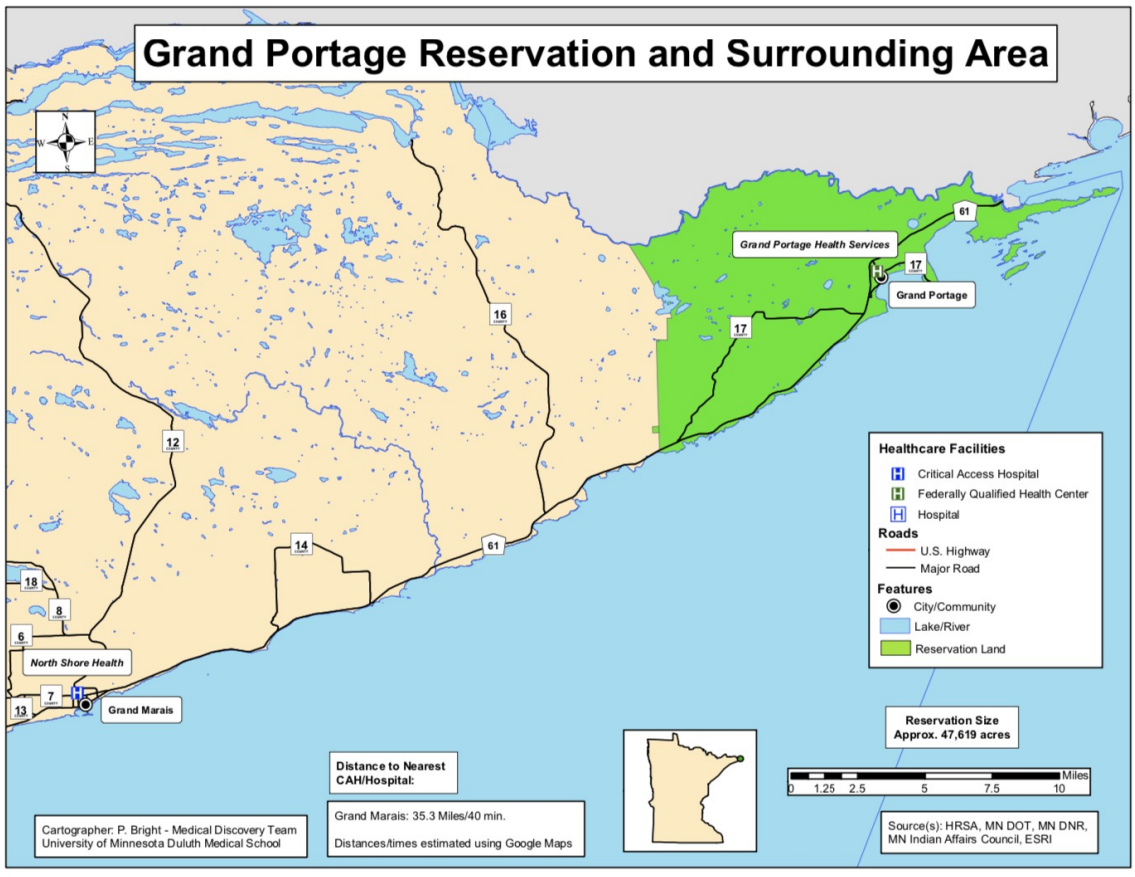

Figure 2. Map of Grand Portage and surrounding area

The people and families of Grand Portage have always maintained close ties with the Ojibwe in Canada. The Ojibwe migration into Grand Portage began in the 1730's around the start of the fur trade in 1731. In the 1760's, the British took over the post and eventually relocated it to Fort William, now known as Thunder Bay, Canada. To date, many families have relationships and family ties dating back to this period when many chose to relocate and continue working at the newly established post at Fort William (Thunder Bay), Ontario area. Today, the international border between Canada and the United States separates many extended family members of Grand Portage Ojibwe heritage.

Governance

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). The federal government's numerous efforts of genocide and complete termination of the culture and sovereign structures are many. However, in 1968, the Tribal Self-Determination era began and continues to this day which led to many laws, policies, and structural changes in dealing with Indian Tribes. Although multiple opinions, arguments, and policy problems on the state and federal level continue today over the true governing nature of the Tribes, the Presidents and Congress have made strides in upholding or reaffirming the true nature of the Tribal sovereign governmental structures and autonomy through numerous acts that uphold their right to self-governance and to work with Tribes on a government-to-government basis. Grand Portage, like all other Tribes, exercises its right to self-govern the people and works on a government-to-government basis with the federal and state governments (Executive Order 19-24. Grand Portage is the smallest member Ojibwe Tribe in the state.

The Grand Portage Tribal Council consists of a Chairman, Vice Chairperson, Secretary/Treasurer, and two at-large members. The band is a part of the Minnesota Chippewa Tribe (MCT), a conglomerate Tribe consisting of six of the seven federally-recognized Ojibwe tribes in Minnesota. Since 1996, the Tribe has administered its own programs from the BIA; entering the self-governance program in 1996. The Tribe set up its own court the following year in September 1997. The State is responsible for criminal and some civil matters.

Language and culture

Few original Anishinaabe speakers remain; however, revitalizing the language and culture are the focus in the K-6 school located on tribal lands. Because of the small population, the Ojibwe language is not often heard. Regardless, the efforts to restore the language are strong.

The reservation is home to the 300-year-old *Manito Geezhigaynce*, a twisted cedar known as the "little spirit cedar tree." This tree has significant spiritual significance, requiring a tribal member guide to visit.

Today, the Ojibwe people remain dispersed throughout seven federally-recognized tribes in Minnesota, each maintaining their own membership and often considered separate from one

another in political, social, economic and in self-governance of their own lands and membership.

The cultural ways of Ojibwe people remain to date in multiple ways and throughout multiple venues: drumming and dancing, songs, storytelling, art, harvesting and cultivating original foods
such as wild rice, moose, fish, and through maintaining spiritual traditions and ways. One of the greatest losses experienced which is perhaps the leading tie to cultural integrity is the Anishinaabe language. Great efforts throughout all Ojibwe Tribal Nations and communities are happening to bring back a flourishing language to this land. It is well understood throughout the communities that language revitalization is necessary to restoring the communities, healing the people, and will finally restore the cultures that have been lost.

Demographics

According to the United States Census Bureau, 2020 American Community Survey five-year estimates (ACS), 722 people were reported as residing on the reservation. Just over half or 50.3% were female, while 49.7% were reported as male (U.S. Census Bureau, 2020). Grand Portage has a relatively small youth population with 21.1 percent of the population reporting age 19 or younger. Population 55 and older makes up 28.9 percent of the population and is the largest segment of the population. Age 65 and older make up 13.2 percent. The median age was 38.2 years (U.S. Census Bureau, 2019). In 2022, tribal enrollment was reported at 1,018. Approximately 22% of enrolled Tribal members live in Grand Portage (personal communication).

Population Totals:

Tribal Enrollment	Total Tribal Population on Reservation (estimated)	Age 55+ Total Population %	Age 65+ Total Population %	Male	Female	Median Age
1,018	222	28.9%	13.2%	48.3%	51.7%	38.2

Age Cohorts:[6]

Age 0-9	Age 10-19	Age 20-34	Age 35-44	Age 45-54	Age 55 and Over	Age 65 and Over
12.2%	8.9%	22.4%	13.9%	13.7%	28.9%	13.2%

Income and economics

In 2018, the top three industries employing residents were: Arts, entertainment, recreation, accommodation, and food services; retail trade; and public administration (U.S. Census Bureau, 2019). In 1971, the Grand Portage Development Corporation was established to spur tribal economic development. The most successful operation has been the Grand Portage Lodge and Casino. The casino is the single largest employment source in the community as well as Cook County, Minnesota. An estimated 18% of casino employees are First Nation Ojibwe from the Thunder Bay area. A gaming official at the Grand Portage Lodge and Casino reports in an unofficial estimate that approximately 10% Grand Portage members are employed by the tribe in the casino industry. A large percentage of the workforce is from other countries other than

Canada. Unemployment was estimated at 2.1% of the total population (U.S. Census Bureau, 2019).

Median household income in 2020 was reported at $54,022 per the Census Bureau; on average,13.9% of the population is below the poverty line, with 6% below the poverty line among seniors (65 and older) (U.S. Census Bureau, 2020). Further household income information is found below (U.S. Census Bureau, 2020):

Household Income Breakdown:

Total Households	Under $50K	$50K - $100K	$100K - $200K	Over $200K
346	41.6%	44.5%	10.7%	3.2%

Employment Information:

Industry	Percentage of Residents Employed
Arts, Entertainment, Recreation, Accommodation & Food Service	28.8%
Retail Trade	19.6%
Public Administration	18.4%

Housing and education

The band runs a tribal housing program and receives federal NAHASDA (Native American Housing Assistance and Self-Determination Act of 1996) dollars from the United States Housing and Urban Development Department (HUD) to administer affordable housing dollars to member residents. There is also a housing owned and operated by the Tribe. In 2018, the average household size was 2.0 for owned households, and 1.9 for rental households (U.S. Census Bureau, 2019).

Grand Portage operates the Oshki Ogimaag Charter School serving grades Kindergarten through grade six, with a mission based in Anishinaabe culture and language. Middle and high school students are transported 30 miles off reservation to the Grand Marais public school. Overall, 90.9 percent of the population had a high school degree or equivalent and 15.2 percent had a bachelor's degree or higher (U.S. Census Bureau, 2019).

According to community members, culture and language teaching is in every aspect of curriculum and teaching throughout the kindergarten through grade six education experience.

Health services

Because of the Grand Portage Band's remote location, access to adequate healthcare services of any kind has always been difficult. This has resulted in disparities and inequities figures reported out by the state and Tribe showing greater gaps and largely due to the travel distance to large metropolitan area healthcare services where greater emergency and specialty care is available. Grand Portage members travel to Duluth and the twin cities metropolitan area for

services not offered at the Grand Marais hospital and clinic, such as birthing centers, extreme trauma care, and other specialty services.

The Grand Portage community operates its own small health center and ambulance service. The nearest medical clinic and hospital are in Grand Marais, MN, which is 30 miles away. Sawtooth Mountain Clinic, a Federally Qualified Health Center (FQHC) out of Grand Marais, MN, operates a satellite clinic in the Grand Portage health center, providing a visiting physician once a week (Sawtooth Mountain Clinic, 2022). The Sawtooth Mountain Clinic offers family practice medical, behavioral, and community health services. North Shore Health Hospital and Care Center is also located in Grand Marais and staffed by Sawtooth Mountain Clinic physicians. The hospital is a 16-bed critical access hospital and a 37-bed skilled nursing facility. There is also a home health agency, ambulance service, and a variety of diagnostic and therapeutic services (North Shore Health, n.d.).

Elderly Health Services

The Grand Portage Band is part of the Minnesota Chippewa Tribe (MCT) with access to MCT programs. Minnesota Indian Area Agency on Aging, located at the MCT headquarters in Cass Lake, MN, provides programming and contract for services to elders aged 60 and above within the Grand Portage community. A range of services are available, including: training and technical assistance to tribal nutrition providers and health services, information and access to resources, counseling, education, medical management, health promotion, and training for elders in the betterment of their quality of life (Minnesota Chippewa Tribe, n.d.).

The tribe runs an Elderly Nutrition Program, supported by both the Tribe and federal funding, with the following services: case management, congregate meals, elder abuse and prevention, emergency response systems, financial assistance, government-assisted housing, home delivered meals, home modifications and repairs, information and referral services, legal assistance, senior center programs, telephone reassurance, and transportation (National Resource Center on Native American Aging, 2022).

Off-Reservation Elderly Services

Grand Portage members can access certain elder services through Cook County and the Arrowhead Area Agency on Aging.

Wisdom Steps

Wisdom Steps encourages Tribal Elders to participate in activities to build their health. Founded in 1999, Wisdom Steps began in Minnesota and represents a partnership among the eleven Minnesota Indian tribes (Wisdom Steps, n.d.). Wisdom Steps continues today 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 (Wisdom Steps, n.d.).

Health insurance

86.6% of the population in 2018 reported having health insurance coverage: 70.8% reported having private coverage, and 27.6% reported having public coverage. People may have both public and private coverage. 13.4% reported having no insurance coverage, which is significantly higher the than the Minnesota state average of 4.7% (U.S. Census Bureau, 2019).

On the statewide level, qualifying Grand Portage members are eligible to apply for both Medical Assistance (MA) and the MinnesotaCare Program, which are health care programs for low-income individuals and families (Minnesota Department of Human Services, 2020). MA is the state of Minnesota's Medicaid program for low-income individuals who are at or below 138% of the Federal Poverty Guidelines (FPG). MinnesotaCare 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. 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; Minnesota House of Representatives - Research Department, 2017).

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 and Groups

Prior 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 Grand Portage, we worked closely with the previous Health Director, Paula Shaefbauer, to hire the community-based researcher, Collette Pederson, and set up the Community Advisory Group (CAG) in year one of the research. The CAG consists of respected members within the community able to provide guidance on the research activities specific to the ICARE project. Members represent a variety of diverse backgrounds including, but not limited to: Health Care staff, Health Director, Tribal Council member, caregivers and family members caring or who have cared for individuals with dementia; individuals representing traditional cultural backgrounds who are familiar with dementia.
The research team works closely with the CAC / CAG at each site to review, negotiate and refine the methods, including interview questions, and identifying participants. The CAC / CAG 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 / CAG 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 Grand Portage is Collette Pederson. Collette was hired through the Grand Portage Health Center for the ICARE project in September 2019 on a part time basis. She was contracted by the ICARE project as a full-time CBR in April 2021 and became 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 XX. 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 X. 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.

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 Grand Portage, the recording device failed to record one interview with a Traditional Knowledge Keeper. Due to timing and circumstances, a rerecording was not attempted.

Grand Portage sample

Data reported here is from research conducted in Grand Portage, specifically. A local community-based researcher (CBR; Collette Pederson) worked closely with the community advisory members to identify and recruit participants. The advisory members helped generate a list of names for potential key informants at a series of community advisory meetings. 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.

Participant Group (n)	General role participant
Traditional Knowledge Keepers (5)	• Elders • Knowledge Keepers • Caregivers
Administrators (5)	• Directors within the community • Director at the County level • Director within a long-term care facility • Former ENP staff
Providers (5)	• Physicians, including retired country physician • Nurses
Sequential Focus Group (5)	• ENP Staff members • Mental Health worker • Psychologist

The Traditional Knowledge Keeper interviews took place between November 2019—March 2020. Administrator interviews took place between November 2019 – June 2020. Provider interviews took place between November 2019 – July 2020. Grand Portage Sequential Focus Groups occurred between December 2020 – January 2021 and took place over the course of four sessions via Zoom.

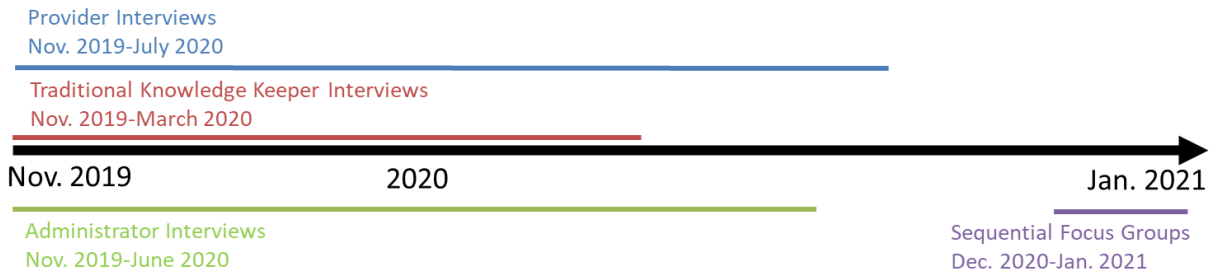

Figure 1. Timeline of research activities in Grand Portage.

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 Grand Portage.

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. One Traditional Knowledge Keeper noted that while there was still some confusion in the community around ADRDs, people were learning more.

> *Here in Grand Portage, I don't think it's totally understood. I think people accept it as a part of getting older and they think it's a natural thing to happen when you age and it's not. It doesn't have to be normal. I think over the last maybe five years, I think that people are getting more knowledgeable about what dementia and the different types of dementia, including Alzheimer's. (TKK-02)*

Traditional Knowledge Keepers provided many stories of the connection between mental and physical health, and how they impact each other. Specific to ADRDs, Traditional Knowledge Keepers made the connection between spiritual health and physical health:

> *So dementia comes in so much to, to the old people. Why? I don't know all the reasons, but we do know that it's spiritual. First it's physical and then it's spiritual, so that the brain is not working. (TKK-01)*

While there was no known word or words in the Anishinaabe language to describe dementia, one Traditional Knowledge Keeper used the phrase *giiwashkwe niinindib* "dizziness of the brain". This dizziness could be caused by many different ailments, including depression, as well as spiritual repercussions from not following traditional teachings or ways of life.

Traditional Knowledge Keepers also identified the importance of language, and the support of that person's traditional language, as a person with ADRD declines.

> *The one thing I will say here though is when somebody gets dementia, when somebody gets Alzheimer's and let's say they end up in the care center people will revert back in time. So although we don't have a lot of traditional speakers here anymore we do have some people that Ojibwe was their first language. And I'm aware of one person that ended up in the care center and would revert back to Ojibwe and you know if you can't talk to somebody in your language when that happens that can be very frustrating and very frightening. So that is something to consider. People need to be aware of because that can happen. (TKK-02)*

Administrators reported that they felt people living with dementia may downplay early symptoms and as such, they may need to work with family members in order to get certain information about the loved one. Providers likewise mentioned that they felt the AI/NA population they interacted with was more “reserved” and thus less likely to want to discuss dementia. Another provider felt that because AI/NA populations have dealt with hard circumstances all their life, a dementia diagnosis is handled better than among white populations. They further explained:

> *I think they're [Native Americans] a little more willing to accept it maybe. I was just talking about this, this morning, just about how I hate to put people in any kind of group, but I think there is ... I don't know if it's just because Native American people have had a lot of harder things they've had to deal with in general all the way along. "This is just one more hard thing and we can deal with this too," whereas a lot of ... Especially ... Again, this is categorizing people, but if you're a white privileged person who hasn't had to deal with that many hard things, when you get dementia, it can be devastating. Not that it's any less devastating because you're Native American, but I think there is an ability to "Okay, this is just one more hard thing I got to deal with. I can deal with this." There's almost a little bit more of an acceptance that it's okay. I don't know if I'm making this up even, but I think they might be a little better at it. (PR-04)*

While this statement could be construed as a positive stereotype, with the idea that Native Americans are more resilient, it is still a stereotype. Stereotypes paint a generalized picture about people based on their race or gender rather than as individuals, and can have harmful repercussions even if they are presented in a positive manner (Czopp, Kay, & Cheryan, 2015). Providers need to be aware of any biases and how that may impact the care that they provide.

Dementia & stigma

As stated above, interviewees noted that there may be some reluctance in the community to discuss ADRDs for various reasons. Participants in the Sequential Focus Groups provided context for why being diagnosed with ADRD may be stigmatized, not only for the patient but for the family members:

> *I think personally too a lot of it is the stigma around being labeled as you have it, because once you're labeled as a person that has like the beginning stages of dementia or whatever, it's like you no longer, they're no longer seen as a person. I noticed that with my aunt. Once my aunt [identifier omitted] was diagnosed with it, she was no longer [identifier omitted]. She was [identifier omitted] who has dementia, you know, and I think that's hard for the family to deal with. And the people that are around those individuals every day is, you know, they become labeled as-as that disease rather than just seeing them as the person that they were or are. (SFG-01)*

Being seen as a disease, rather than a person, may create a barrier to those seeking medical help or for their loved ones in pursuing a ADRD diagnosis.

Aging

Aging is intimately connected to ADRDs, and discussions with Traditional Knowledge Keepers resulted in a story outlining what people should expect as they move through the "four hills of humankind":

> *The first mountain we must go over is zero to eight years old, that of a child. The second is that of a teenager till you grow up, that could be anywhere from eight, nine, 10, 11, 12 to 18, 20, 30 whatever it takes for a person. The third is that of an adult, of a, well of a, of a, an adult mother, father, grandmother, grandmother. The fourth mountain that you go over is that of, of white snow on its top is to live that long to get white hair is what the elders explain in the teaching. You have made it over all of them. The two worst of all of those mountains are that of the teenager, because in the path of life there are seven trails which lead off of it. Once you're off on the wrong path of life, any human could do that. Could be drugs, alcohol, being a robber, a thief ah, could be hundreds, thousands of things. Somebody completely lazy, it could be anything, but you have to get back yourself on the path of life. So that second mountain is the most dangerous. Why? Because that's where suicides happen more than any other age. Who attempts suicide more, the boy or the girl? The girl. Who commits the death more? The boy. The second hill that is the most dangerous is the one with the white snow on top, is the [akiwenzii minaadenim 00:14:59], that of an old man, he of the earth year. Has, has hunted his way everything through life, being blessed to, to, to make it on this [aki] on earth to an old age and [mindimooyenh 00:15:16] she who, and people think that's a bad joking name. Oh [mindimooyenh 00:15:22] no, comes from the word [mingemandim 00:15:24], to hold on to. She's the one who holds on to the family, she's the grandmother. She's the one who keeps everything in the family together, that is why the word [mindimooyenh mingemandim Ojibwe language 00:15:36]. So why the, the, the old mountain, the old age is, is, is, is one of the most dangerous too is because it's hard to do things. You can't, you get old, the motor doesn't work right and the brain is not as strong [equating the motor of a car to the brain]. That is where, that is where, I also have a hard time with this word, what is the word of the illness we're talking about? [interviewer answers dementia] Dementia, that's where it comes in the most. It can come in earlier too, but that's when the most because the motor, the, like the car you drive is weaker. All the parts are 'cause the brain is not as strong. (TKK-01)*

This Traditional Knowledge Keeper also spoke about the importance of keeping one's mind and body active as a person ages. This included Elders conferences, bringing in speakers, playing games, as well as sharing the four sacred medicines, tobacco, sage, cedar, and sweetgrass. Ensuring healthy aging was also discussed among various participants. Administrators spoke about the importance of keeping elders active in order to support healthy aging, in addition to supporting aging in place. Aging in place was an important concept, and is spoken about more

in the following section. If people did end up in a care facility, Administrators wanted to ensure that they created a resident-centered facility that works towards the “7 domains of well-being".

Participants also described scenarios which they felt may not help the overall health and aging of community members. For example, Providers described the shift to paid work in order to make a living, which they felt may have added stress and thus preventable health issues at earlier ages among AI/NA populations. As a result, they felt that AI/NA do not live as long and are not as active or able-bodied and non-AI/NA populations.
Still, one of the Traditional Knowledge Keepers described how ADRDs may not be perceived by community members in a negative way. Instead, it was framed as a natural part of the aging process:

> *I've seen more of our community members are elders because they're living longer, developing dementia, but I don't think people think it's a bad thing or an evil thing. I think they look on it as just a natural part of aging. (TKK-02)*

Similarly, Administrators reported that they felt that the AI/NA population they worked with are more tolerant of growing older and do not need medical interventions quite as soon as other populations.

Caregiving: Cultural and community understandings

Caregiving is an essential component to understanding how persons living with dementia are navigating their lives. In this section, participants gave examples of, and describe the importance of, formal, family, and community caregiving.

Family caregiving

Administrators and Sequential Focus Group members noted Grand Portage families want to keep their loved one in the home for as long as possible. A Traditional Knowledge Keeper echoed this sentiment:

> *People here just take care of their own. People do not go away. They will try and keep them here as long as possible and for the couple of people that I've worked with that have had Alzheimer's or early onset, trying to set up services and work with them, it was never they're going to the nursing home. It's, they're going to stay home. They're going to age here in place. We're going to keep them home here. This is where they're going to pass away. This is where they're going to stay. (TKK-02)*

The Traditional Knowledge Keeper continued:

> *...as a whole this community wants to keep their family members here and in the house and they will do that. They'll move them in to their own house if the person is older and*

has their own place. They'll help them downsize the family steps up and takes care of their family member. It's what's always happened here. (TKK-02)

Family caregiving was recognized along many dimensions. For example, some Providers felt that elders took good care of their younger family members, but the effort was not reciprocated. As a result, they felt that there should be more community support for elders.

One thing that I see that is different, is I actually see the grandparents in the community taking care of the younger generation more than the other way around. I think there is tremendous value in that, but I think the caregiving is … A lot of elders are on their own. I think they need a broad spectrum of supports as they age, from food, shelter, bathing, shopping, making sure that they got clean clothes, all of those things. That their nails get cut, basic … Getting their medications. I think the clinic here does a lot of good things on that front, but I was actually hoping that families would be more engaged than they are. (PR-04)

However, not all Providers agreed with this statement. Another Provider stated, "I think the families really come together when there's a need within the family. I see a lot of family support" (PR-02). Multiple providers noted that when family members live outside of the community (providing long-distance caregiving), it could be harder to provide care to loved ones as they age.

It's always tricky to have a family member who lives in [on the East coast], who is trying to micromanage things from afar because they're not … What I've often seen in the past is there's one … The daughter lives close by and is doing a lot of the caregiving, and the son who lives in [Colorado] is criticizing what's going on and doesn't think there's anything with mom or dad, but usually we solve that by having them come and take care of things for a week and that usually straightens them out. I think one, just being local. Two is making sure that we welcome those people to visit and to be engaged in helping to take care of the elderly parent or family member. I think that's … I think we could do better probably with that. (PR-04)

The strain that caregiving can put on family members was not lost on participants. Providers voiced concerns about family caregivers and burnout associated with taking care of their loved one.

The people who suffer the most in an Alzheimer's or any dementia situation are the caregivers. The patient so often is kind of beyond even being aware of what's happening but the caregivers, they never get a minute's rest without worrying that something's going to happen. (PR-05)

While taking care of a loved one with ADRD can indeed be difficult, Sequential Focus Group participants pointed out it could also be a great act of love, even under trying circumstances.

So, we know a woman whose husband took care of her, kept her at home, took care of her till the very end, you know, and he would say, she's like a baby. And I mean, it was such an act of love, um, to keep her home the whole time and take care of her. And I just don't think most people would be able to do that 24/7. He took care of her all the time, everything. I mean, she went back to being like an infant. (SFG-03)

In order to avoid burnout, a Traditional Knowledge Keeper suggested numerous respite options.

> *I think offering people, again for the caregivers, the opportunity to get a break and for somebody else to come in and sit with their family member or take them to the beading class or take them to a community potluck. Just so that caregiver gets a break. Those are services, I don't know how much people use them, but I think if they're not provided, they need to be beefed up. (TKK-02)*

This same Traditional Knowledge Keeper gave the following advice to families taking care of loved ones with ADRDs.

> *Take care of yourself. If you don't take care of yourself and refill yourself up, you're not going to be good for anybody. If you get sick, then whatever services are in place, it could all go down the drain. (TKK-02)*

Community caregiving

Sequential Focus Group participants made an explicit connection between cultural values and community caregiving, citing the importance of elder care, rurality, and sharing of resources.

> *...she [SFG participant] and I are on another committee looking at rural aging and keeping people in their home. And I'm so touched by the fact that the reservation, um, does such a good job. And I wanna mention it because it's the cultural piece. We take care of our elders. It's just a part of who we are in rural family. And we look out for each other and we share. So that's one thing that's distinctive to the reservation and to the cultural traditions. Those services aren't available in other places in Cook County. (SFG-02)*

Multiple Providers identified their “small community” as a strength in helping to identify ADRD issues amongst members.

> *...it's a small community, but it's also like one big community. Everybody knows everybody, and they are looking out for each other and it's just kinda like one big family. (PR-03)*

Administrators expressed an interest in creating a dementia-friendly community by increasing general awareness around ADRDs. Similarly, Traditional Knowledge Keepers showed interest in

finding ways to keep individuals active and included within the community, as well as supported at home:

> *I think making sure the person isn't left out, that they're still included in the community and activities. I think that finding resources either on the reservation or in the county that can help this person feel safe and stay at home is appropriate and I think support for the family is very important because so many people here stay home and the family ends up caregiving. (TKK-02)*

Again, the importance of allowing loved ones to stay in their home by supporting family caregivers was highlighted. Additionally, Traditional Knowledge Keepers encourage a model where community members are included, regardless of their cognitive capacity.

Formal caregiving

Formal caregiving, or caregiving provided by medical or social services providers, was also described by participants. In this setting, Administrators stressed the importance of cultural competency training and education:

> *...for us to provide that compassionate care, we need that awareness of cultures, and the cultural differences, and the way that culture plays into how a person looks at healthcare and accesses healthcare, and receives healthcare, and accepts it. (AD-04)*

As another example of formal caregiving, one of the SFG participants checks in on people in their homes. As a result, they help identify problems or potential health risks and can help connect community members to needed services.

> *One of the things that is part of [SFG participant]'s job is to get into the homes and see the people. And while she's in the home, she has the opportunity to see, um, what kind of health risks are there. So for example, if somebody is not real steady, um, the reservation is willing to put in bars along the walls for them, or she's, she's able to see firsthand what is needed and bring that back. And the tribe is really willing to help people with the things that they need; shower bars and reminders to get rid of those slippery rugs that cause falls. And she has the firsthand perspective that Cook County doesn't get. (SFG-02)*

These type of formal caregiving services are important forms of outreach for vulnerable populations, especially isolated or elderly individuals who could benefit from increased access of services and personal visitation.

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.

Symptoms

When asked to describe how they would explain mild cognitive impairment to a patient, one Provider outlined the conversation as such:

> *...there are changes that happen in everybody's brain that makes it harder to say, "Find that word", or remember somebody's name or keep track of what you're doing. Those are normal aging changes. But sometimes we also start seeing more severe symptoms that are more judgment or being able to do calculations or problem solve. Those things are more what we see in early dementia or cognitive impairment and when those are happening then we need to start making plans for who's going to take over those parts of your life when you can't do it because those changes are probably happening over time and I would start to identify family members or support people in their life who would help us watch and add those services as we needed to and we talk about meds that would be possible. (PR-01)*

Administrators noted that, most often, friends and family were typically the first to notice memory issues and/or behavioral changes, Providers said that either the patient or a close family member would bring up symptoms as concerns:

> *...most people will say or tell me "I can't find words anymore" or "I'm having trouble with names" or "I'm worried about my memory. I'm forgetting things. I'm having people having to repeat things to me. I can't keep track of stuff." That's usually the complaint. Or it's a spouse telling me that. (PR-01)*

Risk factors

Administrators and Providers identified a range of pre-existing conditions, chronic diseases, and health behaviors that they felt were risk factors for developing ADRDs. For example, Providers noted that chronic, vascular diseases cause people to age faster and have memory issues at a younger age. Specifically, they identified diabetes, hypertension, and heart disease, while Administrators also listed cancer and COPD as diseases that could increase the risk of ADRDs.

Sequential Focus Group members made a hereditary connection to ADRDs. One participant noted that because they had family members who developed dementia, they felt they were at risk of also developing dementia and wanted to learn more about the disease.

Diagnosis

Participants acknowledged that diagnosing ADRDs can be difficult, but the use of cognitive screening is helpful.

Doctors have traditionally thought they were really good at figuring it out without doing anything specific to find it out, but the studies have shown that when left to our own devices, we don't diagnose it very early. It's usually middle to late that we get around to diagnosing it. However, we do cognitive screens now, which have been found to be very simple questions that we have. (PR-04)

This same provider noted the advantage that living in a small community can have in recognizing and diagnosing ADRDs, since they acknowledged that doctors aren't very good at diagnosing at early stages.

One of the great things about living in a small place is that often the presentation is family and friends will come up to me and talk to me, because a lot of patients are good at covering it up. They either use humor or they're really smart people who can cover things up. When you see people in a very short 15, 30-minute visit, you can miss a lot. So often its other people telling me that. That's often the way it comes to my knowledge first. (PR-04)

Lastly, Providers felt that an earlier diagnosis was important in helping to "get things in order" and help family members make a plan for the future before ADRD symptoms worsen. One Provider described how they routinely do cognitive screening on individuals 75 and older, which may help to lessen stigma about ADRDs:

I think we are routinely screening which helps you identify situations and I think we're getting better at talking about or thinking about those diagnoses earlier. Like I would've said when I first started practicing it was a little taboo to talk about patient... It would be very uncomfortable for a patient to be told, "Oh, I think you're starting to have memory problems." And now I think it gets talked about a lot more or a lot more people are comfortable with that. (PR-01)

Prevention, treatment & delay

Providers mentioned that there are medications to decrease memory impairment progression, which Sequential Focus Group members also knew existed but did not have much information about. However, Providers also noted that medicine is less important than having good community support for loved ones as well as support for family caregivers.

Prevention of ADRDs was not discussed extensively among participants, but one Traditional Knowledge Keeper spoke about attempting to delay the onset of ADRDs and brought up the importance of not only physical health but social and mental health as well.

Good nutrition, exercising, not smoking, if you have diabetes or heart disease or something else, take your medicines as prescribed. The other thing is interactions. People need people and the more active you are the more connected you are. I think that all helps. There's others things. Reading books, doing bead work, doing activities

that stretch your mind, also help to make other connections so those are things that I am aware of. (TKK-02)

Administrators noted that they were not aware of any traditional healers available for referral. Yet some Providers were aware that their patients went to traditional healers and were supportive of that choice, while other providers did not work with traditional healers. One Provider noted that perhaps one of the reasons they didn't see AI/NA patients often for medical appointments was because they sought treatment from traditional healers and home remedies.

***PR-03**: I guess I have noticed that with American Indians, it's not as frequent that they come into the doctor for follow-up visits or annuals or just to be seen if something's going on. It's more like if something's really wrong, then they will come in and be seen. Otherwise, they just like to take care of things themselves.*
***Interviewer**: Why do you think that is?*
***PR-03**: I don't know. Maybe the growing up and having so many different alternative ways to treat yourself and home remedies where that was a huge thing in the Native culture.*

While Providers had spoken briefly about available medication to slow ADRD progression, Traditional Knowledge Keepers described several other ways to treat ADRDs:

Depending on the medicine man or woman, what they see sometimes they have to wear something around their head. Sometimes cedar in it. Sometimes certain things. They're told to put tobacco out for four days, or eight days to work on their dizziness, dementia, all these different things to be pulled out. They're told to drink certain medicines. (TKK-01)

This Traditional Knowledge Keeper went on to describe the problem of ADRDs and how to help overcome the disease:

The, the sponge like brain is not breathing strongly, it is not coming through to everything, so it must be cleansed and washed and given something that will strengthen it back so that it is stronger and working, with us that would be certain medicines. Physically, well that and spiritually, they must start in their mind telling their brain that I want to live. (TKK-01)

Services and barriers to care for a PLWD and their caregiver(s)

While numerous services were outlined by participants, including transportation and respite, barriers associated with rurality and low usage were highlighted.

Barriers and challenges

Administrators were very attuned to new regulations for assisted living companies that they felt may cause funding challenges due to the need to adhere to the regulations. They also voiced

concern that because they are unable to pay living wages, they could not recruit and retain staff. SFG members also noted some of the work with elders was not high paying but was “a lot of hard work”, which made it hard to fill open positions in the area.

Despite Administrators identifying that short term respite care exists in Grand Portage, both Providers and Administrators stated they would like to see more respite care. In addition, Administrators identified in-home care and assisted living (since the closest facility is in Silver Bay) as services they would like to see available. Providers identified distance, both in regards to access to services and specialties as well as long-distance family caregiving, as barriers to care. Providers noted that even if finding transportation is not a problem for someone (which it is in many cases), individuals might have to travel at least a few hours away to access specialty medical services.

Sequential Focus Group participants also identified how difficult it can be to keep services in the community given the low level of use. For example, they provided stories about hospice and assisted living.

> *You know, we do not have hospice and we've tried several times to start a hospice, but we just don't have the numbers to be able to do that. So I think about how communities come up and right now, um, and step up. Right now, I'm thinking about, um, an elder that lived at the end of my road. And as she got ready to die, um, she would ask me to, she'd call me and she'd say, will you come and sit with me when I go to bed tonight, I'm afraid I'll die in the night. And I would go sit, sit by her bed till she fell asleep and then I would come home. We have a nurse in the community who has really stepped up. And, um, if somebody needs, is in their home and needs to be on an IV, evidently you need to have a nurse, she would go sleep at the home. Um, so I think that we create from among us, um, take care of the needs as best we can, because we don't have palliative care. We don't have a hospice. I think that Participant 01 does her best to give respite care where she can do it, but there really isn't a respite program I, that I'm aware of where people can come in and just really give those care takers much of a break. Um, so the community steps up. I mean, we just really do take care of our own. (SFG-03)*

> *My mom was in Hillhaven too and she was there when they closed. And it was fascinating to me to see that they could not stay open. They, um, with the need in the county, they, I think they had capacity for 10 rooms and sometimes they'd only have two. There's no assisted living anywhere in all of Cook County where people can have their own little apartment and maybe get a meal a day or have somebody on site, uh, um, LPN, an aide or somebody who puts out medicines. And, um, they've never been able to justify building one, which astounds me. Um, so there's a real need for something like that. (SFG-03)*

Along the same lines, SFG members noted that for services that *do* exist, there can be a two to three year waiting list that family members must proactively think about and sign up for. In the same conversation, SFG members noted that

...one of the things that we [community boards] did was we bought or built three residential care centers like we're talking about. And over a period of years, all three of them were not sustainable and had to be let go. And so for whatever reason, that model is not financially sustainable in Minnesota. And I don't know if there's a better model because it's sure in my mind, in Participant 01's mind, it just makes sense that we would have that kind of a setting. Um, but they're just not financially feasible. And so they're closing and they're not building new ones. Um, Cook County certainly needs something. (SFG-03)

Services and programs for caregivers and PLWD

Administrators detailed various services available to community members including rides to medical appointments, respite care, volunteers for companionship, and a caregiver support program. A SFG member noted that the reservation offers a transportation program that can take people on shorter trips such as between their home, the store, or the post office; sometimes they have even taken people to medical appointments in Grand Marais and elsewhere throughout the state. Providers also noted that nurses were available for homecare services and home health, in addition to a nutrition program. The Sequential Focus Group members noted that there is a community support line for mental health that advertises on local radio as a general resource.

We're as rural as it gets in Minnesota. We don't have a lot of services, but what we do have is a lot of community people who do care and are very invested in their community. I think that's a tremendous asset, actually. (PR-04)

Sequential Focus Group members also highlighted a group in the community who helps provide guidance, support, and respite for individuals and their families at the end of life.

You know, there's a new group in town who called themselves the Death Doulas. A doula is somebody who, a midwife who brings a baby into the world. These are four women who help shepherd people out of the world and take care of their families. Um, and they do a little bit of respite care. But one of the things they do, they have a monthly, um, online meeting where they talk about death and all things death. And it sounds really gruesome, but it really is a loving, um, opportunity to talk about impending death or, um, any kind of questions you have around taking care of a parent or somebody as they're headed that way. And the things that the caregivers need. And they are the only thing in the county that I'm aware of that offers that kind of a service. (SFG-03)

Recommendations to improve dementia care

Administrators stated that they would like a better understanding of what services are available from the tribe in order to connect with and work more coherently with the tribe. They also noted that they would like to see more services to allow elders to age in place such as in-home care or companion services.

> *...it'd be nice to get extra funding for in-home support programs like we have through the county. Um, and these are people that go into the people's homes, you know, help them with chores, help them just visit them. Um, 'cause right now we don't have any staff through the county. We're actually low on in-home support workers. And I know a lot of people in Grand Portage that would benefit from that program, you know, and that would, I think, would be able to keep more people at home rather than seeking other services, like the care center and whatnot. Um, so I think if we could ever get more funding for that, I think that would be amazing. (SFG-03)*

Both providers and administrators voiced the need for respite care as well as more education and awareness around issues with ADRDs. Respite would be especially important in combating caregiver burnout.

> *They [caregivers] have to be relieved at least periodically. People who try to take care of these loved ones at home. I got to the point where I was pretty blunt with the caregiver. I said, "What good are you doing your family if you are so run down that pretty soon you're in as bad shape as the person you're taking care of?" (PR-05)*

Providers mentioned wanting an assisted living facility in Grand Portage, which Administrators noted would allow couples to move in together (e.g., since one may need care but the other does not).

> *There's no assisted living anywhere in all of Cook County where people can have their own little apartment and maybe get a meal a day or have somebody on site, uh, um, LPN, an aide or somebody who puts out medicines. And, um, they've never been able to justify building one, which astounds me. Um, so there's a real need for something like that. (SFG-03)*

A Sequential Focus Group participant suggested that more education and community awareness about dementia could lead to more acceptance and willingness to speak about ADRDs. A Traditional Knowledge Keeper also suggested that information about ADRDs and associated services would ultimately help community members.

> *People are afraid to ask the questions, you know, kind of like when you hear someone has cancer, they're afraid to ask questions or even bring it up. So I think the more education that you have out there and the more awareness about these issues, I think the more comfortable people will get about talking about it. (SFG-01)*

I think one of the biggest needs that I would like to see if we had a magic wand is, um, the education. If we could get Grand Portage to have everybody understand there's something called Alzheimer's and this is how it affects a family, and this is how it affects caregivers. And this is how we, as a culture can take care of our elders and take care of the people taking care of our elders, I would really love to see us do some kind of a huge education push maybe through the CACHE program that they are already doing pieces of that, but to add Alzheimer's to it. Um, I think that would go a long way if we could build capacity and build a big community of care minded people. (SFG-03)

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 Grand Portage, a total of 15 Key Informant Interviews were conducted, along with 4 Sequential Focus Groups with 5 participants. The preliminary findings reported above will be explore in the next phase of research, and is currently ongoing.

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