

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

Oneida Nation, WI | Community Report, April 14, 2022  
Community Report presented to the Oneida Community Advisory Board  
on May 18th, 2022



  
**Medical School,  
Duluth Campus**  
UNIVERSITY OF MINNESOTA  
Driven to Discover®

# Table of Contents

|                                                                        |    |
|------------------------------------------------------------------------|----|
| Acknowledgements .....                                                 | 4  |
| Abbreviations .....                                                    | 5  |
| Executive Summary .....                                                | 6  |
| Key findings .....                                                     | 8  |
| Comments from the Oneida CAB .....                                     | 11 |
| Introduction .....                                                     | 12 |
| Background .....                                                       | 12 |
| Oneida Nation, WI: Community Profile .....                             | 14 |
| History .....                                                          | 14 |
| Culture .....                                                          | 15 |
| Geography .....                                                        | 16 |
| Population .....                                                       | 16 |
| Employment .....                                                       | 17 |
| Housing .....                                                          | 17 |
| Education .....                                                        | 17 |
| Health Services .....                                                  | 18 |
| Health Status .....                                                    | 19 |
| Methods .....                                                          | 19 |
| Community-based and Indigenous approaches .....                        | 19 |
| Community Advisory Board .....                                         | 20 |
| Community-based Researchers .....                                      | 21 |
| Key Informant Interviews and Sequential Focus Groups (SFGs) .....      | 21 |
| Data analysis .....                                                    | 23 |
| Limitations .....                                                      | 23 |
| Oneida, WI Participants .....                                          | 23 |
| Findings .....                                                         | 24 |
| Dementia: Cultural and Community Understandings .....                  | 24 |
| Circle of life .....                                                   | 24 |
| Language used to describe dementia .....                               | 25 |
| Importance of Native Language: Ways of knowing and understanding ..... | 26 |
| Stigma .....                                                           | 26 |
| Importance of Humor .....                                              | 28 |

|                                                                                       |    |
|---------------------------------------------------------------------------------------|----|
| Caregiving: Cultural and community understandings .....                               | 28 |
| Family Caregiving .....                                                               | 28 |
| Community Caregiving .....                                                            | 29 |
| ADRDs in the community: Risk factors, symptoms, prevention .....                      | 29 |
| Risk factors .....                                                                    | 29 |
| Signs and symptoms .....                                                              | 30 |
| Diagnosis .....                                                                       | 31 |
| Prevention, delay & treatment of ADRD .....                                           | 33 |
| Impact of Colonization on Preventative Health and Traditional Healing Practices ..... | 34 |
| Services and barriers to care for a PLWD and their caregiver(s) .....                 | 35 |
| Services and programs for caregivers and PLWD .....                                   | 36 |
| Barriers and challenges .....                                                         | 37 |
| Recommendations to improve dementia care .....                                        | 38 |
| Community services .....                                                              | 38 |
| Dementia care environments .....                                                      | 38 |
| Education .....                                                                       | 39 |
| Summary .....                                                                         | 41 |
| References .....                                                                      | 41 |

By:

**University of Wisconsin-Madison Research Team**

*Carey Gleason, PhD*

*Nickolas Lambrou, PhD*

*Lois Strong, MSW (Oneida Nation)*

*Marlene Summers (Oneida Nation)*

**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*

**Oneida, WI Community Advisory Board**

*John Breunninger*

*Dellora Cornelius*

*Debra Danforth*

*John Danforth*

*Christine Garstka*

*Kristal Hill*

*Jay Kennard*

*Ericka Kowalkowski*

*Pat Lassilla*

*Sacheen Lawrence*

*Lauren Yowelunh McLester-Davis*

*Crystal Metoxen*

*Eli Metoxen*

*Kerry Metoxen*

*Melissa Metoxen*

*Rhiannon Metoxen*

*Debra Miller*

*Florence Petri*

*Lois Metoxen Strong*

*Marlene Summers*

*Marie Summers*

*Cassandra Thomas*

*Kristen Waukau*

*Jennifer Webster*

*Annie Wells*

*Sunshine Wheelock*





## Acknowledgements

This project was a collaborative effort, and could not have been completed without the support of the Oneida Nation (Business Committee Resolution # 04-24-19-A) and the contributions of so many people. We extend sincere thanks to the Oneida Business Committee, Oneida Nation Community Health Services, and all of the individuals and organizations in Oneida, WI who contributed their time and expertise to this research.

Yaw^ko to our Oneida Wisconsin Alzheimer's Community Advisory Board Members. Lois Strong and Marlene Summers are the community-based researchers for this project.

We would also like to thank and acknowledge the entire ICARE team:

From Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth and Minnesota at large: Dr. Kristen Jacklin (PI), Brooke Metz, Collette Pederson, January Johnson, Melinda Dertinger, Brandylyn Arredondo, Patrick Bright, Tracy Kemp, Dr. Wayne Warry, Dr. Jordan Lewis, Dr. Melissa Blind, Dr. Dana Ketcher, Annamarie Hill, Red Lake Nation, Grand Portage Band of Lake Superior Chippewa.

From the University of Wisconsin Alzheimer's Disease Research Institute: Dr. Carey Gleason (site PI), Dr. Megan Zuelsdorff, Dr. Nikolas Lambrou, Marlene Summers, Lois Strong, Wes Martin, and the Oneida Nation.

From Ontario, Canada: Seven First Nations on Manitoulin Island (Wikwemikong Unceded Reserve, M'Chigeeng First Nation, Sheguiandah First Nation, Sheshegwaning First Nation, Wauwauskinga First Nation, Zhiibaahaasing First Nation, Aundeck Omni Kaning First Nation), Wikwemikong Health Centre, Mnaamodzawin Health Services, Noojmowin Teg Health Centre, M'Chigeeng Health Services, Rhonda Trudeau, and Karen Pitawanakwat.

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

KII: Key Informant Interviews

KTE: Knowledge/Translation Exchange

PLWD: Persons Living with Dementia

SFG: Sequential Focus Groups

TKK: Traditional Knowledge Keepers

# Executive Summary

*“And it is also understood that as time goes on, as they get older and then we have the responsibility is to care for them. Because then we have to remind ourselves as to the time when we were born, they were there, that the elders and the older people were there to also take care of us at that time. And so, as we get on in age where we also reciprocate the same thing to them, as well...and when they get older that were there to assist them. And it also, uh, states to say that, uh, in one, in one point it talks about where the young people are going to become the old people and the old are going to become the young.” (WI-TKK-03)*

## Shekoli!

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 The Oneida Nation in Oneida, WI.

On April 24th, 2019, the Oneida Business Committee approved the Oneida Nation’s ICARE research partnership with Drs. Kristen Jacklin, Carey Gleason, and the Memory Keepers Medical Discovery Team (Resolution No. 232-18).

During the first year of the grant, we worked closely with the Oneida Nation Community Advisory Board (CAB) and Elder Services to help guide all aspects of the research process. The CAB ensures that research activities are culturally safe for participants and ensure that findings are reflective of the community and its culture and members. The Oneida CAB was formed in 2015, prior to the ICARE research project, and holds regular meetings on a monthly basis.

We also hired two Oneida Community Researchers, Lois Strong, MSW and Marlene Summers. Lois and Marlene have completed extensive training for their roles, 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 their roles as Community Researchers, Lois and Marlene have taken the lead in writing updates within the ICARE project newsletters and ensuring wide-spread distribution in the Oneida, WI Tribal Community.

*The ICARE R56 project collected preliminary, community-level data on demographics, health status, health services, and social determinants of health in four tribal communities located in WI, MN, and Ontario, Canada. Additionally, we conducted interviews with members of each community. In Oneida, our Community Researchers conducted:*

- Key informant interviews with Traditional Knowledge Keepers (n=6), Administrators (n=5), and providers (n=2), and
- Sequential Focus Groups with health care providers for older Indigenous adults (n=4, 4 sessions).

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

ICARE research updates are presented through bi-yearly community newsletters. Newsletters are distributed via social media and direct mailings throughout the Oneida community. Additionally, beginning February 2022, the research team began presenting quarterly updates to the Oneida Business Committee.

The executive summary outlines the major findings from the R56 preliminary data detailed in the Oneida, WI 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

The next phase of the research will continue to build on research activities conducted during the R56. We will continue our research partnership with Oneida Nation, WI, Red Lake Nation, MN, Grand Portage Band of Chippewas, MN, and the seven First Nations on Manitoulin Island, ON. The five years of 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 (10 participants, ideally diversified in gender identity)
- 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 Oneida CAB will continue to guide all aspects of the research. Lois Strong, MSW and Marlene Summers will continue in their roles as Community Researchers.



# Key Findings

---

Preliminary findings from Phase 1 of this study:

- **Dementia: Cultural and community understandings-**
  - **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. Some Traditional Knowledge Keepers described the changes as "revisiting a particular stage of life again."
  - **Language used to describe dementia:** Participants often used the word "forgetful" to conceptualize dementia. Traditional Knowledge Keepers noted that, in Oneida, a person living with dementia (PLWD) might be described as being "absentminded" or "missing a moment." Sequential Focus Group participants referred to terms such as "old-timers' disease" and "losing it."
  - **Importance of Oneida language to ways of knowing and understanding:** All groups interviewed acknowledged that effective communication was key in understanding dementia. Traditional Knowledge Keepers elaborated on why Oneida Native language, in particular, is important to identity, culture, well-being and understanding in a non-Western way. They explained how the loss of Oneida Native language connects to colonization, resilience and ways of knowing.
  - **Stigma:** Participants noted a reluctance to talk about dementia in the community, which may serve as a barrier to care. Sequential Focus Group members noted that people in the community talk about dementia "kind of in a negative way." Additionally, Sequential Focus Group members suggested there may be a relationship between stigma and fear, and stigma (e.g. "shame") may partially explain why some dementia related community services are underutilized. However, they felt that with more education, people may become more comfortable discussing ADRDs. For example, awareness and information may provide a pathway for people to connect through storytelling.
  - **Humor:** Participants pointed out that sometimes when a hardship is identified, AI/NA people will rely on humor. This was echoed by a Sequential Focus Group participant, who noted that humor was a way to cope, communicate and understand when a loved one has dementia.
- **Caregiving: Cultural and community understandings**
  - **Family caregiving:** Participants understood family as immensely important in taking care of a PLWD. Additionally, it was widely acknowledged that it is important to keep their loved one with dementia in the home as long as possible. Traditional Knowledge Keepers described the relationship between cultural values and caring for family, along with cultural values like respect when caring for elders with dementia.

- **Community caregiving:** Elders and those dealing with illness were described as taken care of by community members, and this was viewed as a strength of the Oneida community. For example, providers and administrators noted that if someone in the community was dealing with dementia or any other illness, community members would step up to help. Overall, participants described community caregiving as closely related to family caregiving, cultural values and resilience.
- **Alzheimer's Disease and Related Dementias (ADRDs) in the community:**
  - **Risk factors:** Administrators and providers mentioned the impact of chronic disease (e.g., diabetes, cardiovascular disease), health behaviors (e.g., substance use, lack of physical activity), and mental health challenges on the development of dementia. Sequential Focus Group members noted issues with diet and toxins. Traditional Knowledge Keepers pointed to genetics, vascular issues, brain injuries, diet, and substance abuse as potential impacts for developing ADRDs. Additionally, Traditional Knowledge Keepers made a connection between the effects of colonization and potential risk factors for ADRD.
  - **Signs and symptoms:** Common signs and symptoms identified by all participants included behavior changes, memory loss, repeating stories, and functional changes in activities of daily living. Traditional Knowledge Keepers described "forgetting" as a first sign of dementia, and viewed changes as a "tendency to go back to their younger life."
  - **Diagnosis:** Many times, it is family members who bring 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. As such, Traditional Knowledge Keepers explained how, overall, dementia diagnoses are not necessarily commonplace. While the diagnosis/referral pathway was unclear, participants largely agreed that early and accurate diagnostics are beneficial in a multitude of ways. For example, early diagnosis can help families prepare, adjust, and tailor treatment plans -ultimately leading to better care and quality of life.
  - **Prevention, delay & treatment:** Keeping active mentally, physically and spiritually was reported as important in keeping one's mind healthy. Mental activities, such as conversing and interacting with family or community members were thought to prevent social isolation. 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. Traditional Knowledge Keepers mentioned the importance of ceremonies, social relatedness, Indigenous diets, singing, dancing and traditional medicines; learning and speaking a Native language was noted as a particularly effective way to keep the mind active and healthy. At the same time, TKs acknowledged generational disconnection from Indigenous culture as a barrier to good health. 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.

- **Impact of Colonization on Health and Traditional Healing Practices:** Interviews with Traditional Knowledge Keepers yielded stories and themes that recognized the impact of colonization on health and health behaviors over time and connected cultural identity with resilience.
- **Services and barriers to care for people living with dementia and their caregivers**
  - **Services and programs:** Providers and administrators described many available facilities, services, and programs for persons living with dementia and their caregivers. Administrator responses were particularly detailed, and suggest a high level of engagement with PLWD and their caregivers. Participants in the Sequential Focus Groups were more uncertain of the services and programs for dementia. Overall, participants identified services such as a long-term care facility, the community health center, elder services, day services and evidence-based classes for caregivers. Oneida community members[BA1] also provide respite and support for PLWD and their families.
  - **Barriers and challenges:** Participants noted various barriers to caring for people with dementia, such as financial hardships, programing cuts, eligibility for services, staffing shortages, geographical issues, and a need for specialized dementia training and education for all health care providers and community members. Moreover, many services have been limited or cut due to COVID-19, and there is a lack of access to technology enabling community members to remain engaged via video platforms. Additionally, while there are many services available in the Oneida community, awareness can sometimes rely on “word of mouth” and informal relationships to disseminate information. This is viewed as both a benefit and deficit to receiving care/services, and can be helpful for some and not others. Participants spoke to the impact of trying to balance work and life, and caregiver stress increasing as dementia progresses. A lack of awareness and potential stigma regarding ADRD can serve as barriers to support, and dementia education was frequently linked to the reduction of barriers.
- **Recommendations from participants to improve dementia care[NL2].[MB3]**
  - **Community support services for PLWD and caregivers:** Respite and adult day care services were consistent recommendations.
  - **Dementia care environments**
    - Keeping PLWD in their homes for as long as possible: Recommendations included prioritizing services designed to keep elders in their home.
    - Attention to environmental settings for PLWD, such as engagement with nature, was viewed as a way to promote well-being and quality of life for PLWD and families.

- **Education:** Participants frequently highlighted the need for more ADRD education in the community. Education, communication, and sharing experiences were viewed as pathways to start conversations, increase connectedness, and potentially reduce any stigma-related barriers.
  - Building trusting relationships:
    - Participants elaborated on the importance of educators building relationships to establish trust in the community.
    - Administrators added the need to keep Tribal leadership engaged and informed regarding research in order to increase awareness and further initiatives.
  - Engaging younger people in dementia education, potentially in schools.
  - Preparing families with information on what to expect, how to care for someone with dementia, and how to care for themselves.
  - Recommendations to researchers and healthcare providers: including sensitivity and respect of other cultures, and the “philosophy and understanding of the world that we live in.”

## Comments from the Oneida CAB

On May 18th, 2022, the Oneida, WI Community Advisory Board motioned to approve the contents in this Community Report. Specific feedback is offered below:

“Great job by the overall team of providers, care givers, interviewers all on behalf of our loved ones who have become a part of moving into the realm of aging. The overall report is outstanding and it is great to see and read that our efforts of the research team and the CAB are proving positive. Thanks to everyone! Easy to follow. Put together well. Quotes were great to see. Looking forward to next steps. Very indicative of what CAB is doing and their goals... far-reaching benefits.” -Oneida CAB Member

“This is always something we wanted... getting the information out to the community. This is it.” - Oneida CAB Member

# Introduction

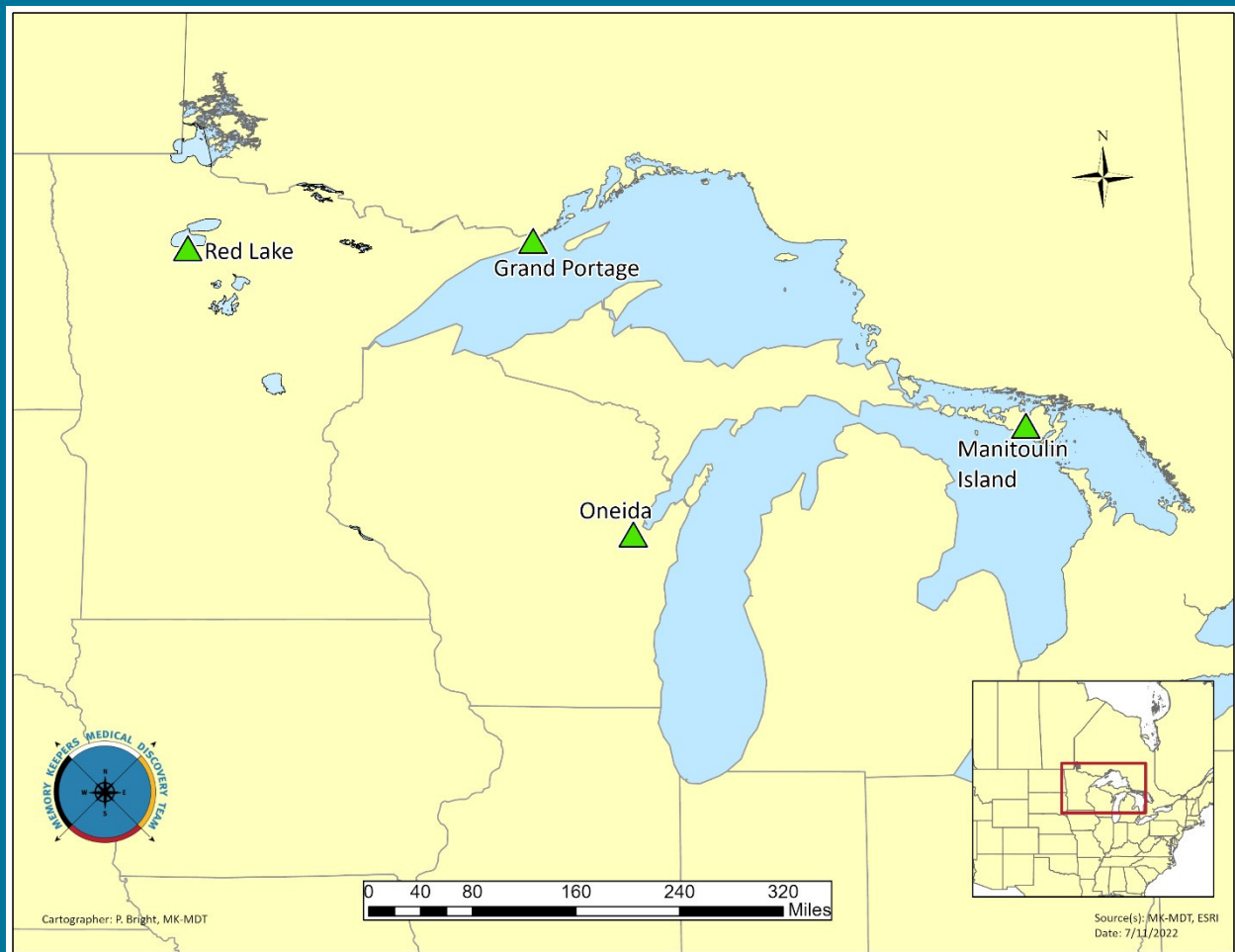
The focus of much of the research conducted at Memory Keepers-Medical Discovery team is to improve the lives of persons living with dementia (PLWD) by examining the impact of dementia across the disease trajectory on Indigenous PLWD, families and communities. The origin of the name, “Memory Keepers” 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 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 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 AD/DR on families, caregivers, PLWD and communities.
  - a. 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.

## Oneida Nation, WI: Community Profile

### History

The following quote and subsequent adapted material regarding Oneida culture and language originated from the Oneida Nation of Wisconsin website <https://oneida-nsn.gov/our-ways/our-story/>.

*"It is said that to be Oneida is a heritage, a legacy, and identity. It is a gift received from those who journey before, shared with those who journey with, and passed on to those who journey after. The Oneida Nation values a healthy perspective on life, and a generous sense of humor. They have good thoughts about themselves, their Nation, and all people. They seek to have harmony with themselves, their families, their neighbors and all humanity. It is understood that Oneida people have the ability to strengthen others' fires with a good mind, a good heart, and a strong fire."*

*The Iroquois clans were developed in a time where there were fewer people than today, and the clan system was created to help organize how Oneida people were related to one another. There are three clans: Turtle Clan, Bear Clan, and Wolf Clan. In the Iroquois Creation Story, the earth was created on the back of a turtle. It was there that life began to grow. The Turtle Clan represents the shifting of the earth and the cycles of the moon. The people of the Turtle Clan are considered the well of information and the keepers of the land. The responsibility of the Turtle Clan is everything that has to do with the environment. The Bear Clan people are known as Medicine People, the healers. There are stories passed down about how the Bear Clan people were given the gift of medicine from an elder woman who had the knowledge of all the medicine plants here on earth.*

*The Wolf Clan represents the pathfinders. Their responsibility is to guide the people in living their lives in the way the Creator intended.*

*The Oneida History Department of the Oneida Tribe of Indians of Wisconsin promotes the culture, language, history, traditions, and genealogy to all enrolled Tribal members. The department collects, organizes, preserves, and makes*

*available materials that pertain to the history and development of the Oneida Nation and its people. It not only has history of Oneida Ancestors, but also has information about relocation from the East to Wisconsin, how and where the Oneida Nation settled, and non-native people that were involved in the move."*

## Culture

The Oneida Nation has extensive Cultural Heritage departments and a museum that houses Oneida artifacts, Iroquois traditional outfits, a Longhouse replica, and a history migration. The Haudenosaunee (Iroquois) are "People of the Longhouse." Ceremonies held by the Haudenosaunee follow the cycle of the seasons, and are determined by Faithkeepers who observe agriculture, the moon and the seasons. Examples of ceremonies include: Wahsá-sé (Thunder Dance) and Thuwi-sáhs (Moon Dance).

Onnyote'a-ká (symbolism) is drawn from oral traditions, and can be found throughout the Oneida reservation. Examples of symbolism include: Tree of Peace, arched domes, and wampum belts. The color purple holds particular significance, as wampum beads are made from the quahog shell which are purple and white. In addition, the three clan animals (Turtle, Bear, and Wolf) can often be seen depicted in artwork and imagery.

## Language

Native language is a vital part of Oneida existence. Oneida culture, ceremonies and language are taught from the Oneida Head Start program to high school. There are native language classes held throughout the community, which anyone can attend. For the Oneida Nation, culture and language go hand in hand.

The Oneida Nation established the Oneida Language Revitalization Program (OLRP) in the 1930's. The program's mission is to promote and assist Oneida people in learning and speaking the language, as a way of keeping the history and culture of the language alive. In its early years, the OLRP hired fluent-speaking elders to write in journals and teach adult learners in the Oneida community. These adult learners would subsequently attend University of Wisconsin-Green Bay to earn a degree to teach at the Oneida Nation School System. By the late 1990's, there were only 25-30 elders left whose first language was Oneida, so the program connected these elders to language culture trainees to cultivate more Oneida language speakers and teachers.

Presently, trainees learn the Oneida language through second language speakers during weekly classes. Some trainees go on to teach family members, as well as administer classes to the Tribal departments. High school students, from the Oneida Nation school system, attend the Language House for morning language classes.

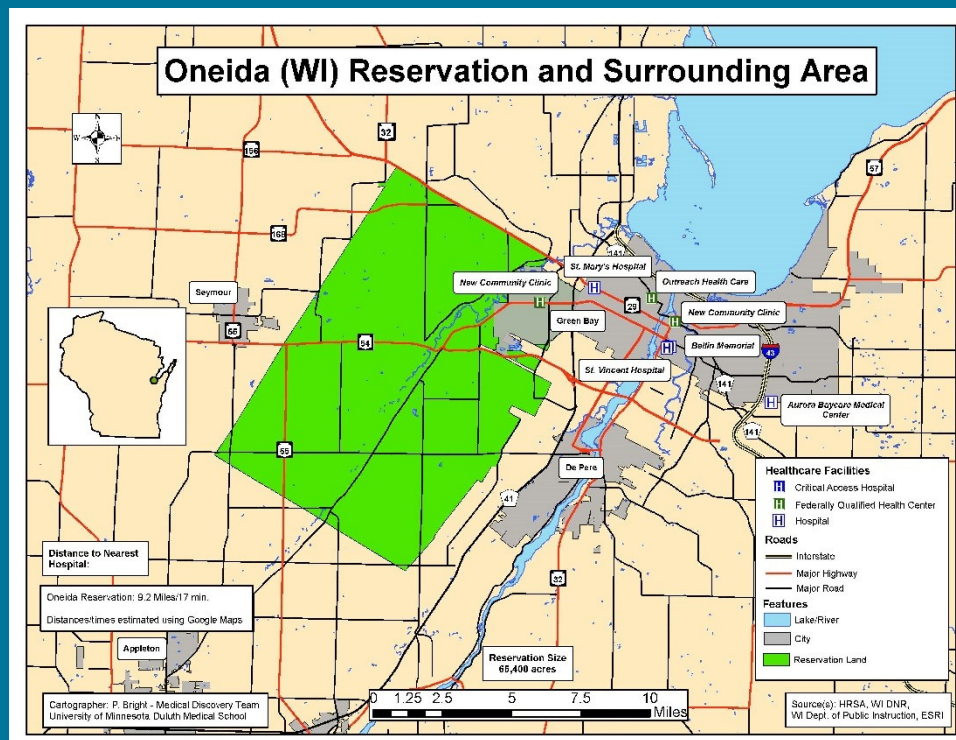
An Oneida Language speaker remarked on the current state of fluent native speakers, and stated: "We have three types of fluent speakers. The old people are the fluent speakers. Second language speakers are those that can understand and speak, and at times in a conversation

they have to answer in English. Then there are those that are in training and learning the basics of the Oneida language. We have two fluent speakers, and they are Elders. The others are second language speakers. The third are trainees and those that are learning our Oneida Language,” (Summers, 2020).

[Excerpts above originated and adapted from: <https://oneida-nsn.gov/our-ways/our-story/>]

## Geography

The Oneida Nation is located in northeast Wisconsin. The Nation holds just over 26,000 acres, with the Oneida reservation comprising approximately 12 square miles of land, 233 miles of streams, and 12,000 acres of wetlands. Five municipalities (Ashwaubenon, Green Bay, Pittsfield, Hobart, and Oneida), have land located within reservation boundaries. Major cities close to the reservation include Green Bay, WI (5 miles east), Appleton, WI (30 miles southwest), Oshkosh, WI (45 miles southwest), Sheboygan, WI (54 miles southeast), and Milwaukee, WI, (113 miles southeast). [Data Source: EPA, Tribal Wetlands Program; Genealogy Trails]



**Figure 2.** Map of Oneida, WI Reservation and Surrounding Areas

## Population

There are approximately 4,627 enrolled Oneida people living on the Oneida Reservation, comprising approximately 17.1% of the total reservation population. Of this population, 48.6% are male, 51.4% are female, and 26.8% are Elders. The median age of enrolled Oneida people living on the Oneida Reservation is 35.2.

There are 17,296 total enrolled Oneidas living throughout the world. Enrolled Oneida people also live in surrounding areas. For example, 3,276 live in the overlapping counties of Brown and Outagamie, 2,117 live in the Milwaukee area, and 2,389 live throughout the state of Wisconsin. [Data Source: Oneida Nation Enrollment Records as of 12/21/21].

## Employment

The Oneida Nation serves as one of the largest sources of employment in Brown County, with approximately 57% being enrolled Oneidas and 7% enrolled in another tribal nation. The Nation has entered into partnerships with other tribal nations for economic collaboration, most notably in the construction and operation of several hotels in major metropolitan areas. The nation itself owns and operates three gaming operations within reservation boundaries. Major economic activities include government, agriculture, recreation and tourism, gaming, and manufacturing. Unemployment was reported in 2020 at 3.4% for all residents living on the Oneida Reservation.

According to the Oneida Quality of Life Survey, the median household income of enrolled Oneida households on the Oneida Reservation was \$42,521. The poverty rate of enrolled Oneidas on the Oneida Reservation was 24%. The unemployment rate of enrolled Oneidas on the Oneida Reservation was 9.0%.

## Housing

The Oneida Nation operates the Comprehensive Housing Division, which provides affordable housing for Oneidas within the reservation. Within the division, the Resident Services Department offers several rental programs: Income Based Rental Program, Income Based Rent-to-Own Program, General Rental Program, and Elder Rental Program (Elder Service Apartments). The Elder Rental Program oversees 29 1-bedroom rental units. Eligibility criteria for these rental properties includes: one tenant on the agreement is Oneida enrolled, meets financial requirements, and is aged 55 or older. The Elder Village, which is part of the Income Based Program, currently consists of 1 to 2-bedroom cottages that are walking distance from the Elder Services, Anna John Resident Center Care Community, and Oneida Health Center. The Elder Villages is in a multi-phase expansion that once completed will consist of 32 residential lots.

## Education

The Oneida Nation operates the Oneida Nation School System, which contains both elementary and high school. The system is supported by the Bureau of Indian Affairs (BIA) and is considered a BIA school district. Many school-aged children though are also bussed to public school districts within and surrounding the reservation. A higher education office exists on the reservation to assist enrolled Oneidas with applications for financial assistance and other applications. The University of Wisconsin maintains a branch campus in Green Bay. The Northeast Wisconsin Technical College is located within the reservation's boundaries, and the College of Menominee Nation maintains a branch within the boundaries as well. Of the total population aged 25 and over living on the Oneida Reservation, 95.4% have a high school degree

or equivalent, and 37.6% have a Bachelor's degree or higher. According to the Oneida Quality of Life Survey, of the enrolled Oneida population aged 25 and over living on the Oneida Reservation, 95.3% have a high school degree or equivalent and 32.8% have a Bachelor's degree or higher.

## Health Services

According to the 2020 American Community Survey (ACS) 5-Year Estimates by the U.S. Census Bureau, 73.0% of American Indians and Alaska Natives on the Oneida Reservation have health insurance. That would equate to 3,378 enrolled Oneidas with health insurance coverage and 1,249 without. This rate is similar to the results in the 2022 Oneida Community Health Study, where 74.5% of enrolled Oneida adults in Brown and Outagamie Counties have coverage. The Oneida Nation has a variety of medical services that are available on the reservation. The Oneida Community Health Center (OCHC) – Medical Clinic is an inpatient/outpatient facility that offers a wide range of services. Internal medicine, Family Practice, Pediatrics, Podiatry, OB-GYN, Physical Therapy, Radiology, Diabetes support and Triage are some of the major services present. Additionally, a pharmacy, dental clinic and optometry services are located on site. Several physicians are contracted to provide care in specialized areas. Also on the reservation is the Employee Health Nursing facility, which offers walk-in care for employees of the Oneida Nation at no cost. Services offered include injury/illness evaluation, blood pressure monitoring, blood sugar and cholesterol monitoring, tobacco cessation & support, weight management, immunizations, TB screening, and domestic violence screening & referrals. The Oneida Nation runs both a behavioral health center on the Oneida Reservation in Green Bay, WI and a skilled nursing facility in Oneida, WI. The Behavioral Health Ka'nikuhliyo Family Center provides outpatient substance abuse treatment, mental health services, tobacco & drug abuse programming, suicide prevention & intervention. The center works to incorporate Oneida norms, values, and beliefs into its treatments. The Anna John Resident Centered Care Community (AJRCCC) is a 24-hour skilled nursing facility for long term and rehabilitating patients. The closest additional medical services are found in Green Bay, WI within a 10-mile radius, which include 4 major hospitals.

### *Additional and Elderly-Specific Services*

The Oneida Nation operates several assistance programs. Oneida Elderly Services offer services ranging from assisted living, caregiver programs, elder abuse prevention programs, meal services, personal care, respite care, retirement communities, senior center programs, legal assistance, transportation and volunteer services. Within the Community Health Services Department, the Long-Term Care Case Management program works with state and federal long-term care programs, offers home respite and in-home chore programs, and also has a tribal dementia care specialist.

The Registered Nurse Chronic Disease – Case Management program has registered nurses helping with (up to 1 time a week) in-home medication management, in-home chronic disease

monitoring of vitals, education and treatment programs, and management of medical appointments if unable to do so themselves. This, however, is not a home health program.

Financial aid is administered by the Community Health Representative Program to provide public transportation passes for Oneida Nation members to access medical related services.

## Health Status

According to the 2022 Oneida Community Health Study, 54% of the enrolled Oneida adult population living in the CHISDA (Brown and Outagamie Counties) are obese and an additional 31% are overweight. The obesity rate of the general population in the same area is 31.7% and 36.6% are overweight according to the Wisconsin Department of Health Services 2020 Behavioral Risk Factor Survey.

According to the 2022 Oneida Community Health Study, 25% of the enrolled Oneida adult population living in the CHISDA (Brown and Outagamie Counties) have been told they have diabetes. The rate of diabetes for the general population in the same area is 7% according to the Wisconsin Department of Health Services 2020 Behavioral Risk Factor Survey.

According to the 2022 Oneida Community Health Study, 18% of the enrolled Oneida adult population living in the CHISDA (Brown and Outagamie Counties) have been told they have asthma. The rate of asthma for the general population in the same area is 8% according to the Wisconsin Department of Health Services 2020 Behavioral Risk Factor Survey.

In the 2022 Oneida Community Health Study, respondents were asked how often they had to give up day-to-day activities as a result of confusion or memory loss during the past 12 months. Of those enrolled Oneida adults aged 55+ living in Brown and Outagamie Counties, 4% responded always or usually and 13% responded sometimes. Of the enrolled Oneida adults living in Brown and Outagamie Counties, 5% provide regular health-related care to a person with Alzheimer's, dementia or other cognitive impairment disorder.

## 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.

Our 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 Board

Previous to this research, a Community Advisory Board was established in Wisconsin. The Oneida, WI Community Advisory Board (CAB) consists of respected members within the community who provide guidance on research activities and collaborations. Members represent a variety of diverse backgrounds, including, but not limited to: clinical 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 community organizations such as Great Lakes Native American Elders Association (GLNAEA).

The research team works closely with the community advisory groups at each site to review, negotiate and refine the methods, including interview questions, and identifying participants. The community advisory groups are also involved in the analysis and dissemination of results, which will yield opportunities for co-authorship if desired. The research team meets with each community advisory group at least quarterly to ensure community perspectives and understandings are prominent throughout the project. In Oneida, WI, the CAB meets on a monthly basis.



## 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 / CAB 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 CBRs for Oneida, WI are Lois Strong, MSW and Marlene Summers. Lois and Marlene were hired in April 2019 as part-time University of Wisconsin employees conducting community-based research.

## Key Informant Interviews and Sequential Focus Groups (SFGs)

Across all sites data was drawn from the following sources: (1) Interviews with Traditional Knowledge Keepers (TKKs), Providers and Administrators, and (2) Sequential Focus Groups. Key informants were selected in consultation with community advisory board members and key community stakeholders for their expertise in different aspects of prevention, diagnosis, and care for people with ADRD. Key informant interviews 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 1.** 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    |

|                      |          |          |                                                                          |           |
|----------------------|----------|----------|--------------------------------------------------------------------------|-----------|
| <b>Wisconsin</b>     | <b>6</b> | <b>5</b> | <b>2</b>                                                                 | <b>13</b> |
| <b>Grand Portage</b> | 5        | 5        | 5                                                                        | 15        |
| <b>Red Lake</b>      | 5        | 5        | 3<br>(2 full interviews, 1 emailed response – not included for analysis) | 13        |
| <b>Total</b>         | 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 living 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 2.** Sequential Focus Group information across all study sites

| <b>Location</b>     | <b>Grand Portage</b>         | <b>Ontario</b>        | <b>Wisconsin</b>  | <b>Red Lake</b>        | <b>Total</b>         |
|---------------------|------------------------------|-----------------------|-------------------|------------------------|----------------------|
| <b>Time frame</b>   | December 2020 – January 2021 | March 2021 – May 2021 | <b>April 2021</b> | April 2021 – June 2021 | Dec 2020 – June 2021 |
| <b>sessions</b>     | 4                            | 5                     | <b>4</b>          | 5                      | 14 sessions          |
| <b>participants</b> | 5                            | 5                     | <b>4</b>          | 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 Oneida, WI, the interviews started later than the other sites. Only the Traditional Knowledge Keeper interviews were conducted in-person during the months of January and February 2020. All other interviews were conducted virtually due to the pandemic.

## Oneida, WI Participants

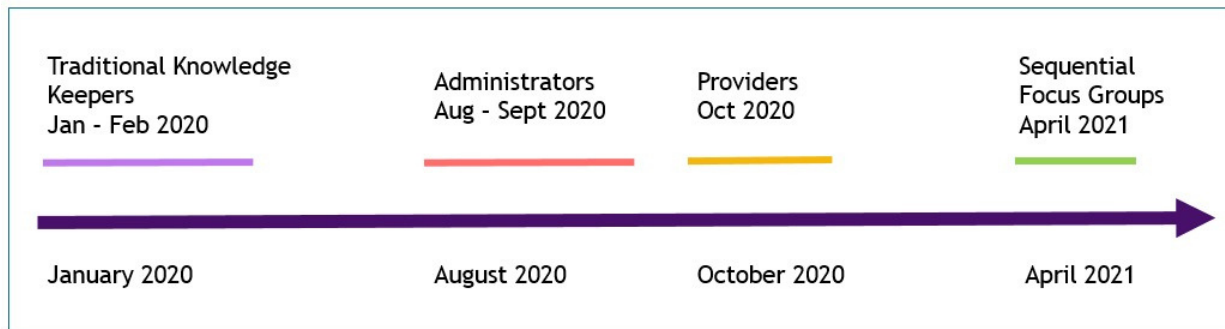
Data reported here is from research conducted specifically in Oneida, WI. Local community-based researchers (Lois Strong; Marlene Summers) worked closely with the community advisory members, health care managers and administrators Oneida to identify and recruit participants. Additionally, we asked participants 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 3.** Participant group type and roles at the Oneida, WI study site

| Participant Group (n)             | General roles of participant                                                                                                                         |
|-----------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|
| Traditional Knowledge Keepers (6) | <ul style="list-style-type: none"><li>• Elders</li><li>• Knowledge Keepers</li></ul>                                                                 |
| Administrators (5)                | <ul style="list-style-type: none"><li>• Health Services Administration and coordination</li><li>• Educational specialists and coordinators</li></ul> |
| Providers (2)                     | <ul style="list-style-type: none"><li>• Health Care Providers, (e.g., Nursing)</li></ul>                                                             |

|                            |                                                                                                                                                 |
|----------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|
| Sequential Focus Group (4) | <ul style="list-style-type: none"> <li>• Health services coordination, administration, and outreach</li> <li>• Health care providers</li> </ul> |
|----------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|

The Traditional Knowledge Keeper interviews took place between January 2020-February 2020. Administrator interviews took place between August 2020-September 2020. Provider interviews took place in October 2020. Oneida, WI Sequential Focus Groups occurred in April 2021 and took place over the course of 4 sessions.



**Figure 2.** Timeline of Participant Interviews

## Findings

Our findings from this R56 project are preliminary. We have organized these preliminary findings into five large categories which will be further explored in the funded R01 project. Each of these five large categories have subthemes, and represent topics that emerged as important considerations for Oneida, WI.

## 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. Language used to describe dementia, including the importance of Oneida Native language in meaning making, was noted. Finally, in understanding and coping with dementia, participants described how stigma and humor come into play.

### Circle of life

Participants in all groups 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. For example, as one Sequential Focus Group participant stated:

*“I think it was, uh, it just is, and it's mostly brought on by age. That's what I feel like... as you get older, you get forgetful.” (WI-SFG-03)*

Traditional Knowledge Keepers described how changes were expected, and understood as “revisiting a particular stage of life again”:

*“I've never heard any stories or any kinda mention of that [dementia] anywhere. You know and I think mostly the only thing I could say like from my own perspective and my own that it's, it's just a, a process of aging, you know? That's the only thing I could think of.” (WI-TKK-01)*

*“I guess, one of the things... what I was speaking about before were the young are going to become old and old become the young. It's, it's kind of like, in a sense to say that you're... revisiting, you know, that particular stage of their life again. And, kind of like reliving of their... it can go as far as toddler age and even maybe, I wonder... maybe of seven or eight years old. You know they go back to that, that state of mind again in times and or become, you know more playful... so it's kind of like that what they refer to it as [yeksha as'?u'tu and la'ksha sha?tu]. And, and in, in that, in that word, it's like, to say they have gone back, to a, to a child again. That's what it means.” (WI-TKK-03)*

## Language used to describe dementia

Participants often used the word “forgetful” to conceptualize dementia. Traditional Knowledge Keepers noted that, in Oneida, a person with living with dementia (PLWD) might be described as “absentminded” or “missing a moment.” In the example below, Sequential Focus Group members used terms such as “Old Timer’s Disease” and “losing it” to describe dementia, and phrases such as “sharp as a tack” and “still have it going yet” to describe healthy cognition.

**Participant 01:** *“And I, a lot times th-they call it Old Timers. Old Timers Disease- “*

**Participant 03:** *“Yeah.”*

**Participant 01:** *“... you know.”*

**Participant 04:** *“(laughs)”*

**Participant 01:** *“Like it, like it's part of aging, you know, to-“*

**Participant 03:** *“Yeah.”*

**Participant 01:** *“... to start kind of losing it. Or like, when you meet someone that's sharp as a tack yet, and they're very old, it's like it-it leaves a-a good impression, that they're, that they still have it going yet. (laughs)”*

As SFG Participant 03 later noted:

*“For me, I hear 'em talk about it as sarcastic. Ol-, ‘I am getting old. I can't remember,’ or, ‘Don't mind me, I just, I'm being old.’ That's all I mostly hear from the elders.” (WI-SFG-03)*

## Importance of Native Language: Ways of knowing and understanding

All groups interviewed acknowledged that communication was important for understanding dementia. Traditional Knowledge Keepers elaborated on why Native language is particularly salient in how information is given and received:

*"I heard [Elder's name] say that like the difference between, uh, English and, uh, uh, and, uh, the, our Native language, he said that, uh, when you, when you hear somebody talking in Indian, it's like watching something in 3D and color, and he'll, uh, or it's not even comparable to that in English. And he's right." (WI-TKK-01)*

Furthermore, Traditional Knowledge Keepers emphasized how Native language is incredibly important to identity, culture, well-being and understanding in a non-Western way. They explained how the loss of language connects to colonization, resilience and ways of knowing and understanding:

*"So, what, what do you have to show from your own language, and your own identity, and your own culture, what about that education? Do you have that education from that standpoint of view, you know? Can you understand, can you understand your ceremonies, your identity through your own language? Can you speak your own language? And a lotta people can't, you know... we've lost our contact with that. So, when we, when we talk about anything, um, quite often it's from the European viewpoint. It's from the western viewpoint, because that's where our education is, that's where our language comes from... you know, from our own language, and our own ceremonies, and our own, our own ways, our own culture... to me the answer still lies within the circle for our people. The answer is within our culture, it's within our ceremonies, it's within our language. If we lose our language, we've lost everything." (WI-TKK-01)*

## Stigma

Participants noted a reluctance to talk about dementia in the community, which may also be conceptualized as a barrier to care. For example,

*"And they don't want- they don't want, uh, other people to know. So they're not getting that support, that meal that would be so helpful, or someone coming and maybe, um, even, you know, picking up your mail for you or running to the grocery store. Those things just aren't happening." (WI-PR-02)*

When Sequential Focus Group members were asked how people in the community talk about dementia, they responded:

*"It's kind of in a negative way." (WI-SFG-01)*

SFG group members described how they perceived a stigma associated with dementia, and that there may be a relationship between stigma and fear. On the topic of why they believe people do not utilize services that are available, SFG participants responded:

**Participant 03:** *Shame, that they weren't all there... Folks don't wanna be known as someone with Alzheimer's or dementia.*

**Participant 01:** *Yeah, that's true.*

**Participant 03:** *So they just don't wanna do it.*

**Interviewer:** *Do you think that goes for caregivers too, or family members-*

**Participant 03:** *Mm-hmm (affirmative).*

**Interviewer:** *... is the, is there shame there?*

**Participant 03:** *Yeah...*

**Participant 01:** *"I think, along with the shame, there's also ano-, a-a-a factor of fear. Like, if my mom got Alzheimer's, what are my chances? Is that, does that increase my chances? I know there was a situation where, one of my first cousin's father got Alzheimer's, and then eventually he died from it... And, um, they had a-a-a thing going on in Oneida where you could come and see if you're prone to getting Alzheimer's, you can get testing done. And my s-, cousin was gonna go and then her brother told her, he says, "I don't wanna go, I don't even wanna know."*

However, they felt that with more education, people may become more comfortable discussing ADRDs. Additionally, awareness and information may provide a pathway for people to connect through storytelling:

*"Reach out to somebody. Maybe their dementia care specialists, maybe their doctor. It's okay to talk to-to family members. It's encouraged to talk to other family members. Something like that. Like a brochure..."*

**SFG-04:** *I think maybe what would grab attention too, is if people in the community that have people um, like, you know like... how you're sharing your experiences and-and... be willing to share their stories. Like, how we noticed their... like our parent or our uncle was showing signs of dementia. And I think that could put a personal, uh, tone to it all and maybe people will actually read and say, 'Hey, I noticed my so-and-so doing that.' There will be different stories in there. Like someone may have um, forgot where they parked their car... if they owned a dog, or where... owned a cat, something like that you know, just so they can kind of pin-point, 'Oh yeah, I remember so-and-so...' you got to put-put it out there somehow so people will be interested in it. And can connect to it*

**Interviewer:** *I agree... Sharing of stories is, um, I think really important.*

**SFG-04:** *Yeah, we're story tellers.*



## Importance of Humor

Participants pointed out that sometimes when hardship is identified, AI/NA people will resort to humor. This was echoed by a Sequential Focus Group participant, who noted that humor was a way to cope and understand when a loved one has dementia, and stated: “Sometimes it's better to laugh than cry.” (WI-SFG-04)

## 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 described the importance of, both family and community caregiving. They also connected aspects of caregiving to traditional knowledge.

### 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 Provider and SFG member described family caregiving as such:

*“Uh, they- they gather together to care for each other for as long as they can. You know, they've got different family members that they'll go to for help, and they, um, they help each other, um, as long as they can. And then... when they can't, they just don't leave them to the wayside, they will find some place to help them. Like our programs.” (WI-PR-01)*

*“A lot of times they have to be placed in a nursing home, because the caregivers are no longer physically able to care for them.... But, it seems like in this community, they keep their loved one with them as long as possible. Well, that's very encouraging.” (WI-SFG-04)*

One Traditional Knowledge Keeper described the relationship between cultural values and caring for family as:

*“I guess, we just kind of um, part of life was taking care of your family. Um, I think you don't just decide you know, ‘oh yeah, just because I am Longhouse, now I gotta do this and that.’ Those values were there before.” (WI-TKK-04)*

Another Traditional Knowledge Keeper spoke to the value of respect when caring for elders with dementia:

*“Well, I think first of all, you have to respect the person for, you know, dementia I guess is just viewed in, from my perspective as someone that's in a stage of life where they've had a lot of life experiences. Um... you don't have to be an elder to have dementia. But- generally speaking, when I think of dementia, I think of an elder person. And so I've known that, you know, I've been taught to respect my elders.” (WI-TKK-05)*

## Community Caregiving

Providers and Administrators noted that if someone in the community was dealing with dementia or any other illness, community members would step up to help. Here, a Provider describes the relationship between family caregiving, community caregiving, cultural values and resilience:

*“Um, and I think that's- that's really, um, something unique and- and really helpful. Uh, it helps because, you know what- as a caregiver you're gonna get stressed. And you're gonna burn out. And it's nice to know that maybe somebody else within your family or within the community is gonna step up and help you with that. And I think just, like, your beliefs and your, um, you know, the- the- the culture I think supports that. And I think that's really good.” (WI-PR-02)*

An Administrator recognized strengths of care in the Oneida community:

*“And, I think that's what kind of sets [Oneida] apart in that sense too, 'cause, you know, being a smaller community, you know, we all, for the most part know one another or know, you know, know each other's families, and you know kind of makes it easier to work with, and, um, I think, um, our services are- are pretty, you know, easily accessible.” (WI-AD-03)*

## 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 mentioned the impact of chronic disease (e.g., diabetes, cardiovascular disease), health behaviors (e.g., substance use, lack of physical activity), and mental health challenges on the development of dementia.

These ideas were also reflected by some of the SFG members, who pointed out issues with diet and toxins:

*“I think, I think a lot of contributing factors are our diets, the garbage that's in our food, um, even our cooking utensils. Our-our pots and pans we use, um, is, can be a lot of side effects. Like, for a long time I know they talked about aluminum being a big factor in causing mental foggy and stuff, g-getting an overload of-of aluminum in your system. And then, even in the water, there's so much chemicals, everything, there's chemicals in our, in the air. It's all around us and that all has to have an effect on our brains.” (WI-SFG-01)*

Traditional Knowledge Keepers also pointed to genetics, vascular issues, brain injuries, diet, and substance abuse as potential impacts for developing ADRDs. Additionally, Traditional Knowledge Keepers made a connection between the effects of colonization and potential risk factors for ADRD:

*"... I guess it can be food, nutrition, how you live your life, things that happened to you, illnesses. Um accidents, you know, if you have been in any trauma, traumatic situations...It's not like we depend on Jesus anymore for living. We depend on the sun and the moon and the stars and the water and the stones and the earth and the you know, it feeds us. It's got everything there, medicine, you know. And if we learn out medicines we can survive. On, you know, and maybe that's what happened is that we, we lost our, um, some of our culture and they gave us commodities to replace that. And there was no more nutrition in that, so, we got dementia and Alzheimer's." (WI-TKK-04)*

*"I think one of the things it's, it's, something that is more prevalent today than I believe was in the past. I think today, um, we are, um, um, I guess you could say, um, a lot that we are subjects of the food that we eat today. Everything that we today virtually has a chemical in it. Unless its organically grown and its grown in an organic climate. Other than that, everything that we eat has a chemical. Um, I believe that, prior to, um, European contact, we didn't have those types of problems. Um, that we have today. And I think you could probably say that for a lot of races as well. The chemicals that have been ingested, um, by our people over a 200-year period of time affects our health today. Dementia is one of those... from my understanding." (WI-TKK-05)*

*"I think that, uh, a, a big contributor to that as the type of diet that a lot of people follow today cause we've gotten so far away from our indigenous diets. And that's, that's something that I'm trying to bring back into, into my home. And, and you know, what the program, programming that, that, that my sister is doing is re, re-introducing that, you know. So um, and what are the things too is that um, like when we were kids we ate a lot of fish. You know, we went fishing all the time. We ate a lot of fish and, and I don't know if people, people do that today, you know, uh, like when we were kids. Um, and, and that's what they say, anyhow. I've read some stuff about it and that, that fish, fish is supposed to help with your memory or something like that." (WI-TKK-06)*

## Signs and symptoms

Participants mentioned similar signs and symptoms when it came to ADRDs. Traditional Knowledge Keepers often mentioned "forgetting" as a sign of dementia. They described how people with dementia may tell the same stories over and over, forget how to navigate familiar places, forget how to complete daily tasks like "making a sandwich" or "getting dressed." They also noted behavioral changes in the ADRD trajectory, and a tendency to "go back to their younger life." For example:

*"Well, I think some of them, um, I guess I could relate to my... my uncles. Cause they have a tendency to repeat things. And um, they'll go back to a certain era in their life.*

*What I've noticed... they go back into their younger days of life, and they kind of really, are not living in the present, so to speak... hardly. Physically they are... and their memories go back and forth between those experiences. But they have a tendency to repeat more, um, their... younger life.” (WI-TKK-05)*

As the signs and symptoms progressed, the PLWD requires additional care and assistance with activities they used to take part in. For example:

*“Mm-hmm (affirmative) mom was being real quiet and just not moving around as much not she would always be sitting in the same place when I get home from work and went to check on her. She would be, um yeah, and it bothered me at the time. I thought somethings wrong. Something is not right with her... gradually whatever she was doing with the elders slowly just disappeared. You know now she can't ride the bus, she can't attend any goings without someone being with her. You know, she can't go shopping with them anymore.” (WI-TKK-04)*

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 administrator described how functional changes become challenging and a safety issue as ADRD progresses:

*“Oh gosh, just, you know, the incontinence, once they start becoming incontinent issues, um, you know, then it's a tougher task for the caregivers, uh, wandering, then we gotta put door alarms and window alarms. So there's other, um, issues, yeah, that do come with it.” (WI-AD-04)*

A Sequential Focus Group participant described caring for a loved one with dementia, and meeting them where they are:

*“And I know another time I had to go with him again, he kept saying he had to get his car. It was outside, and it had snow stormed that day. So, I had to take them all around the nursing home, look every... through every single window, and kept telling him, ‘It must be underneath the snowbank. I can't find it. (laughing). Till he finally got onto another path, (laughs).... But I learned my way around the nursing home.” (WI-SFG-04)*

## Diagnosis

Participants mentioned various ways in which a loved one may get a diagnosis of an ADRD, and mentioned that often it is a family member who brings their concerns to the attention of the provider. Administrators and Providers talked about performing cognitive screening assessments, and Providers noted making referrals directly to primary care physicians. For Administrators, next steps in the diagnostic process were less clear. They mentioned several different points of contact for receiving a dementia diagnosis, including primary physicians, the Oneida Dementia Care Specialist, the Tribal Aging and Disability Resource Center Coordinator, and the Native American Family Caregiver Coordinator. While the diagnostic/referral pathway

was somewhat vague, both administrators/providers agreed that accurate, early assessments are necessary to build appropriate care plans for a PLWD and their caregiver(s). Providers, Administrators and SFG participants felt that an earlier diagnosis can help families provide better care, emotionally adjust, and helps prepare everyone for the future. As one Provider described:

*"You know, if you're early, you know, if you have early detection you can tell your family, you can be part of that decision making and say, 'Hey, you know'... you can decide, like, who your power of attorney's gonna be, where do you want, um, where do you wanna live? Like, how long, like, do you wanna be in your house forever? Or, I mean, are you gonna say to your family, 'You know, at some point I- I know you might- you might not be able to take care of me and it's okay if you have to take me somewhere, you know?' Um, you can be part of that whole discussion. Or, 'You know, I want, I really don't want so and so to, you know, be my caregiver.' What- whatever that discussion is. And making sure you're having, you know, all your- your legal stuff in place, you know, your will, your power of attorney, your- your bank accounts, all that stuff. That person then who has dementia, and diagnosed early, can be part of that decision making process."* (WI-PR-02)

As an Administrator explained:

*"Nope. I don't know. I just know how to get the screening done and get them, let them get to the doctor. I don't know what they do there."* (WI-AD-04)

Traditional Knowledge Keepers explained how, overall, dementia diagnoses are not necessarily commonplace:

*"I don't think I really remember saying oh the diagnosis for her is dementia. Or you know it was like, she's getting forgetful. She's getting really forgetful."* (WI-TKK-04)

Not only was early diagnosis mentioned as important, but one Administrator made a connection between dementia specific diagnostics and quality of life:

*"I think how that ties into it is, it... It ties together very closely, because we are trying to figure... I mean, provide our elders a way to live independently, but also healthy lifestyle, and through any avenue. And, I guess, through dementia care and- and- to me it- it's just... that's just a real thing, you know? That our elders can go through, and... How can we- how- how are we able to provide assistance so that they can live a productive life even, you know, with something as, like, dementia."* (WI-AD-03)

Moreover, the importance of diagnosing dementia type was emphasized:

*"I think it's important to know the specific diagnosis because different forms of dementia have different forms of treatment. Like, if you're looking at medications- some of the medication is contraindicated for different types of, um, dementia... if you give it the wrong, if you give it to somebody who has let's say, um, Lewy bodies or something it can make them worse. And, you know, it can make them maybe more agitated. Um, and it- it makes, it doesn't help them. So it's really important [...] because every form of dementia, every form of dementia is a little different. Not all of it has memory loss. Um, not all, you know, some of it has, um, delusions and hallucinations. That's good to know that that's the type of dementia they're dealing with. Um, and it's important for the providers themselves to know so that they can, um, give the people the right medications if that's what they need, you know? If somebody's having delusions you wanna take care of that. I mean, how awful if you have a really scary delusion going on, you know." (WI-PR-02)*

## Prevention, delay & treatment of ADRD

In relation to prevention and delay of ADRDs, Providers recommended modifications such as healthy diet and physical activity. Providers also encouraged loved ones and family members to reach out to organizations and services that can assist with planning after a dementia diagnosis. Neither administrators nor Sequential Focus Groups spoke about prevention efforts associated with ADRDs.

In relation to treatment of ADRDs, both administrators and 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. For example, one Administrator explained:

*"I do. Um, even if they do live off the reservation, I give them the number to a traditional healer we have within our tribe- And then they can contact them. Otherwise, if they lived on the reservation, I would call that traditional healer and we would all work together." (WI-AD-04)*

While one Provider commented regarding not having made referrals to traditional healers:

*"No, I have not, I'm surprised, because they're all, you know, elders." (WI-PR-01)*

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.

*"I think that if a person's physically fit or, uh, takes care of themselves, and tries to watch what they eat and everything, they have more of a chance of being, uh, you know to avoid it I guess I would say, you know?" (WI-TKK-01)*

Learning and speaking in Native language was noted as a particularly effective way to keep the mind active and healthy:

*"I do think of, uh, like, uh ... 'cause again, dementia or Alzheimer's, it all has to do with the brain. You know? And, uh, I always think, uh, you know you have to exercise your brain, um, just like anything else. Well to me, like if I think in my language. If I, if I do that, uh, that's, uh, mental gymnastics right there, you know when, when you do that. 'Cause you know it, it's, uh ... I think a lotta people don't, uh, realize how tremendous of a language this is. And then, and then on the other hand, how difficult of a language it is to relearn- Uh, keeps you, keeps it spinning so it don't rust up." (WI-TKK-01)*

## Impact of Colonization on Preventative Health and Traditional Healing Practices

Interviews with Traditional Knowledge Keepers yielded stories and themes that tied identity to resilience, and recognized the impact of colonization on health and health behaviors over time.

As one Knowledge Keeper explained:

*"Uh, well, you know, we have that story about how the medicines came to the bear clan and, um, and that those people are, or they're just naturally inclined to be in that kind of a profession, helping people, whether it's the emotional, the psychological, the spiritual or the physical. There's those, those, are the four professions there. And, and as helpers, it not necessarily has to do with medicine per se, but you know, sitting and listening to somebody talk about their stuff, struggles or whatever is a medicine for that person... You know? And, um, um, like in, our grandparents' generation, you know... they knew about that. That was still alive here, you know, and, um, it's only been the last couple of generations here where we've gotten away from that, where the acculturation is escalated to the point where our kids don't even go out in the woods. Um, unless they go to tribal school (laughs), then they're forced to go out there" (WI-TKK-06)*

Other Traditional Knowledge Keepers mentioned the importance of ceremonies, social relatedness, Indigenous diets, singing, dancing and traditional medicines to maintaining good health:

*"But, um, like I say I, I hear this sa- saying in our ceremonies, as a, as a powerful one because I hear this all the time. It says for us to always go along with a good mind... and for us to have a good mind and have that love and that compassion for each other between us.... You know, between everybody. So that's... Those are powerful things right there. And that's, uh, I guess that's where the understanding comes from." (WI-TKK-01)*  
*"Our corn beans and squash and how to cook and activities with our social, socials that we have for birthdays. You know, the singing and you go to one of these and it really makes you feel good about being there and singing and dancing and eating." (WI-TKK-04)*



*"Yeah, I think it's the utilization of various different, medicinal plants that we have. Prayer, ceremonies. We have a number of, ceremonies that we conduct throughout the year. Or someone that has, you know, um, you know, to speak towards their wellness and to help them." (WI-TKK-05)*

*"...these medicine plants that we have help address those things and it's the same thing with, dementia. You know, when our elders come to these ceremonies and, and these various, and partake of these plants, that refreshes them, you know, that clears their mind. For an example, I know through the use of medicine, is that there's a plant that's, it's a sage. And I know that that plant can be used in different ways. It can be boiled. Um, it can be used in a sweat lodge. And I also know that if you take the plant itself and you crush it in your hand, grind it up in your hand, then you hold it up to your nose and you inhale that, that fragrance or that aroma from that plant, that goes directly to your brain. That ends up giving you a calming experience. So there's things like that and knowledge like that that's been handed down from generation to generations that, that we use today." (WI-TKK-05)*

One Traditional Knowledge Keeper acknowledged the impact of colonization on passing down certain cultural teachings, ceremonies, and medicines. Older generations who attended Indian Boarding Schools, or who were heavily influenced by Christianity, may have hidden their cultural teachings, ceremonies, and knowledge of traditional medicines out of fear of being punished. As such, these older generations may have never passed this information on to their children or grandchildren, creating a cultural generational gap.

Traditional Knowledge Keepers recognized that more Oneida people want to learn about the culture, including the language, ceremonies, and teachings. One Traditional Knowledge Keeper shared that revitalization of culture takes time, along with a healthy dose of humor:

*"You have to want it, you know? Um, and, and, but it's planting a seed, you know, that's all we can do really for the ones that you know, that don't want to change. Is just plant that seed, you know, and let them think about it, to, to, to a time when they're ready. Um, so, you know, but other than that, you know, um, you know, like all the ceremonies, you know, it's all about, um, being thankful. And so how thankful are you? You know, what's your relationship to the natural world, eh? Um, do you have a relationship to the natural world? And, and if, if you don't, why not? And if you do, well what kind of relationship is it? Is it like a family? Do you look at it like a family? You know, 'cause that's, we've got the same maker, that blade of grass, that bird ... That, that owl that's trying to eat my little dog, (laughs)." (WI-TKK-06)*

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

Providers and administrators described many available facilities, services, and programs for persons living with dementia and their caregivers. Administrator responses were particularly detailed, and suggest a high level of engagement with PLWD and their caregivers. Participants in the Sequential Focus Groups were less certain about the services and programs for dementia.

Sequential Focus Groups reported a vague knowledge of services and facilities, identifying Elder Services, the nursing home, and programs in nearby areas:

*“Well, I know Elder Services used to have all that to some degree. Well, when they had the caregiver program... and, um, they would do a lot of what you're mentioning. But it sounds like the, with this Lakeland and stuff like that, that's even more, um, in-depth assistance.” (WI-SFG-01)*

## Services and programs for caregivers and PLWD

Administrators/providers detailed numerous available resources, facilities, services, and programs for PLWD and their caregivers. For example, within the community there is a long-term care facility, Elder Services, Oneida Community Health Center, Dementia Care Specialist, the Cloud Family Center, and a contract with the Lakeland facility that offers help/services for elders and people with disabilities (e.g., homemaking, transportation, respite, day services, medication management, etc.). Additionally, individual and group support is available for caregivers (e.g., Powerful Tools program, Dementia Friends, support groups). Overall, participants reiterated the importance of family in providing support to a PLWD. For example, a Provider commented on caregiver goals and engagement:

*“Um, they get involved knowing that they're looking out for, um, their loved one, for sure. But then, I believe that they also know that they want to have them, um, have the best quality of life. So they do, um, enroll them in different day programs that around the area....Curative, and Clarity Care, and Aspiro. Um, so there's different programs like that. So they know that they want, um, them to have, uh... be very engaged with other people. Wh- but what also gives them their, um, their peace [is] that they need to think and, you know, reevaluate things.” (WI-PR-01)*

Administrators spoke of Native community members who provide respite and support to help families keep their loved ones in the home as long as possible. In addition, administrators described many services and needs in particular detail:

*“I have support groups for caregivers. I help caregivers find resources for, um, the recipients who they care for. I- I've been working with, um, economic support and using the funds that the tribe has put aside for recipients who need medical equipment at home. So, since the COVID that's what I've been doing, um, helping them get ramps and lift chairs. And, um, if they don't have the medical insurance to get those things through Medicaid, if they don't got that Medicare part B, which they can't get any kind of stuff like that...But also I normally hold a Powerful Tools for caregivers to help relieve, um, show them techniques to help relieve stress... and what comes with caregiving duties when it's 24/7. It can be overwhelming to the caregivers, especially for the ones who have loved ones with dementia. It's a little more, the task is a little more, um, harder for them... so they are able to use respite dollars that we have through the, um, national family caregiver support program. We get to help pay for respite care, where they can*

*go on to an adult day center to give the caregiver a break during the day. I transport and I pick them up... and on my outreach side... during this COVID time... I go shopping for them or I take them to the bank or, and we always use precautions. We gotta have mask and of course, six feet apart.” (WI-AD-04)*

## Barriers and challenges

Awareness, or lack thereof, is a potential challenge to those seeking support, along with described financial hardships, caregiver stressors, programing cuts, eligibility for services, staffing shortages, geographical issues, and a need for specialized dementia training and education for all health care providers and community members.

Sequential Focus Groups spoke to the impact of trying to balance work and life, with caregivers becoming overwhelmed as dementia progresses:

*“And I think, I think too, another contributing factor to not getting care is, you know, most-most people have to work outside the home, you know, to make ends meet. And, uh, a lot of times, people fall through the cracks that are getting this, because it's-it's, uh, everyone's so busy with their own lives, that they don't have or take the time, to look out and say... Or like, even like, say for instance, with the different classes they had at elder services, I would tell my mom, or my brother, and them, about it. But, they never came. And, I couldn't go and get them because I was working.” (WI-SFG-P01)*

*“Yeah, I- I see that a lot where it just progresses, like [participant 1] just said. They, they just can't. They can't. They don't have the resources anymore. There are services out here but the services become overwhelmed, too, with what they need and they are unable to support 'em 24 hours a day eventually. And a lot of them, I- I see going to a facility, which you don't want, but with our lives now, we really can't take care of them. Even if you were home all the time, that's, that's just too much for anyone in time.” (WI-SFG-P02)*

Administrators named caregiver stress, lack of access to technology, and challenges related to COVID as barriers:

*“... I think, um, I can really see a lot of, uh, stress among caregivers who, um, take care of their loved ones who live with them in the homes. So right now it's difficult to find, um support groups virtually only because sometimes our caregivers don't have the, um, technology, laptops or computers to participate in those caregiver groups. So what I do is I contact everyone on my caregiver support program and just have a sit down, talk on the phone with them and, you know, see what their needs are and if they're getting met. So that's kind of what I do here.” (WI-AD-04)*

## Recommendations to improve dementia care

Participants frequently highlighted the need for more caregiver/community support services (including respite and adult day services), attention to dementia care environments, the importance of relationship building, and a need for more ADRD education. Recommendations included education for families regarding signs, symptoms and what to expect in caring for someone with dementia, along with education to reach younger people in schools. Finally, Traditional Knowledge Keepers advised health care professionals and researchers working within tribal communities to integrate respect for culture and multiple ways of knowing into their perspectives.

## Community services

Respite care was one specific recommendation amongst Sequential Focus Group Members:

*"I liked the idea about the day services for respite care... You bring your... your loved one there, and you don't have to explain what you're gonna do. Just, you need some time, three, four hours, five hours maybe. And then on the weekend, everything's closed on the weekends. And sometimes the respite care workers, um, can only get away on the weekends... But there's nowhere to go, because they're obligated." (WI-SFG-02)*

One provider spoke about the importance of respite care and helping caregivers stay healthy so they can care for their loved one:

*"I think more education has to, um, has to be out... oh, I don't know how to say it. But to offer more education, like, um, to the resp- to the caregivers... to let them know that there's respite services out there for them so they don't have to feel, um, their health could also suffer. But... they don't have to go to that extent if they could get help, um, earlier. Get help to help them..." (WI-PR-01)*

## Dementia care environments

In general, participants discussed the benefits of keeping PLWD in their homes and communities for as long as possible, and generally in places where they have long-term connections and memories. Additionally, in considering other caregiving settings (e.g., adding a dementia care unit to the nursing home) participants thought it important to consider environmental surroundings for PLWD. They recommended nature-based surroundings, explaining that:

*"It would be easier on their brains and their minds if you look. And it's very serene, and peaceful, and humble. You really don't have to think anymore. You don't have to think about, 'Am I going... walking the right way to my room? Am I walking the right way to dinner?' They don't really have to think about anything, just about what they're seeing is just peaceful. And then, like, if it was birds or animals, just, they're, they're, they're natural, natural sounds. No arguing or yelling." (WI-SFG-02)*

*"I think a lot of times, too, um, s- some, eh, some, uh, people with dementia go back to their childhoods. And that would be memories that they can pull from their childhood- being in the nature, playing outside, and stuff like that." (WI-SFG-04)*

*"But we always try and, we always want to try and get the elders out of their home. You know, there's certain ones that don't go anywhere. Or families don't go visit them and whatever. They still need to go and smell the air, go for a ride or something." (WI-AD-02)*

## Education

Education, communication and sharing experiences were discussed as pathways to start conversations, engage loved ones, increase connectedness, and reduce any barriers that are potentially due to stigma.

### *Importance of relationship building in research, education, and outreach*

Prior to considering any ADRD education outreach needs, participants noted the necessity for healthcare providers and researchers to begin this process by building trusting relationships in the community:

*"...you know, like, you have to do, um, you need to do an education thing. I'm like, oh okay, okay. But it wasn't like I could just run out and do it. I had to- I realized that I had to, uh, you know, get accepted by the community." (WI-PR-02)*

Administrators added that part of relationship building in the community requires collaboration with Tribal leadership. It is important to understand, from the community perspective, where the gaps are and how to address them:

*"I think for leadership to know that... you know... that you're doing this research so you can gather more information on this- Is, uh, very important, so you could get their take on it, like, where do they... how do they see this and what- what gaps do they feel, um... 'cause they're the ones that can, you know, can green light it or, you know, put a halt to it.... And what I was gonna say, too, is that ... in regards to like our business committee, you know, it's like some of, them... they're young... and I know they're- they're aware of Alzheimer's or dementia, but maybe not so... educated on the topic... so I- I think it would be valuable to- to get their perspective on it... a good reminder for them, I guess, too." (WI-AD-03)*

### *Engaging young people*

Additionally, Sequential Focus Group Members recommended ADRD education for young people in the community:

**"Participant 1:** ...like say, just for like, even like, young people, like in high school. If like, in health education, maybe they could have a segment on-on Alzheimer's and stuff like that, to make them aware of what to look for.

**Participant 2:** Yeah.

**Participant 1:** That's not something that they're gonna want to check into by themselves. But if it's a mandatory class, they have no choice but to learn about it... And have the teachers who put that in as part of their curriculum of like, you know, what's wrong with ga- grandma, what's wrong with grandpa or that type of thing. You know, how come grandma doesn't recognize me anymore? You know, things like that...Then our children would be educated before they even get up into their own adulthood.

**Participant 2:** I agree with that. I like that, uh, that start, anything starts young."

### Caregiver and community education

"I think there's... I think there's a-a-an amount of people who don't wanna talk about it. They don't like to acknowledge that-that it's happening in their family. Um, and then there's a lot of people that just don't know enough about it." (WI-SFG-01)

"I think another thing to that would be an important thing would be um, giving the caregiver information as to what to expect from their loved one. Like how- how does the progression of the disease happen? I know- I know I talked to some people today and they were saying that when their loved one was getting in the end s- very, very end stages, um, they stopped eating because the brain wouldn't tell- tell the rest of the body you need to eat. You know." (WI-SFG-01)

"Maybe those, um, programs, if there was like, um, mm, support groups also offered through the clinic, or behavioral health and, um... But really have people there, uh, that are, um, acclimated in the dementia care. Like maybe members in the community that are caring for their loved ones, uh, to support the, the new people coming in." (WI-SFG-02)

"I think what might help is-is if they had like, a-a group of like, the outreach workers, to go in and spend time with the caregivers, in talking to them on a one-on-one basis of what their experiencing, and what-what tips that can be given to them to help." (WI-SFG-01)

### Healthcare provider and researcher education

Finally, Traditional Knowledge Keepers advised health care professionals and researchers working within tribal communities to integrate respect for culture and multiple ways of knowing into their perspectives:

"Um, I would advise them to be sensitive. Um, with respect to, other cultures... and their philosophy and understanding of how the world that we live in." (WI-TKK-05)

"I think at the health center it seems like their giving um, their having [traditional knowledge keeper] coming in to talk with them. Having their little meetings to learn about um, Oneida ways or especially the cultural ways because when they go sometimes in the hospital and people want to come and do a smudging or you know, to help that

*person and I think they're getting to learn that this is good for them to do because um, I mean just seeing for instance, one person was about, it was like he was dying and they brought him the Indian um, the Indian medicine you could call it, and to this day he is living. Mm-hmm ... And sometimes the doctors don't know everything. And I think they are starting to realize that you know, that the cultural way can even be more helpful with their medicines and what they do to help this person. Um, service and get better. And can be still it just wasn't their time to go. They would say it wasn't their time to go."*  
(WI-TKK-04)

## 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 Oneida, WI, a total of 13 Key Informant Interviews were conducted along with 4 Sequential Focus Groups with 4 participants.

The preliminary findings reported above will be explored in the next phase of research (ICARE R01) and is currently ongoing.



## References

- 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.
- Oneida Nation. (2019). Oneida Nation – *Tsi' Niyukwalihó•tł* – our ways, our culture. Retrieved March 18, 2019 from <https://oneida-nsn.gov/our-ways/our-story/who-we-are/>.
- Oneida Nation. (2019). Oneida Nation – Who We Are. Retrieved March 18, 2019 from <https://oneida-nsn.gov/our-ways/our-story/who-we-are/>.
- Oneida Nation. (2020). About the Oneida Language- History. Retrieved February 5, 2020 from <https://oneida-nsn.gov/our-ways/language/history/>
- Oneida Nation. (2020). Where to Get Started. Retrieved February 5, 2020 from <https://oneida-nsn.gov/resources/housing/where-to-get-started/>
- Oneida Nation. (2019). Comprehensive Housing hosts Elder Village Open house. Retrieved February 5, 2020 from <https://oneida-nsn.gov/blog/2019/11/21/comprehensive-housing-hosts-elder-village-open-house/>
- Oneida Nation Records and history from Outagamie County, WIS. (2022). Retrieved May 9, 2022, from <http://genealogytrails.com/wis/outagamie/oneidanation.html>
- Tiller, Veronica E. Velarde. (Eds.). (2015). *Tiller's Guide to Indian County, Economic Profiles of American Indian Reservations*. Albuquerque, NM: BowArrow Pub. Co.
- U.S. Census Bureau. (2019). *My Tribal Area-Powered by the American Community Survey (ACS) 2013-2017*. Retrieved March 5, 2019 from <https://www.census.gov/tribal>.
- Wisconsin Department of Health Services. (2018). American Indians in Wisconsin: Health Facts. Retrieved March 15, 2019 from <https://www.dhs.wisconsin.gov/minority-health/population/amind-pophealth.htm>.
- National Resource Center on Native American Aging. (2019). *Service Locator*. Retrieved March 11, 2019 from <https://www.nrcnaa.org/service-locator?state=WI>.
- Oneida Comprehensive Health Division. (April 2018). *Oneida Comprehensive Health Division Patient Handbook*. Retrieved from <https://oneida-nsn.gov/resources/health/about/>.

C. Summers, personal communication, February, 2020

Additional references to add from Community Profile section:

2020 American Community Survey (ACS)

Wisconsin Department of Health Services 2020 Behavioral Risk Factor Survey

Oneida Nation Human Resource Department Records 2022

2022 Oneida Community Health Study

2018 & 2020 Oneida Quality of Life Survey

Oneida Nation Enrollment Records. (December 2021).