PERCEPTIONS OF ALZHEIMER’S DISEASE AND RELATED DEMENTIA AMONG ABORIGINAL PEOPLES IN ONTARIO

THUNDER BAY COMMUNITY REPORT, OCTOBER 2013

By: Dr. Kristen Jacklin, Northern Ontario School of Medicine
Dr. Wayne Warry, Centre for Rural and Northern Health Research, Laurentian University
Mr. Devin Dietrich, Centre for Rural and Northern Health Research, Laurentian University
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This project was a collaborative effort that could not have been completed without the contributions of many people. We extend sincere thanks to all of the individuals and organizations in Thunder Bay who contributed their time and expertise to this research. We gratefully acknowledge the contributions of the Thunder Bay Indian Friendship Centre and the Anishnawbe Mushkiki Aboriginal Community Health Centre. A special thank you to our many key informants including physicians and specialists providing services to seniors in Thunder Bay and the traditional healers, knowledge keepers, and Elders who shared their wisdom. We would also like to express thanks to our local research assistant Wanda Fox for her knowledge and commitment to the project and project research associates Agnes Kanasawe, Melissa Blind and Lisa Boesch.

Chi Miigwitch to our Advisory Group members:

Bernice Dubec, Executive Director (TBIFC)
Ernie May, Long Term Care Program (TBIHC)
Kathy Spence, Long Term Care Program (TBIHC)
Charlene Baglien, Director of Operations (TBIHC)
Corrina Gagnon, Executive Director (Anishnawbe Mushkiki)
Shannon Gustafson, Health Promotion Seniors/Elders (Anishnawbe Mushkiki)
Teresa Magiskan, Traditional Health (Anishnawbe Mushkiki)
Debbie McGoldrich, NP/Clinic Manager (Anishnawbe Mushkiki)
Darren Borg, Social Systems Navigator (Anishnawbe Mushkiki)

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This report was submitted to community partner organizations in October 2013 and was presented in draft to the Advisory Group members on January 22nd 2014. Advisory group member comments were solicited and the report was finalized in September 2014.
EXECUTIVE SUMMARY

The purpose of this research was to engage Aboriginal peoples with dementia, Aboriginal seniors, caregivers, healthcare practitioners and other key informants in order to gain knowledge about the attitudes, beliefs and behaviours relating to Alzheimer’s disease and related dementias (ADRD) in diverse Aboriginal communities in Ontario. A qualitative research approach was used that was respectful of Aboriginal methods of gathering information. A community-based research design was employed that involved partnerships with Aboriginal communities on the design, development and implementation of the research protocol. Community members guided the development of funding proposals, key questions, methodologies and data analysis. Several methods were used to gain this knowledge including interviews, focus groups, and participant observation.

This report outlines the findings from the interviews, focus groups, and participant observations carried out in Thunder Bay as well as relevant information from the academic literature. There were 30 participants in total from Thunder Bay. We present Western understandings of dementia as a backdrop to local perceptions concerning the symptoms and meaning of dementia, practices relating to detection, treatment and care, and healthy aging. We examine our participants’ understandings of the causes of dementia and what dementia means in their communities. We also present our findings relating to local strengths in coping with dementia as well as indicating barriers to dementia detection, and care and service needs within the community.

KEY FINDINGS

1) Views on Healthy Aging

- Participants generally shared a view of what it means to age well. They agreed that to be healthy in old age a person would need to maintain meaningful relationships, and be socially involved with friends, family, and the community. Participation in social and cultural events was viewed as having a positive impact on old age. Having a sense of purpose and being able to continue to contribute was a key factor for many participants who felt that working part-time, volunteering and doing work around the house would all contribute to healthy aging.

- Participants shared that they have seen many changes to traditional family structures and elder’s roles that are contributing to more elders living alone or being placed in care facilities. Typically, this means that elders are moving from their community to Thunder Bay in order to access specialist care and care facilities. The added stress of moving to the city and becoming accustomed to a new environment may be impacting healthy aging for these Aboriginal seniors.

- Urbanization and urban life may be a barrier to healthy aging for Aboriginal seniors. Participants experienced a sense of disconnection from land and family, isolation, disrespect, inability to speak in their Aboriginal language, racism and fear in Thunder Bay. Housing and transportation
were viewed as unaffordable. Seniors expressed the desire for better connections to one another and put forward the idea of establishing a senior’s network.

- Access to traditional foods was considered important for healthy aging. Many of the participants felt that processed foods and other foods they were unfamiliar with that are typically available at grocery stores in Thunder Bay were not good for their health. Getting traditional foods in Thunder Bay is difficult and many of the participants cannot gather it themselves because of mobility issues and could not make it back to their communities because of lack of transportation. Gathering and preparing traditional foods also provides social interaction which is important for health. Traditional foods were sometimes provided by family coming to visit or by the Thunder Bay Indian Friendship Centre.

2) Understandings of Age-Related Dementia

- Memory loss and confusion/dementia was most often discussed as a normal part of aging and traditionally, those with these symptoms were generally accepted and cared for at home. Words such as ‘natural’, ‘normal for that stage of life’ and ‘second childhood’ were used to describe this as a natural process. Many spoke about the attitude of ‘acceptance’ when it came to age-related memory loss. However, some health care workers speculated that the naturalized view of memory loss may be changing as contemporary ideas of aging are becoming more common.

- Particular expressions of dementia (symptoms) that usually occur in the later stages were described to have cultural and spiritual relevance to those we interviewed. Child-like behaviours and the need for supervision and care similar to children’s needs were explained in relation to one’s spiritual journey and taking on the spirit of a child at that stage of life. Others related the experience of hallucinations to those of visions which would be normal at a later stage of life where one had one foot in the spirit world.

- The potential for dementia to carry stigma was discussed by the participants but most felt that dementia was not highly stigmatized in Aboriginal people. Some caregivers did express fear that they would experience stigma or shame but overall stigma was not part of the dementia experience for these participants.

- Participants felt that there was no word in their languages (primarily Oji-Cree and Ojibwa) that would translate to ‘dementia’ as it is understood by Western medicine but there are words for particular behaviours such as “forgetful”, “confused”, and “memory loss.” Participants also shared words in their language that describe the experience of dementia from their cultural understanding: ‘returning to childhood.’ In English, people used words such as ‘forgetful’, “memory loss”, “senile”, “sickness in the brain”, and “second childhood” when talking about Alzheimer’s and dementia.

- Many of the participants from Thunder Bay who understood memory loss and dementia as natural also offered non-natural explanations of why symptoms may have come on when they
These explanations included those that are:

- **Physiological**: such as having other illnesses (multi-morbidities), prescription medications, family history, food additives.
- **Psycho-social**: such as stress, unresolved grief, trauma, residential schools, culture shock, alcohol abuse.
- **Indigenous**: disruptions in the relationships to land, urban migration, cultural continuity.

### 3) Diagnosis

- Most Aboriginal seniors in this study were dealing with multiple conditions (diabetes, cardiovascular disease, etc.) in addition to dementia.

- Symptoms experienced by participants included: **Mental** – forgetfulness, confusion, difficulty problem solving, lack of sense of direction; **Emotional** – frustration, irritability, anger, fear, sadness; **Physical** – impaired mobility, falls, difficulty speaking and writing; and **Spiritual** – visions, messages from the spirit world, one foot in the spirit world. By far the most consistent re-occurring emotion expressed by the participants was “frustration”.

- Most participants felt that dementia is under-diagnosed and/or mis-diagnosed in Aboriginal people in Thunder Bay. Reasons for under/mis-diagnosis included a reluctance to discuss what is felt to be family/personal business with physicians; the lack of culturally relevant cognitive assessment tool.

- There is a need to develop culturally relevant cognitive assessment tools for Aboriginal people. The results from this study indicate that for Aboriginal people living in Thunder Bay such a tool would need to take into account Aboriginal languages, levels of historical trauma, appropriate communication styles, relevance of the questions, and the health care environment. There was a desire for a tool that could be administered by someone in a trusting relationship with the patient (Aboriginal health care worker or family member). This was also identified as a key need by the advisory group when the project was first initiated.

- Virtual Health Care (Telehealth/Telemedicine) is viewed as a tool that can improve access to dementia screening and care for Aboriginal people in remote Northwestern communities. These modes of health care delivery could significantly reduce stress, financial and emotional burdens associated with travel or migration to urban centres for the purposes of accessing health services.

### 4) Treatment

- The findings suggest that Aboriginal people are seeking treatment for dementia at a later stage in the illness than non-Aboriginal people. This may stem from an acceptance of the illness as natural, reluctance to take prescription medications, and/or from a general reluctance to
engage with the health care community in Thunder Bay.

➢ Prescription medications are not widely accepted by Aboriginal seniors. Many participants disclosed that they would stop taking medications without speaking to their physicians. Reasons for the discontinuation of medications included: not trusting the motivation of the physicians in prescribing the medication, not understanding the purpose of the medication or the instructions provided, inability to get renewals on their medications (due to changing NIHB policies and or lack of resources), and the side effects.

➢ Traditional medicine was used by some of the participants for overall healthy living but not for dementia symptoms specifically. The Thunder Bay Indian Friendship Centre and Anishnawbe Mushkiki were discussed as important resources for Aboriginal people seeking traditional approaches for their health and wellness.

5) Dementia Care

➢ Most often Aboriginal people with dementia in this study were being cared for at home by family. There was a deep reluctance among these participants to consider moving their loved one to a nursing home environment. Key challenges in providing care to a person with dementia in the home included: having to deal with health care workers who lack knowledge of their culture, racism, the emotional toll on the caregiver, physical challenges related to providing care, stress caused by the multiple roles of the caregiver, and dealing with multi-morbidities.

➢ It is believed that institutionalization (confinement, routine, structures) experienced by Aboriginal people as they go to long-term care homes may cause unresolved trauma related to residential school experience, the Sixties Scoop and Children’s Aid, TB sanatoriums, correctional facilities and mental health facilities, to resurface causing a more rapid decline.

➢ Though memory loss and confusion are primarily thought of as something that comes with getting older, most agreed that there is a point when symptoms get more severe and outside care and support is needed.

➢ According to these findings ideal care for a person with dementia would include having Aboriginal people with dementia cared for at home by a family member supported by culturally safe care providers and programs.

6) Dementia Related Programming and Information

➢ Key to the family model of care described above is the need for specific services to address the caregiving needs at the different stages of dementia. Specifically, there is a need for: adequate and increasing respite care throughout the disease process; access to information about the illness; and additional supports from local health agencies. As the illness progresses, care
becomes more complicated and the burden on the caregiver increases.

- The results from this study suggest a lack of programming available for older Aboriginal people in general and even less so specific to those with dementia. Participants suggested programming should be interactive and appropriate for the people with dementia, delivered in the local Aboriginal language, and supported by transportation programs.

- There is a pressing need for more information about dementia at all levels of care. Those with dementia, their family based caregivers, and community healthcare practitioners all expressed a need for more specialized information to assist with coping with or treating dementia.

7) Culturally Safe Dementia Care

- The study revealed that there is clearly tension and dissatisfaction when older Aboriginal people access health care services in Thunder Bay. Participants shared experiences of racism and fear associated with clinical interactions and a lack of knowledge on the part of health care providers of their culture. For the most part this resulted in a reluctance to seek care.

- Participants stressed the need for culturally appropriate policies and programs that would keep Aboriginal seniors with illnesses in in their home communities rather than relocate them to Thunder Bay, as well as improve access to traditional foods and Indigenous medicines for those in Thunder Bay.

- Cultural differences in communication styles are a barrier to the delivery of culturally safe dementia care for Aboriginal people. Participants in this study shared that clinical dementia care may be particularly challenging in health care environments where there is no continuity of care with family physicians. Important to the disclosure of ‘family business’ and ‘personal issues’ is the establishment of a relationship and eventually trust with a care provider which can only happen over time.

- Participants stressed the importance of family in providing care and the need for health care practitioners to understand the role of family in individual health care interactions.

- Delivering healthcare services and especially doctor patient interactions in the language of the patient was identified as important for getting accurate information and achieving an appropriate comfort level for the Aboriginal patient. Some described how their thought processes and memory worked better in their own language.
RECOMMENDATIONS FROM THE ADVISORY COMMITTEE BASED ON KEY FINDINGS

Meetings with the advisory group to review the report took place in Thunder Bay on Jan 22nd, 2014. Two separate meetings were held that day with the TBIFC and Anishnawbe Mushkiki in order to accommodate different schedules. This summary represents the combined response to the report. The advisory group discussions reinforced the validity of the findings and emphasized specific needs and service gaps. The advisory group agreed that many more cases of dementia are being seen in recent years and many seniors coming to Thunder Bay for services are displaced and face discrimination. They identified a need to enhance community based services at the Thunder Bay Indian Friendship Centre and Anishnawbe Mushkiki to better support seniors with dementia. The group reinforced the unique health care challenges faced by Aboriginal people in Thunder Bay, especially around continuity of care and access to family physicians, discrimination, and communication barriers. Those on the advisory group also made many comments that translate well into recommendations:

In relation to health care services there was acknowledgement that enhancements to services and training are required.

- The group recommended promoting services that allow seniors to communicate and interact in their first language (Oji-Cree, Cree and Ojibwa in most cases).
- Cultural safety or sensitivity training should be implemented to reduce experiences of racism and discrimination within the health care systems in Thunder Bay
- Pharmacists should become part of the care team and be involved in patient education
- Train-the –trainer programs to address knowledge gaps around dementia and dementia care should be implemented.
- Patient resources similar to the Medicine Wheel representation in this report should be developed for patient and family education.

The two meetings also resulted in recommendations and ideas for future action-oriented research on the topic:

- Work with local language experts using the results from this study concerning Aboriginal words and language for dementia to develop resources and teachings in the language.
- Develop appropriate cognitive screening tools.
- Conduct research with communities in the NAN region who did not participate in this research but with a focus on healthy seniors in remote Northern First Nations – what factors contribute to their longevity (e.g., impact of physical activity, diet, social and family connections in remote FNs); and how are seniors in those communities cared for?
INTRODUCTION

BACKGROUND

The purpose of this research was to gather foundational information about knowledge, attitudes, beliefs and behaviours relating to Alzheimer’s disease and related dementias (ADRD) in diverse Aboriginal communities in Ontario. Qualitative methods including participant observation, semi-structured interviews, key informant interviews and focus groups were used to gather data pertinent to our research questions. Our research questions are: What knowledge, attitudes and beliefs concerning ADRD exist amongst Aboriginal people in Canada? How do these influence health care seeking behaviour and decisions around care? What cultural and structural differences exist between urban, rural and remote Aboriginal communities? What cultural attributes are viewed as effective in the care and treatment of ADRD? What are culturally appropriate types of health promotion materials concerning ADRD? What is current practice and experience with diagnostic tools used in Aboriginal contexts? The long-term objective of this research is to seek to improve sensitivity of care and to inform efforts to create culturally appropriate diagnostic and health promotion tools for diverse Aboriginal populations in Canada.

The need for this type of research was highlighted in January 2007 when First Nations Health Authorities in the Manitoulin District supported the need to address ADRD in their communities. In March 2007, Mnaamodzawin Health Services Inc. and Noojmowin Teg Health Centre organized a roundtable forum on ADRD concerning Aboriginal peoples. Aboriginal representatives from around the Province, as well as government representatives, physicians, researchers, and members of Alzheimer’s Societies in Ontario were invited to attend a roundtable in Sudbury, ON, to discuss what was felt to be an emerging health issue for Aboriginal peoples. There was a general consensus that Alzheimer’s disease and dementia were becoming health concerns in Aboriginal communities, that issues around dementia in Aboriginal communities are poorly understood by health care professionals, and that there is a need to improve services and care for Aboriginal people living on and off-reserve. Participants at the Roundtable identified the need for culturally appropriate screening tools and health promotion materials, more Aboriginal people trained to deliver services and cultural competency training for health care workers.

This report outlines the findings from the interviews, focus groups, and participant observations carried out in Thunder Bay as well as relevant information from the academic literature. We present Western understandings of dementia as a backdrop to local perceptions concerning the symptoms and meaning of dementia, practices relating to detection, treatment and care, and healthy aging. We examine our participants’ understandings of the causes of dementia and what dementia means in their communities. We also present our findings relating to local strengths in coping with dementia as well as indicating barriers to dementia detection, and care and service needs within the community.

Our aim is to highlight unique understandings of memory loss and dementia from Aboriginal participants in Thunder Bay so that the knowledge can be used to begin a discussion focused on how Aboriginal specific understandings and meanings can be incorporated into culturally appropriate and sensitive
WHAT DO THE DOCTORS THINK? WESTERN UNDERSTANDINGS OF DEMENTIA

Within the biomedical model, Alzheimer’s disease and related dementia are understood as progressive and degenerative age-related syndromes that affect the brain (Alzheimer Society 2010). Symptoms of these conditions include memory loss, confusion, behavioural and personality change, and difficulty with communication (Cohen 1991). Psychiatric symptoms including agitation, anxiety and depression may also be present and physical symptoms including incontinence and loss of the ability to swallow may emerge in the later stages of the condition (Thornton and Winkler 1988). There are reversible and irreversible dementias. Reversible dementias are usually caused by other illnesses or medications and can be successfully treated. By contrast, irreversible dementias, such as Alzheimer’s disease, vascular dementia, frontotemporal dementia, Lewy Body dementia and Creutzfeldt-Jakob disease are caused by progressive neurodegenerative diseases that cannot be cured (Alzheimer Society 2010).

The primary non-modifiable risk factors for developing Alzheimer’s disease are age and genetics. There are also modifiable risk factors which include Type 2 diabetes, head injury, strokes and mini-strokes, high cholesterol, high blood pressure, mild cognitive impairment (MCI), chronic inflammatory conditions, a history of clinical depression, lack of cognitive stimulation, and obesity (Alzheimer Society 2010). A lack of formal education, low socio-economic status, smoking, and alcohol abuse may also be linked to a higher risk for developing dementia (Alzheimer Society 2010). The Alzheimer’s Society of Canada (2010) recommends healthy lifestyle choices as a means of reducing the risk of developing dementia. A healthy diet, aerobic exercise, cognitive stimulation, and active social life are all considered to be beneficial in preventing the onset of dementia. Preventing head injury and seeking adequate treatment for other medical conditions (i.e. diabetes, high cholesterol, and high blood pressure) are also factors that can aid in the maintenance of brain health (Alzheimer Society 2010).

What is Dementia?

“Dementia is an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgement and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person’s ability to function at work, in relationships or in everyday activities”

Alzheimer’s Society Canada
Clinical treatment for dementia includes diagnosis, disease management, and care for the person with dementia. After the onset of symptoms a diagnosis may be made by a doctor using a combination of the person’s clinical history, cognitive testing (memory tests/screening) and, in some cases, diagnostic imaging (Alzheimer Society 2010). Once a diagnosis is in place, a physician may prescribe medications to moderate dementia symptoms. The type of medication that is usually prescribed is a cholinesterase inhibitor. However, no drug therapies currently exist that conclusively slow, stop or reverse cognitive decline (Alzheimer Society 2010). Other medicines may also be prescribed to address other symptoms and people with dementia will often be referred to the Alzheimer’s society or to other services available in their communities such as respite, support groups, home care, or adult day programs (Alzheimer Society 2010). As the disease progresses, long-term care may be required to ensure that a person with dementia and their family have adequate support to manage the condition.

**Risk Factors for Dementia**

**Modifiable**

- Age
- Heredity

**Modifiable**

- Type 2 diabetes
- Head injury
- Strokes and mini-strokes
- High cholesterol
- High blood pressure
- Mild cognitive impairment (MCI)
- Chronic inflammatory conditions
- History of clinical depression
- Lack of cognitive stimulation
- Obesity
- Lack of formal education
- Low socio-economic status
- Smoking
- Alcohol
METHODS

COMMUNITY-BASED APPROACH

The data presented here are drawn from a larger ethnographic study entitled: Alzheimer’s disease and dementia among Aboriginal Peoples in Ontario. This is a large multi-sited anthropological study conducted in partnership with Aboriginal communities in Ontario, Canada (figure 1). Following a community-based research design, academic investigators worked in partnership with Aboriginal communities on the design, development and implementation of the research protocol. Local community members guided the development of funding proposals, key questions, methodologies and data analysis. Ethical clearance was obtained from several academic institutions as well as community-based ethics review boards on Manitoulin Island and in Six Nations. All participating First Nations provided a Band Council Resolution and/or Health Council motion giving community consent and support for the project to proceed and all urban Aboriginal organizations provided appropriate consent and support for the research partnership. In Thunder Bay the investigators worked with the Executive Directors and key staff at the Thunder Bay Indian Friendship Centre and Anishnawbe Mushkiki beginning with telephone consultations in the Fall of 2009 and a subsequent meeting of all partner organizations (including the Thunder Bay Alzheimer’s Society) in February 2010. This group of stakeholders, including the Executive Directors agreed to engage in a research partnership and support the investigators by assisting with the hiring of a local community—based researcher and in recruitment of potential participants. Executive Directors advised the researchers on local protocols which consisted of their verbal agreement as recorded in the meeting minutes and their responsibility to inform their respective Board of Directors.

Across the Province, Community health centres, Aboriginal health access centres (Thunder Bay), Friendship Centres (Sudbury, Ottawa, Thunder Bay), and local chapters of the Alzheimer’s Society (all sites) provided the team with support to identify key informants to help guide the research and participate in early interviews where community-specific challenges and circumstances were discussed. Partner organizations also aided in the recruitment of community-based researchers for the project. Across the sites, six Aboriginal community-based researchers (CBRs) and one project coordinator were hired for this project. Each received training over two days from the investigators in Sudbury. Community based researchers roles went beyond data collection (interviews and focus groups) as the CBRs were encouraged to participate in analysis of the interviews via an interview summary process and through participation in team meetings.
Community advisory groups were struck for each research location usually including health directors, staff, and community volunteers. The role of the advisory group is to review the data analysis as presented in draft reports and presentations to ensure the information is an accurate reflection of the community and to ensure that any local knowledge in the reports or publications is presented respectfully and accurately. The advisory group also provides guidance on the best methods of dissemination of the research results in their communities.

**THE INTERVIEW SAMPLE**

Data reported here is from the research conducted in Thunder Bay only and is drawn from three sources; (1) interviews with seniors (people 50+), people with dementia, family caregivers caring for people with dementia, and key informants; (2) focus groups with care workers and a senior advisory group; (3) ethnographic fieldwork. This study used a convenience sample. A local community based researcher worked with local research partners in Thunder Bay to recruit participants. Potential participants were identified and first approached by a long term care or home care nurse with...
knowledge of a person’s symptoms. They were asked if they would be interested in being contacted by a researcher to participate in the study.

All Interviews were face-to-face, semi-structured interviews following an interview guide. Interviews were carried out in the location of the participant’s choice, usually in their home or office. Interviews lasted between thirty minutes and two hours. Each participant received a seventy-five dollar honorarium for their participation. Interviews were carried out with persons with dementia, caregivers of people with dementia and a general group of seniors to ensure that a complete picture of the dementia experience could be reported. We recognize that interviewing people with dementia for this type of information is challenging. In general, interviews with people with dementia were less successful in obtaining some of the specific information reflected in our interview questions, however we did learn a great deal through these interviews that help us contextualize their experiences. Although the information is limited, we have consciously worked to ensure their voices are adequately reflected in this report. Focus groups conducted with community health staff were thirty minutes to an hour long and a meal was provided. The Thunder Bay sample also included a focus group with a senior’s advisory group. All participants provided informed consent prior to being interviewed.

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<th>Research Site</th>
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<td>Interviews</td>
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<td>People with Dementia</td>
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<tr>
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<tr>
<td>Number of Focus Group Participants</td>
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<tr>
<td>Key Informants</td>
<td>2</td>
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<tr>
<td>Total Participants</td>
<td>30</td>
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People with dementia were generally undiagnosed in our sample. Early interviews with physicians suggested this would be the case. Therefore our approach was to allow the person with dementia and/or their caregiver to define memory loss or dementia based on the symptoms they were experiencing. Without any information available on the possible incidence of dementia in Aboriginal peoples our approach was to not limit participation to those with an official physician’s diagnosis. Our only exclusion criterion was that participants could not be in late stages of dementia where it would be too difficult for them to participate in a meaningful way. Our inclusion criteria required that anyone in the ‘person with dementia’ category must agree that they are experiencing symptoms of memory loss and/or confusion. Symptoms people were experiencing included forgetfulness and repetition, a loss of a sense of time, suspiciousness, inability to manage activities of daily living, and unsafe behaviours including wandering, forgetting to turn off appliances, or manage health issues. People with dementia ranged in age from 51 to 83 there were 2 males and 3 females. People with dementia had lived in Thunder Bay as few as 2 years and as long as 70 years. All people with dementia were community-
dwelling. That is, they lived in their own home or the home of a relative.

Caregivers in the sample included wives, husbands, adult daughters and sons. There were 2 male caregivers and 2 females.

Seniors who were interviewed could be included if they were 50 or older. In our sample they ranged in age from 50 to 81 Senior participants were Oji-Cree, Ojibwa and Ojibwa/Odawa and had been living in Thunder Bay between 14-60 years. There were 3 males and 2 females. Seniors who were interviewed are not a homogeneous group some having complex medical issues of their own, some who are healthy, a mixture of those who express a traditional orientation and sometimes great knowledge of traditional ways and those who follow Christian teachings.

Key informants included 1 physician specialist and 1 traditional knowledge holder. Focus group participants were nurses and personal support workers of which there were 11 females and 3 males.

DATA ANALYSIS

Interviews were digitally recorded and transcribed verbatim. The transcribed interviews were coded and entered into the qualitative data software package NVivo. This software was used to manage the data (store, code, organize, query) but not to analyse the data. We used a phased thematic data analysis approach. Emergent themes were identified during the early community consultations and on-going debriefing sessions with RAs and CBRs conducting interviews. These analytic categories were subsequently built into the coding structure and analysis so that community-based perspectives were reflected in conjunction with our theoretical foundations. Following the coding of the transcripts another de-briefing session with RAs was held to identify and clarify any further themes. The research team worked on subsequent clustering and identification of relationships between themes.

LIMITATIONS

The findings represent people who agree they are experiencing symptoms of memory loss and dementia. Confirmation of a clinical diagnosis was not part of the research design.

Small sample size at the regional level makes it difficult to make generalizations about gender differences in the experience of dementia or caring for someone with dementia. We anticipate the provincial report will have the numerical power to include a fuller gender analysis.

NOTE: Quotes from Focus Groups and Interviews presented in the report have been modified only to the extent that we have changed names and sometimes gender to protect the identity of the participants.
FINDINGS

LOCAL PERCEPTIONS OF HEALTHY AGING

Understanding how Aboriginal peoples perceive a healthy or ideal old age can be an important factor in the prevention of dementia and in devising appropriate care strategies for people who are experiencing the condition. Interviews with older adult participants revealed several common perceptions of a healthy old age and the factors that influence a person’s ability to age well. Thunder Bay participants described healthy aging primarily in terms of their ability to continue to contribute and have a role in the community. Participants did not discuss healthy aging in relation to the absence of illness or disease. Collectively, they felt that healthy aging would include having family around, maintaining connections with all generations (young to old), being socially involved, maintaining a traditional diet and continuing to honour culture.

ENABLERS FOR HEALTHY AGING

“I am happy when I run into somebody in the city and drink coffee and tea with them, it makes me happy to see them my relatives and it’s really what I think, wherever I go my relatives are.” (Person with Dementia WF05)

Participants shared that relationships, connections with community and social opportunities contribute to the maintenance of good health in old age. Remaining social by getting out and interacting with others was considered important. For our participants, socializing meant interacting with people from all facets of life, not just other seniors. Specifically, there was a desire to have more interaction with young people, family, and Elders. Participants talked about grandchildren as one of the best parts of growing old and how interaction with grandchildren maintains the connection with both family and young people. One new idea that was shared by participants was the idea of an Elders network. An Elders network could provide an opportunity for Aboriginal seniors to interact with Elders, especially if a consistent time and place for them to meet was provided.

Participants felt that participation in cultural activities such as Pow-Wows, crafting, or the gathering of traditional foods provides an excellent opportunity for socializing and exchange of knowledge. Other social activities such as Bingo or card games were also mentioned when talking about socializing.

“When you sitting around nothing to do you getting sick eh and if you work a little bit doing something like a crafts or maybe writing design just like we do right now and then if you going anywhere you getting sick, lonesome, you missing somebody lots of friends where you see them before that what I found the sickness (speaking in Oji-Cree about living without sickness, eating right, talking) you talk a lot that what I mean that’s what I found was the good life
Continuing to have a role in the community was also considered important for health aging among Thunder Bay participants. For some there was a desire to volunteer and add value to the community for others working was expressed as a necessity for paying bills. Participants also shared that being active for example, walking or using crafting skills built up through a life-time were activities that would help one age well. Family support and encouragement was also expressed as helpful in maintaining a healthy lifestyle – the level of actual family support varied among participants.

Participants described the need for support at different levels. Family was the first level of support for most. Many participants talked about getting help from family with money, getting around town, and household chores. Other participants talked about needing this help but not receiving it from family or having no family living nearby. Support was also discussed in relation to First Nations communities to which participants belonged. One participant shared positive stories about interactions in the Thunder Bay community such as bus drivers. Municipal supplied services such as Handi-Transit were also considered supportive.

Many of the participants were dealing with other health concerns unrelated to dementia such as diabetes or arthritis. Some of these participants told us how coming to terms with their illnesses, accepting these as a part of who they are, and getting on with their lives has been essential for healthy aging.

“You know I looked at myself in the mirror one day after taking a hot hot shower, so I can move around, I said to myself, I said oh my god, I said what am I going to be like in fifty years, where even if I live that long, like what am I going to be like in twenty five years. I have, I had to terms to accepting my disease and how deforming it can, it could be, or can be and how I could help myself ... and I am here today and I function almost as normally as everybody else, I do, I work, I treat my disease you know as it is, I can’t pretend I don’t have it. I tell everybody I know I have it, you know really”. (Focus Group WF03)

Maintaining the health of the mind was also discussed something that can contribute to aging well. Some participants thought that reading, doing crossword puzzles or puzzles, and continuing to learn are beneficial.

**BARRIERS TO HEALTHY AGING**

The interview questions asked participants to identify any barriers to healthy aging in their community. We found that some of the participants were living in Thunder Bay because of the need to access specialized healthcare services only available urban centres. While this improved access, participants also felt a sense of social isolation from a lack of existing social networks in a new environment. Isolation was also discussed in relation to an inability to speak to others in their language. Some other participants were uncomfortable in the city and felt fear of going out because of concerns of crime and
not having a general idea of how to live in a city.

“...well just the fact that I said there that they are afraid of everything like they don’t want to go out more or less more afraid of white people that’s what I found before even when I was in Kenora. A lot of them had good schooling but they don’t want to use it either they don’t want to speak English just their own language so therefore it seems that they don’t understand what you try to say.” (SeniorAK03)

Housing was also raised as a concern. Many talked about not being able to afford their rent and a lack of affordable housing due to long waiting lists.

Lack of family support was also described as a barrier. Some participants who did have family close by still felt isolated because of perceived neglect and abandonment. One person with dementia even went so far as to talk about how their younger relatives would laugh at how they got confused. They considered this Elder abuse.

“I would suggest something, yeah but giving programs for Aboriginals, not only old people but the younger generations to, aye. So, they will know and learn, they don’t have to tease their Elders their memory loss, aye. You know sometimes people tend to abuse their, Elder abuse. Yeah. Because of the memory loss, they start calling you stupid. (laughs) You know there’s a lot of things you’d go find out.” (Person with Dementia WF04)

Physical ability was identified as another barrier by participants. They described how decreased mobility and difficulty walking was impacting their healthy aging. Many others discussed restricted mobility in relation to transportation. Many related stories of being unable to drive anymore and/or having no one to drive them where they need to go. As a result of this, they often took the bus to get to appointments or go shopping for their daily needs. Some felt that bus schedules were inadequate to meet their needs. Other participants talked about how being unable to drive affected their ability to be independent and in some cases their ability to access cultural practices, traditional medicines, and wild meats such as deer and fish. This had a double impact of keeping them from interacting socially at traditional ceremonies and forcing them away from a traditional diet to one of processed foods. Several of the older people interviewed stressed that, for them, a traditional diet was a key force in keeping them healthy as they age and in fighting their sickness.

“I think it’s has to do with mobility, transportation a lot of seniors are that I see in the city are either in the city, taxi cabs, buses and stuff like that they don’t have their own personal way of moving about in the city, so they can’t really go out of the city to get the things that they need, like moose meat and stuff like that, rabbits, the healthy food for us, you know it’s just not there anymore for us when
we get older, so we have to basically rely on the our younger people for donations.”  (Senior WF05)

Other barriers that were noted by participants in Thunder Bay but were not discussed at length included: low incomes and difficulty meeting basic needs; loss of physical function causing an inability to work or do chores; concurrent chronic diseases; and inadequate, unaffordable, or inaccessible home care services.

Often the barriers to healthy aging for our participants were many and connected. For example, mobility issues are amplified by an inability to drive an automobile anymore. This impaired mobility isolates them from their social network (sometimes on-reserve) and limits their access to cultural practices, medicines, and foods. From this, we propose that the barriers cannot be looked at in isolation and there is a need for holistic approaches for tackling these barriers.

TRADITIONAL LIFE AND HEALTHY AGING
As described in the previous section, the questions concerning healthy aging also discuss traditional or cultural continuity during the aging process. We found that participants valued cultural practices such as crafting and visiting/socializing as, important for healthy aging.

Opportunities for sharing traditional teachings especially at gatherings such as powwows and sweats of were also identified as important by some of the participants in Thunder Bay. In addition, Sweat Lodges were described by one participant as a place to heal the mind and body.

Other participants thought that having opportunities to share their knowledge and teachings, was an important mechanism to keep their minds busy and to help maintain their memory in a traditional way.

A key finding from this research is the strong preference for and connection to traditional and wild foods. Thunder Bay participants felt that traditional foods and a traditional diet were essential for health aging.

“I think that would help, like I have seen, encountered older people from up north and they live off the land, I met a 95 year old woman years ago up in [Community] Reserve and she was a pretty peppy old lady. The thing that struck me about her was that her hair was pitch black not a streak of white hair and it is not dyed either, up by [community name] and these people they migrate from trap lines to hunting areas eh that’s all they some people call them nomads they are always moving around eh they live off the land eh like they live off fish, moose, rice, goose.”  (Senior AK01)

Several participants also pointed out that collecting and hunting for traditional foods provides a good opportunity for socializing, getting exercise, and passing on knowledge to the next generation.
The use of Aboriginal languages was also considered important for healthy aging. Some felt that they had fewer opportunities to speak their language in the urban centre due to fewer speakers living in the city.

Traditional family structures were also viewed as an important aspect of culture that facilitates healthy aging. Several of our participants talked about the changes to traditional extended family structures. We were told that traditionally, families stayed together and older relatives were brought into the home of their children as they aged and took on a role of caring for grandchildren; interactions with grandchildren was highly valued by participants. However, according to participants, families today often live far apart, often in different cities, and their traditional role is changing and seniors often live on their own or in care homes.

Some of the participants felt that getting old and having issues with memory and confusion is a normal part of aging and those that experience this should be accepted and cared for and Aboriginal seniors should not be considered deficient. We detail these views in the next section concerning ‘understandings of dementia’.

PREVENTING DEMENTIA

Questions asked about prevention revealed that participant’s knowledge about dementia from medical perspective is quite limited and has perhaps been influenced primarily from mainstream media and organizations (Alzheimer’s Society). Participants’ beliefs about healthy aging are also relevant to preventing dementia.

Keeping the mind active was viewed by some participants as a primary method of prevention. Participants talked about keeping their minds active by engaging in activities like reading, doing puzzles, crossword puzzles, listening to music, and Native crafting. Some also felt that staying connected with friends and family was helpful and socializing at events such as bingo or using the internet to communicate more often with loved ones were discussed as ways to maintain connections. Just, one participant thought that exercise was important for maintaining their mental capacity and engaged in some type of light activity every day for this purpose.

Another participant identified a lack of knowledge of the various forms of dementia and what the impact of the disease might be in order to properly prepare to maintain their health. In other words, questions about prevention of dementia prompted this person with dementia to express their desire to learn more about the illness.

“Since I got sick, sicker ever since I have been on the wheelchair it’s hard for me to get by. It’s nice to maybe get a ride from them or people that can’t really move. It’s hard to get people around that can’t hardly move aye, but it’s good for
them to get out. I know I do (laughs) Like I don’t want to get stuck inside all the time, go to a program that would be nice, learn more about memory loss and stuff like that would be nice, what’s going to happen to you after you have this disease aye, Alzheimer’s whatever you call it.” (Person with Dementia WF04)

Healthcare providers interviewed spoke more about what could help their patients maintain memory and what barriers exist that are negatively impacting their ability to help their patients. They did not have many comments about what might prevent dementia. Again, we feel this is related to a lack of knowledge about the illness or an acceptance of the illness. Health care workers expressed that the biggest barrier was a lack of informational resources available for both healthcare workers to properly treat dementia and for persons with dementia to learn about their condition and what they can do to maintain mental capacity.

Healthcare practitioners also felt that greater awareness of dementia can help to alleviate some of the stigma they perceive to be attached to these conditions and provide those afflicted with them with some relief from any shame they may be feeling.

LOCAL PERCEPTIONS AND UNDERSTANDINGS OF DEMENTIA AND MEMORY LOSS

The predominant perspective of dementia expressed by participants was that symptoms of dementia (including memory loss and confusion) were traditionally considered a normal part of aging. Participants noted that Aboriginal peoples also did not traditionally attach stigma to the behaviours exhibited by those of advanced age such as childishness or hallucinations and considered these a normal part of growing old. The traditional view of this as being a normal part of aging may be changing however as there were some stories of shame related to dementia symptoms and some stigma associated with these symptoms in some cases. Participants held different views about the prevalence of dementia in their community. Some felt that dementia was likely over diagnosed while others felt it was mis-diagnosed.

DEMENTIA IS NATURAL

Many of the Aboriginal peoples who participated in this study viewed loss of memory and some confusion as a normal part of aging, as an accepted natural occurrence in that stage of life. They believed that Aboriginal people are accepting of decline in cognition as a person ages and according to one traditional knowledge holder, opposed to biomedical/Western understandings in Aboriginal culture, traditionally no stigma was attached to the memory loss or confusion that comes with aging.

“It is just a way to let go you know as you get old you forget, nothing you can do about it, if you can change it, well why don’t they change it now but you can’t change it, your only born to live once in this life as a Anishnawbe and the Anishnawbe has a strong understanding of that concept, they don’t complicate it.
They don’t say, oh bring me this to make me look younger, they don’t go out to look for the fountain of youth or something like that, they don’t throw all that mumbo jumbo into their lives they just take it the way it is, just the way it is.” (Focus Group AK01)

Some of the participants also shared their understanding that memory loss and confusion in the very elderly would be attributed to being closer to the spirit world (being ‘half in and half out’). Those at this age may also experience visions which were considered a part of that late stage in life and were not referred to as hallucinations as is common in Western medical diagnosis. This was discussed in a focus group:

WR….. for Anishnawbek it is a natural part of life that they accepted. Well that’s part of it, their memories start to change.

EW….. Yep, exactly. And they understand that.

WR….. Their memories start to change, everybody’s do, even a healthy person in their 80’s, their memories change.

EW….. yeah, they just take it as a way of life. (Focus Group AK01)

Although participants viewed some memory loss and confusion are a normal part of aging, symptoms started to be viewed as problematic when they began to interfere with their daily living. For example, when those with ADRD or age related memory loss start to get lost, have difficulty cooking and cleaning they need support from family and the healthcare system.

SECOND CHILDHOOD

A naturalized and cultural understanding of dementia also came through participants’ discussion of the symptoms of dementia in relation to going through a second childhood. Sometimes people at that age were referred to as “old girls” or “old boys”.

“Will act like old girls, we call them old girls, older men behave like boys you know we just accept this”. (Traditional Knowledge Keeper AK01)

A traditional knowledge holder in the study referred to these older persons as taking on the spirit of the child and acting like children by engaging in behaviours that are considered inappropriate for adults. One of the senior participants was able to express this in their language:

“They older people they always refer to that term going back into their childhood, but they use the Anishnawbe word for that, and that term is “KEEWAY-ABINOOCHEEAWAY”, that’s returning back to childhood.” (Senior WF05)

UNDERSTANDING CAUSES OF DEMENTIA
Participants described many factors that they believed might contribute to the development of memory loss and cognitive decline. The most common understanding of memory loss was that it was a natural movement around the medicine wheel and caused by old age.

“I think that his age, he’s up there in age for starters; he started about when he was in his late seventies, which is a pretty common age area where dementia is frequent with elderly.” (Caregiver WF02)

Yet, at the same time when discussing the onset of dementia or Alzheimer’s, participants incorporated other understandings of causes which in most cases are ‘external’ to their control – chemicals in food, concurrent illnesses, trauma, and stress.

Here we categorize “unnatural causes” into physiological, psychosocial, and Indigenous. Indigenous implies that that cause is something that is culturally specific (or culture-bound).

**Physiological**

- Family history/genetics:
  
  Many of the Thunder Bay participants, whether a caregiver or someone suffering from memory loss, believed that if their older relatives had some form of dementia they would also expect to get it in the future.

  *Even my mom I think she had it, it was 9-10 years ago she died, I think she was getting but she didn’t say anything cause one time I had to come to Thunder Bay for an appointment and she told me she was always like ah homemade chicken soup and little a bit of dumplings she said what if you don’t come back in time I might be gone I told her I would be back the next day and then I asked her if she remembers saying that and she said I never that … so I know it’s coming. (Senior AK02)*

- Other health issues (Co-Morbidities):
  
  Participants understood that other health issues such as diabetes and cardiovascular disease would have an impact on the development and severity of their or their loved one’s dementia. For example:
  
  - Heart attack led to dementia
  - Post-surgery recovery led to dementia
• General sickness with many trips to the hospital
• Urinary tract infections being diagnosed as dementia
• Post stroke, aneurism, or coma inception of dementia

**Prescription medications:**

Some participants felt that the use of prescription medications would cause or worsen dementia. This was true for many participants including health care providers. These participants explained that “strong” medications (perhaps sedatives) were being given to dementia patients in care facilities to treat those who were ‘misbehaving’. Concern was expressed that the side effects of these medications can include memory loss and general confusion which may be more extreme given that they already have issues with cognitive impairment.

**PSYCHOSOCIAL**

**Emotional, physical, and spiritual traumas and stress:**

For some of our participants their dementia was perceived to have been caused by a traumatic or stressful event or change in their life. Participants talked about how the onset of their memory loss coincided with the loss of a loved one and how this traumatic event changed their lives forever.

> “Sometimes only, my memory is working properly and when I lost my 42 year old child he was, since I could remember that my memory has gone bad but I have helped with that.” (Person with Dementia WF05)

Others described general stresses related to family, finances or wellbeing adding up and causing a breakdown that coincided with the onset of their symptoms.

Unresolved trauma was also cited as a cause of dementia among some of the participants. Specifically, healthcare providers, caregivers, and seniors interviewed talked about how many of those with dementia had residential school experiences. They felt that this kind of trauma would have had an impact on a person’s memory and overall mental capacity of these individuals as they age. A careworker from a care facility described how sometimes people with dementia under their care are “living in the past” and they had noticed that living again in an institutional setting can cause some painful residential school memories to come to surface.

> “Ahh yeah because they is going to be dementia in there and they would be suffering because they have their childhood memories are residential school are ... all of a sudden they’re in a institution, they have their bed again and like their workers, it’s like regimented and there’s like you know and it’s like going back to residential school for some of them.” (Focus Group AK02)
**Processed foods, alcohol and substance abuse:**

Many of the Thunder Bay participants were concerned about what they consumed and singled out some of these as potential causes of dementia. One participant believed aspartame was causing dementia. Processed foods were also discussed as something that may have an impact on the onset of dementia among Aboriginal peoples.

Alcohol and solvent abuse were talked about by many care worker participants as a potential cause of dementia. Korsakoff’s syndrome was specifically mentioned in a focus group (Korsakoff’s is a condition that has the similar symptoms to dementia of memory loss and confusion but is caused by excessive abuse of alcohol over a long period of time).

“We had a young fellow because I call him young, he’s probably in his fifties he came in with Korsakoff’s ... so he basically pickled his brain, alcohol is pure poison all it does is kill brain cells, there’s absolutely no benefit to drinking it whatsoever ... So, he drank an excessive amount of liquor every day, literally pickled himself, so couldn’t go to the bathroom, tell you where he was, he couldn’t do anything and he was fairly young and really sad to see.” (Focus Group WF03)

**INDIGENOUS**

**Disruptions in the traditional way of life:**

Changes to traditional lifestyle were often mentioned as being a potential cause of the onset of dementia in Aboriginal peoples. Specifically, the participants talked about changes related to moving from their community to the city and how the different lifestyle and attitudes left them feeling isolated and shut down. There was also discussion about how this transition would leave them without their regular routines and lead to them having nothing to do.

“They come into the city and they are being told, okay you have to live here, you have got to do this, you gotta pay this, you gotta eat at this time, so it is too for them to come into a simple way of living into Thunder Bay or wherever any urban city, it scares them, so maybe that triggers their dementia when they come to the old folks home.” (Focus Group AK01)

Some participants talked about how social isolation in the city and having nothing to occupy their time could lead to a lack of sense of purpose.

It was also speculated that those that move from their community to the city may also be impacted by bright lights, noises and sensations that they are unfamiliar with and which may be more stimulus than their minds are used to.
You know, maybe all the bright lights or noise triggers that, because their use to living quiet, to hearing the birds and seeing the sun come up and over here it is all gone, they are thrown in a barrel that they have no idea of so they get all, I guess their mental status leaves them because they are not use to ah, you know what I mean, they just sort of let go, let go of things, their concept of living.” (Focus Group AK01)

HOW PEOPLE TALK ABOUT DEMENTIA
The words people use to describe dementia can shed light on their thoughts about what causes it, if it is normal, or if it is frightening or unknown. This section presents the words and phrases that participants used to talk about memory loss and dementia in order to get a better sense of what they believe dementia is and how they perceive and respond to a person who is experiencing impaired memory or cognition. A further exploration of these terms with local language experts may be helpful in developing culturally meaningful educational materials.

ENGLISH WORDS FOR DEMENTIA
When participants described memory loss in English, they used terms such as:

- Forgetful
- Senile
- Going down hill
- Reverting to childhood
- Deteriorating
- Sickness in the brain
- Memory loss

WORDS FOR DEMENTIA IN THE LANGUAGE

“In our language we don’t have a word for that, um, dementia of course would be um when somebody’s um (shawnaazit) “in distress or in a state of hopelessness”, or (gee-nii-ket da-nin-mowin) “loss of memory” or “forgetfulness” those are some of the words that would describe dementia but nobody simply comes outright and says that they need help with it.” (Traditional Knowledge Keeper AK01)

Many words and phrases from the participants’ Aboriginal languages were shared about aging related memory loss and confusion. There were not specific words for Dementia or Alzheimer’s. The words and
their respective meanings according to our participants are below:

- **Wandademan** – Forgetful – (Person with Dementia WF03)
- **Dikawandedamon** – Memory – (Person with Dementia WF03)
- “Aakozi-maajaokaaning – You know if you don’t have memory, my my memory is not well, that’s how they would describe” – (Person with Dementia WF03)
- “Natawaneeewaka - Like I said I am often forget things. The things people tell me I often forget” – (Person with Dementia WF01)
- “Do neeka sheeh – meaning forget in Ojibway” – (Person with Dementia WF03)
- “Gii naa ge kaa (laughs) o saa ge de kaa – I guess that would mean what ah you’re at an age where you don’t know what you’re doing” (Ojibway) – (Senior AK01)
- “O saa ge shii yaa – yeah, confused yeah confused” – (Senior AK01)
- “Giu naa dze – not in the right mind” – (Senior AK01)
- “Geen-ta-ne-teg-ge-goo” (He/she is forgetful ) – (Senior AK03)
- “Wa-nen-na-dum” (Confused) – (Senior AK03)
- “N’ta-ne-tek” (Forgetful) – (Senior AK03)
- “Ge-o-ne-ki-nen-da-nin-mo-win” (He/she has memory loss) – (Senior AK03)
- “Oh-nee-kan-da-mun, ja-oh-nee-kan-da-mun” – (Forgetful) – (Senior AK03)
- Mitanaagakun – (Memory in Oji-Cree) – (Person with Dementia WF05)
- “Keeway-Abinoocheeaway” – (Anishnawbe word for returning to childhood) – (Senior WF05)

**DEMENTIA SYMPTOMS**

Dementia symptoms rarely occurred in isolation. There was agreement among reports from caregivers and key informants that a diagnosis of Alzheimer’s disease or dementia ‘only’ is rare in the Aboriginal population. People are most commonly dealing with concurrent diseases especially diabetes, amputations related to diabetes, arthritis, depression and cardiovascular disease.

When caregivers, individuals with dementia, and seniors were asked to describe the dementia symptoms they most commonly experienced, they quite naturally fell into four categories in Thunder Bay: mental, spiritual, emotional, and physical symptoms. These four categories of health are captured in a medicine wheel. Like the medicine wheel teachings these areas were all found to be inter-related.
Some participants expressed that their ‘hallucinations’ are a message from the spiritual world. Participants indicated that in their culture, hallucinations/visions, memory loss, and confusion of those of great age were sometimes explained because they were half in and half out of the spirit world. These were called visions, a normal part of that stage in life. A person with dementia explains his experience:

“When I see something, it’s like something is hanging here, and that’s why I am sad. It’s like someone is telling me something, a G11 ASH” (meaning a spirit that warns someone of something bad is going to happen) (Person with Dementia WF02)

Emotional symptoms included severe mood swings according to those suffering from some form of dementia or their caregivers. This included sudden anger, irritability, and violent behaviour.
“Taking him out in public is difficult. We have a lady take him out and she is experiencing him talking to random people about nothing or weird things. Changes in mood and personality, yeah. At this point, with his mood, he is experiencing aggressiveness, and I think a lot has to do with his frustration. He is experiencing frustration with tying to communicate with us with what he wants. If he’s thirsty or hungry while he’s out, he will stomp his feet. He will scream out loud or hit the wall, and there are definitely changes in mood and personality.” (Caregiver WF02)

Frustration was an emotion that was common among the participants. Not being able to remember people or how to do things that they had been able to for the whole lives was a source of great frustration. Many of those with dementia that were interviewed talked about how they experienced sadness from their condition. Whether this sadness was a symptom or a result of the changes they were experiencing remains unclear, though it impacted them nonetheless. Lastly, fear was a common emotional symptom of dementia for many of the participants. One reason that this fear occurred was from their realization of losing memory and anticipating more loss of memory and mental capacity. One participant with dementia also related their fear of doing or saying things that were inappropriate as a result of their memory loss or confusion.

“Yeah, when you forget things, when you forget things when you start forgetting you don’t want to talk because you’re scared you might you might say something is that not going to be suitable for the person, you might say something different that you’re not supposed to say.” (Person with Dementia WF03)

MENTAL SYMPTOMS
Most people with dementia and their caregivers expressed that forgetfulness was the main symptom that they were experiencing. This included forgetting people’s names, losing things, having difficulty finding the right words, or forgetting to turn off the stove etc.

“Memory loss, disrupts daily life, he doesn’t quite know sometimes who we are, he’s always asking who are you, and asking and reminding himself of who he is to us, so his memory loss is basic identification of who is around him.” (Caregiver WF02)

Symptoms related to forgetfulness can also be related to where and when (disorientation and confusion). Several participants talked about how they or their loved ones would forget where they were and how they got there and losing their sense of direction.

“Forgetfulness, he doesn’t know where he is most of the time, he’s always asking us where am I, or like you know can you take me home not realizing he’s already
home. That’s one of the biggest things with his forgetfulness. Confusion goes along with his forgetfulness, he doesn’t know where he is, he’s confused. Doesn’t think he is at home, he’s confused where he is going, where he’s at, or where he has to be.” (Caregiver WF02)

Sometimes the confusion was compounded when the person moved in their mind between the present and the past. A caregiver shared the degree of confusion experienced by the person with dementia under her care:

“Confusion with time or place, yes. Time has no factor with him, where he lives, he’s been living at home for 35 years and doesn’t recognize his own home, that’s how far his dementia is at that stage; where his identification of where he is confused. He thinks ketchup is okay to drink. And relationships he wouldn’t understand, he thinks sometimes he’s not married, been single and he doesn’t understand the relationships.” (Caregiver WF02)

Some participants shared that they or the person they were caring for would experience auditory and visual hallucinations. These were often noticed because the person would be talking to themselves.

“Hallucinations, I would say that he, I think you know sees things, for example; talk to someone who is not even there. I think he’s done that a few times too, talked to himself in the mirror, stuff like that. So, that would be a few factors that he is experiencing right now anyway.” (Caregiver WF02)

Several participants also described how problem solving skills were impacted and daily tasks became more difficult for those with dementia or became the responsibility of their caregivers to do for them.

“Challenges in daily life and solving problems, yeah definitely, he doesn’t have any ability of solving problems, or basically he has to be taken care of 100% percent with everything.” (Caregiver WF02)

Some of these symptoms, especially forgetfulness, were understood to be a normal and natural part of the aging process. Perceptions of normal versus problematic memory loss were usually related to the severity of symptoms. People recognized that memory loss was no longer normal when symptoms escalated to a point that they were a safety risk, involved marked changes to a person’s behaviours or personality, or significantly interrupted activities of daily living.

**PHYSICAL SYMPTOMS**

Physical symptoms experienced by those interviewed included difficulty speaking and writing and limited mobility due to falls and difficulty walking due to disorientation.
Several of the participants suffering from dementia shared how their physical impairments (in combination with their confusion and memory loss) were impacting their ability to make contributions around the home. This could not be separated from the emotional impact for one participant as they felt that they were not able to help or care for their family like they used to.

“All my grandchildren, children and wife I feel sad and don’t like not being able to provide for them anymore. What I use to do back in the day before I got sick I helped my kids and my wife, I don’t like not being able to do anything to help them anymore.” (Person with Dementia WF01)

**DENIAL**

According to the healthcare providers that were interviewed, denial of symptoms is a common reaction to memory loss and confusion that might result from dementia. Many reasons for this were put forward, such as:

*MJ*: Isolation, lack of knowledge of what it is, family family shame, fear.

*R5----*: I was going to say pride is a big thing among the Aboriginal population, like there is so much pride, you know that sometimes it stops us from. (Focus Group WF03)

**DIAGNOSIS**

Accurate diagnosis of dementia is crucial for appropriate therapeutic strategies, epidemiological purposes, and to prevent medication errors (Rankin, et al. 2008; Zekry and Gold 2010). In addition, it is important to monitor and distinguish between potential causes of cognitive impairment so that treatment plans can be adjusted (McCole 2003).

**TYPES OF DEMENTIA THUNDER BAY**

The participants in this research may or may not have had a formal diagnosis of Alzheimer’s disease or a related dementia. Some participants described their illness as ‘dementia’ and a few caregivers used the word “Alzheimer’s disease” to describe the illness of their loved one. Health care workers cited instances of vascular dementia and Korsakoff’s in their clientele.

**ASSESSMENT**

There are many different types of conditions that can lead to dementia like symptoms. A specialist that was interviewed felt that knowing more about the nature of the type of dementia could lead to better treatment outcomes:
“I think in general the more you know the better and you know if it’s alcohol related dementia I think that’s helpful to know. It may serve as some sort of you know, uh wake up call for some other people. Um, if you have Alzheimer’s disease uh, for example, I think that’s also helpful to know, vascular disease, I think it’s helpful for people to know um, I think there’s a lot after giving the diagnosis that makes it useful to know the diagnosis but it’s not always easy to deliver all that information.” (Physician Specialist KJ01)

For our Thunder Bay participants, a dementia assessment usually occurred when the person who was experiencing memory loss or confusion (or their loved one) approached their family doctor. In most cases, the doctor would have the patient take a “memory test” (cognitive screening) designed to check their cognitive ability. Questions on these tests can include asking the name of the current Prime Minister, specific dates of well-known events, and drawing a clock. Several of these tests are available to physicians and it was not clear from this research which tests were used most often.

“I think he asked him several questions about who, just like basic questions at that time, who I was, personal questions, I think he had a lot of forgetfulness and he couldn’t quite answer all of them. So, that’s how they diagnosed him.” (Caregiver WF02)

The family doctor may also order blood tests as part of the diagnosis and in some very specific cases use imaging such as MRI. They may also decide to send the patient to see a specialist. In some cases, the family may be asked to monitor and record unusual behaviour changes or memory issues to help with the assessment.

“Not only that, the doctor, the main way to diagnosis him was talking with us, being with him all the time and for us to relate, you know he’s behavior and how he coped with things and driving for example; we would explain to the doctor he’s starting to do this and do that, so behavior issues, social issues, communication levels were different, so all this factors you know kind of determined with the doctor that you know he’s being diagnosed with dementia at the time”. (Caregiver WF02)

**MISDIAGNOSED DEMENTIA**

There was some concern among healthcare participants that Aboriginal peoples were being misdiagnosed with dementia. One of our healthcare worker participants who works with elderly patients believes that in some cases blood and urine tests are not being undertaken to rule out other conditions and nurses may be making the diagnosis on anecdotal information without proper involvement from a physician.
“Well, the nurses will make a recommendation to the Doctor on increase behavior and they will go on and say they are getting more aggressive, or more confused and what not ... and if nobody actually does lab work or does an aerial (arterial) analysis it gets missed and it happens lots, you know what I mean. I don’t want to say too much because I’ve even seen it even happen with nurse practitioners, and the blood care and the resident wants to die and they’ll take them off their meds, phone the family and the patient’s wishes die, okay that’s what they do and meanwhile they had a UTI” (urinary tract infection). (Focus Group WF03)

It is not at all clear from our research if the risk of misdiagnosis is specific to Aboriginal peoples or just a general failure of the healthcare system for older individuals. There are, according to our participants, some very specific reasons that Aboriginal people may get misdiagnosed with dementia: trauma related to residential schools, lower educational levels, and communication/language barriers.

There was a sense from the participants (especially health care workers) that the cognitive tests (screening tools) were not appropriate for the Aboriginal population. Participants in one of the focus groups related stories about their family’s or in the case of the healthcare workers, about their patients’ experience with residential school. The result of this experience was that many of them were dealing with unresolved trauma and lower educational levels that made them seem cognitively impaired as they did poorly on the standardized mainstream memory assessment tool.

MG..... but you have to look at that too if you’re assessing them what grade English do our people have what grade of math so even at their best without Alzheimer’s or dementia effect their mind they wouldn’t be able to answer those questions I think my dad had grade four.

FB..... I think when my mom got out of Residential School she could write her name.

MG..... they’re still illiterate and they came out of Residential School 10 years half of them so they won’t be able to do that math and English I can’t even to get to read some of them. (Focus Group AK02)

Even many of those who did not have a residential school experience are likely to have lower levels of education when assessed by Western standards and experience the same test bias when being assessed.

Participants believed that communication and language barriers may also results in misdiagnosis and under diagnosis of dementia. Many of our participants talked about cultural differences in
communication styles and how they or their loved ones were uncomfortable talking about personal issues with health care workers or physicians they did not have a relationship with. Health care workers discussed this in a focus group:

\[ \text{GH: But as soon as the doctor leaves they start telling you,} \]

\[ \text{MG..... they know what you are saying, yeah right I think trust and comfort is an issue too.} \]

\[ \text{GH..... that relationship why why would they start spilling their guts to some total stranger,} \]

\[ \text{MG..... they just met you yeah they don’t know you from a hole in the ground they’re not gonna tell you nothing or “she won’t tell me this or she didn’t know,”} \]

\[ \text{ah did you ask her and she didn’t want to tell you obviously and they don’t get that, “what do you mean she doesn’t want to tell me” they don’t want to talk about it simple as that. \text{(Focus Group AK02)}} \]

For these particular individuals there was a need to first establish a trusting relationship with their healthcare provider before they would be willing to divulge their issues with memory. Talking about family was also a topic that was considered too private to talk about.

\[ \text{“But then when she asked certain questions she would say “meeah” (that’s it) meaning she didn’t want to talk anymore because it was getting too personal ...} \]

\[ \text{and it’s not that she didn’t understand she chose not to talk about it I think that the issue, because she started digging into family about family members, yeah in front of strangers, yeah because in our culture you don’t talk about our family business, I talk to you because you are my cousin, I talk to you about him why do I want to talk to a non-Native person that I don’t know about my family business it’s a comfort level too.” \text{(Focus Group AK02)}} \]

Language barriers also provided a potential reason for misdiagnosis. In some cases an Aboriginal person did not speak English resulting in some confusion around diagnosis and care. Interpreters are sometimes provided in these cases, or a family member may serve as interpreter. However, this was viewed as less than ideal by our participants.

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“Nothing much ‘cuz I never check to see if there is something wrong with me, my doctor to tell him about it I never mentioned it to him, so it’s kinda of scary you know sometimes you don’t know what kind of sickness have and you’re in denial and sometimes then things screw up once and then difficulty, yeah.” (Person with Dementia WF04)

Careworkers wondered if shame of having a condition that effects behaviour and memory is sometimes the reason that individuals or their families do not pursue a diagnosis.

“There’s lots of people I believe who are in this community dementia and Alzheimer’s but don’t share it they hide it, they they keep their family memories at home. I had you know a-a- a close friend and I told him you know he was telling me what his mother was doing. I said well have you had her tested you know and and he was so leery about doing.” (Focus Group WF03)

The idea that the experience of dementia symptoms is something to be discussed only within the family was a common response among the participants that were interviewed in Thunder Bay.

“No. I didn’t talk to a Doctor, only my daughter and my son in law and son those are the ones I talk to.” (Person with Dementia WF03)

One participant with dementia expressed regret that they did not seek help for their dementia and felt had they sought help or a diagnosis when they started to notice that their memory loss was impacting their life it would have helped them maintain their mental capacity longer.

The notion that the symptoms and progression of dementia were personal was expressed by all groups of participants. Caregivers and healthcare workers agreed that, from their experience, those with this condition would often be hesitant to share details of their symptoms with doctors and other healthcare providers that they had not established a relationship with. It was suggested that designing and implementing culturally relevant assessment tools and tests may help to alleviate some of these issues and lead to more accurate diagnosis.

**CULTURALLY RELEVANT ASSESSMENT**

As has been demonstrated in the above sections, getting a diagnosis of dementia for Aboriginal patients is anything but straightforward. There are language, communication, and cultural issues that must be overcome in order to properly diagnose dementia. Beyond this, we also have learned from participants that socio-economic issues and historical trauma also need to be considered during an assessment. It is with this in mind that many participants, especially those that work in health care settings with geriatric patients, stressed the need for culturally relevant assessment tools and/or strategies:

“I always tell them about that so that’s what we want more and more of I think we need if you’re going to do something I think you need to know screening tools
“and culturally appropriate screening tools, how they are being assessed and then what kinds of programs and services, and staffing.” (Focus Group AK02)

Another participant from this group suggests that common questions used in a standardized assessments are not relevant for many Aboriginal people and that a culturally specific assessment may be helpful for getting an accurate diagnosis.

“On an assessment tool yeah yeah cause she doesn’t they don’t care what the President’s name is or the day, time yeah see there are different values, I don’t know must be close to lunchtime that’s what they say ... maybe seasons ... well they know the animals they go with the fish, ask them about the seasons they’d tell you probably if they were hunters or trappers see it’s got to be something that applies to them specifically.” (Focus Group AK02)

Some of the family based caregivers and healthcare workers also suggested that in order to overcome the cultural reluctance to talk to strangers about personal issues that culturally relevant assessment tests should be designed so that they could be administered by a family member or someone with an established relationship. From their perspective, the current tests are simple to administer and they believed that there was no reason that they could not be delivered by someone the patient knows and trusts.

TREATMENT AND CARE-GIVING

TREATMENT
Two main treatment approaches for dementia were discussed in our interviews: Western/biomedical medicine and Traditional/Indigenous medicine. Thunder Bay is a hub for medical services for a wide geographical area in northern Ontario and includes many remote Aboriginal communities.

WESTERN MEDICINE
Interviews in Thunder Bay included one specialist physician, a traditional healer, and focus groups that were made up of healthcare workers. The specialist stressed that in most cases Aboriginal people seek medical help later in the dementia disease process compared to non-Aboriginal patients which limits treatment options:

“My exposure, it seems that, and I obviously this would be not everybody but in general there seems to be um, less advocacy and maybe um, certainly uh, at the point that they’re seeing me, they’re, tend to be more progressed in diseases not just um, dementia but if it’s Parkinson’s or whatever it happens to be by the time they come to me.” (Physician Specialist KJO1)
This physician specialist speculates that the late diagnosis may result from a lack of advocacy for people with dementia symptoms. This research suggests that a greater acceptance of symptoms in the early stages and a reluctance to discuss this illness outside of established relationships may also be factors in later stage access of the health care system.

The remoteness of many communities in Northwestern Ontario also limits access to biomedical services. Health care workers expressed that a lack of informational resources and dementia training in remote communities can lead to poorer outcomes for patients. One participant wondered if Community Health Representatives (CHR’s) could have a focus on dementia and deliver information by organizing sessions on the topic.

Telemedicine/Telehealth may also be an appropriate option to access training and specialist care. Currently, telehealth provides those in remote communities with access to specialist care in their home community. Family may also be present in these consults, which according to the specialist we interviewed provides the opportunity for more accurate assessment.

“Whereas sometimes people come down with an escort and the escort has really no familiarity with the person and then it’s hard to get collateral history particularly again if this were a memory problem per say and so at least if we’re seeing people in their home community there’s opportunity for family to be there.” (Physician Specialist KJ01)

Telehealth is also more economical for both the Province and the individuals and their family as the monetary costs associated with travel and accommodation are eliminated. The burden on the individual to travel away from their support network is also removed.

Telehealth also has some challenges that need to be overcome. One challenge was related to the impersonal nature of talking and assessing over remotely. The specialist felt that it was especially difficult to get a good assessment during phone consults because communicating involves body language and expression that is lost over the phone line. This particular physician also explained that though they can engage their patients remotely via the THS, there are limited opportunities for follow up as they are less available to contact by these patients as compared to the ones that come into the clinic.

Following assessment and diagnosis the most common treatment option for dementia is the use of pharmaceutical medication. These medications can have beneficial and negative effects for those taking them. Some of these medications have been shown to slow down the process of memory loss (cholinesterase inhibitors) others are effective in calming mood swings and helping to regulate behavioural changes.

“And it’s trying to educate and sort of um and teach people that sometimes it not a natural part of aging and that if people are experiencing Alzheimer’s or Dementia that there are medications that can help. Because it becomes there are
so many issues around it, you know it becomes an issue about safety and um, whether or not they can live independently and if they have the opportunity to live independently they should have that right and if they can do that with medication it will be a better environment for them.” (Focus Group AK01)

Medication for the treatment of dementia can however have negative side effects that can’t be tolerated. The most common effects that were reported by participants were dizziness, confusion, and loss of sleep from an overactive mind.

“One time, I think one time they give it to me aye. Then I, I read I read what the directions are, that night you know just my mind just the pills were working in my mind just like that. Holy, I couldn’t sleep all night you know, the pills were working in my mind and I said the hell with it, I threw them in the garbage (coughs) I don’t need those pills.” (Person with Dementia WF03)

The over-prescription of medication and the over-use of them by healthcare staff, especially in nursing homes, was put forward as an issue by some of our healthcare participants. They believed that in some cases, “memory pills” are being given to Aboriginal seniors before a proper assessment has been undertaken. Some health care workers worried that sedatives are being overused to maintain order in the care facilities.

“That generation probably never took them the amount of drugs that they take in the Nursing home so you introduce those pills to you that never had that, well of course you’re going to be like this (shows motions of dizziness) yeah you wonder, I wonder if it is like if it’s a practice cause ah maybe cause um they’re short staff, maybe it’s because of falling but go look it there are not too many of them walking around.” (Focus Group AK02)

This potential overuse of medication was discussed as an issue and it was felt this may be especially risky for Aboriginal patients because of a high number of co-morbidities. The number of co-morbidities (e.g., diabetes, heart disease) and the fact that these patients often have multiple physicians and specialists creates a particularly risky environment for negative drug interactions.

Getting Aboriginal patients to stay on their medication was also talked about as a problem. In some cases the negative side effects result in some patients stopping their medications. We also were told that on-going access to medications is an issue. Sometimes this occurs because medications are not available in the remote communities and sometimes it is related to the processes for coverage through NIHB.

“I think as far as starting medications people are, I haven’t noticed a difference. I think continuation uh, taking them, maybe even getting them, I don’t know, is an issue. Um, I, sometimes get upset with the um, with the non-insured health
benefits cause they make me fill in the form every time you have to renew the medication and then they send you a letter saying if you don’t send this form back in 2 weeks we’re going to cancel it, right, it’s just really quite a, a miserable system. Every 6 months you have to renew, renew the um the form, not for every medication but for cognitive enhancing agents.” (Physician Specialist KJ01)

Other reasons participants put forward as leading to the discontinuation of their medications included communication issues such as: translation errors, not informing their doctor about negative side-effects, or a general misunderstanding of how and for how long to take medication. It was suggested that there is need for support from family or care workers to help patients understand the medications and potential side-effects.

TRADITIONAL MEDICINE
Participants we interviewed did not discuss traditional medicines specific for dementia. None of the persons with dementia or their family based caregivers sought out traditional healers to help them with memory issues or confusion. There were some participants using traditional healing practices such as herbal teas, prayer, ceremony, smudging, and sweats as a part of overall healthy living.

“I think she’ll do smudging, but that’s for overall wellness, well-being, and sometimes she will drink, make cedar tea for herself. Again, that’s for her cleansing her body, and any kind of not feeling well or something is not going good, something you know something is wrong with her she’ll drink cedar water, or even if, for bad colds, she’ll do like wiikay (medicine) cedar stem that kind of stuff.” (Caregiver WF04)

Some other examples were given by one person with dementia:

“I just pray to the Creator to take care of me, to look after me, help help me out, just pray that’s all. Light cedar, smudge, or make cedar tea, make Indian medicine.” (Person with Dementia WF03)

The Thunder Bay Indian Friendship Centre and the Anishnawbe Mushkiki health centre are mentioned by many of the participants as places in the Thunder Bay area where Aboriginal peoples can access traditional healing services.

CARE-GIVING

WHO PROVIDES CARE?
Most often, caregivers in this study were direct family members, usually spouses or adult children. Both men and women were providing care, but it is difficult to get a clear picture of the differences between male and female caregivers. Care is most typically provided in the home (either the home of the person...
with dementia or of the family based caregivers). In some cases care was provided in a seniors care/nursing home.

**WHY DO FAMILIES PROVIDE CARE?**

In most cases, the family has decided to take on caring for their loved one because of a desire to have them at home and close to them. There was a deep reluctance for most of those interviewed to consider nursing home care. Although family caregivers felt it was challenging to care for someone with dementia they felt it was appropriate and rewarding.

“As far as I am concerned I would like to keep my dad here as long as possible. That’s a challenge. The reward is the fact that you know on the inside that we done the best that we can, we have been here, we kept him, we kept him, we are keeping him here as long as we can. Keeping him going with his family as long as we can.” (Caregiver WF02)

“So we’ve already been starting to talk about us moving into a bigger place and probably move and live in with us, take care of her until the point where we can’t take care of her, like until it gets to be, she gets really bad, like we can’t manage it, become dementia or she needs more care that we can’t give and like I think putting her in a home is going to the last last last last last thing possible that we avoid even doing it.” (Caregiver WF04)

**EXPEREINCES WITH CARE-GIVING**

**Care-giving tasks**

Care-giving tasks were dependent on the stage of dementia the person was in. Care-giving participants talked about helping their loved one with household chores, getting around town, communicating with doctors at appointments, and cooking meals. Safety was a key priority for caregivers. They were often concerned about the potential for fires from cooking and wandering in particular. Several of our participants talked about the difficulty that their older relatives had with visits to the doctor and how they needed help asking the right questions. Sometimes those with dementia needed help from their caregivers to remember to take their medications or to talk to their doctor to change their dosage or type of medication if it was causing problems for them.

“Sometimes I would ask question that my mom would not even think of asking, it’s one thing I notice with her, my mom is probably the same with other Aboriginal people, they don’t ask questions, you know like she’ll often go to the Doctor and she’ll say well they reduced my medication for the hormones or they gave me memory, well the memory one I’ll use that, they gave me these memory
pills, I started taking them but they were making my head feel funny, and so I stopped taking them. And I said mom you should actually go back to the Doctor and tell him that what this medication, how it’s affecting you.” (Caregiver WF04)

Challenges

There were many challenges that were talked about related to care by both healthcare workers and family based caregivers. For some of the healthcare workers interviewed a major challenge was the lack of cultural awareness among healthcare staff. This and issues with communication or language barriers were identified as problematic for providing proper care as is illustrated by this story:

“A lot of it is communication, lack of knowledge, I even have experienced a an elder here in a hospital here, that was labeled as being dementia, lots of dementia the Nurses didn’t realize that all he was asking for was general pain management and yet they labeled him as dementia, so the communication in our hospital settings here, for First Nations people is lacking in the sense that we are not meeting the health care needs of the client.” (Focus Group WF03)

Racism was also brought up as a challenge that Aboriginal persons with dementia face when trying to access mainstream care programs that are available to help them or their families cope with their dementia.

“Well there’s also, there’s the 55 plus centres they won’t go to those oh no, there’s some deep seeded racism here in Thunder Bay, I mean it’s years of racism so why would you want to go some place where’s no Aboriginal people it’s uncomfortable because none of those people are going to talk to you like they just don’t.” (Focus Group AK02)

Family based caregivers shared many stories of the challenges they faced as part of this role that they took on. Several of these participants talked about the emotional challenges that they faced by not only taking on a care-giving role but because the person they were caring for was a loved one. Some had difficulty watching the progression of the illness in their husband or wife, their father or mother.

“It’s frustrating; it’s discouraging and disappointing to see a father especially change like that. I would say frustration is the biggest one to cope with and like dealing with his daily behaviours and his communication level and you know doing this and doing that.” (Caregiver WF02)

Some of our participants talked about how the relationships that they had with the person they were caring for were affected by their dementia. This is a challenge because one of the motivations for caring for someone at home is a desire to maintain that cherished relationship with their loved one. This relationship may be changed or taken away regardless of keeping them at home with family or not.
“It affects that everything that we do in our own personal lives. Like my mother for example, the relationship with my dad is not the same, they been married for so many years you know and it’s like looking after someone else who’s different now and for me it’s the same, like my dad, he’s not the same person anymore so that’s frustrating.” (Caregiver WF02)

One family member caring for someone with dementia described one of the challenges that they experience with this care. For them, it was all of the other diseases or conditions (e.g. Cancer) that were taking up all of their capacity to deal with which could lead to dementia being ignored or treated as less crucial. For this caregiver (and presumably, for the person with dementia), it was the co-morbidities that were taking all of their efforts to fight.

One caregiver that was caring for a spouse talked about how they want to keep their spouse at home but it is becoming physically more difficult for them to manage as they get older as well. Lastly, caregiver participants talked about how their lives were interrupted by having to take on a care-giving role. Many of the family based caregivers, especially those that were caring for a parent, had jobs or were attending school and had to adjust their ambitions for their lives going into the future.

“Just doing the things that I want to do like with school work looking for work you know it it stops me from going forward with my life, but I still got a lot of time, so it doesn’t really, really worry me. But just thinking about it, I feel the urge to keep going forward though.” (Caregiver WF03)

**Strategies and Coping:** Many family caregivers talked about how they had to learn to cope and get beyond their frustration with the symptoms that their loved one had such as memory loss. We learned that family member’s strategies for care evolved overtime through experience rather than through informational sources, support groups or training. For example, this participant eventually realized that the memory loss and confusion exhibited by their loved one was not their fault and that they needed to show compassion and not always worry about correcting the mistakes.

“My mother it is sad to see her in this stage and as each day goes by it’s a bit more, we use to ah, before she was diagnosed with dementia and what not we just use to try to correct, mom you just said that, mom this you already said that, mom you forgot again and now it’s just we just go with the flow, doesn’t matter if she mentions something three times in five minutes. It’s okay Mom you know because it’s no sense of us getting frustrated with her because that’s just the way it is and we can’t change it, there is no Alzheimer’s, dementia magic wand.” (Focus Group WF03)

There was a sense that caregivers had to come to terms with a degree of acceptance. One caregiver suggested that the caregiver of someone with dementia should expect to face some challenges such as verbal abuse and that it is necessary to maintain calm and let this sort of behaviour pass as it is not the
fault of their loved one, just the nature of dementia. Respite was suggested as something that can help family caregivers to cope with times of frustration by giving them a break if only for a few hours.

“I get frustrated, my mother gets frustrated. Other people that come here that are not use to it, they just wonder you know how do you, how do you cope and do that kind of stuff. But like I mentioned earlier, I will say it again, it’s good to have the Respite care and (ah) we have a lady that comes in and another gentle that comes in, takes him out for four or five hours at a time, so that really helps out with being a caregiver.” (Caregiver WF02)

A lack of acceptance, stigma and shame can affect the care-giving relationship and the quality of care. One participant told a story of a relative that was caring for his wife and how shame of their dementia was preventing them from getting this person involved in programs that may have helped them cope with this condition.

“So they finally had her tested and I encourage him I said take her to the day program because she was at home, give your dad a break for eight hours, he has his rest he can go do what he wants to do but your mother will be stimulated it will keep her going. But no h-h-his dad no I can’t take mother out, can’t can’t, no one can see mother in this way. This is not mother, the way that they know her, you know and so he kept her home and she ended up having an accident, fell down and broke her ankle and ended up in the hospital and never came out of the hospital.” (Focus Group WF03)

## BENEFITS OF CAREGIVING

Although there are many challenges associated with providing care for a person with dementia, there were many benefits to the family care model. Benefits that relate to family care included being able to keep their family member at home with loved ones, maintaining some independence, and better outcomes for the person with dementia. Some participants felt that people with dementia degraded faster when they are placed in unfamiliar environments and/or isolated from their family.

## COMMUNITY AND MEDICAL HEALTH SERVICES

## SERVICE NEEDS AND RECOMMENDATIONS

Both healthcare workers and family based caregivers had many suggestions that they felt would be helpful for the care of the person with dementia or for the caregiver. Healthcare workers suggested that in order to reduce the confusion related to unfamiliar environments that there is an effort made to keep dementia patients in one place rather than moving them around so much.

“They finally had her tested and I encourage him I said take her to the day program because she was at home, give your dad a break for eight hours, he has his rest he can go do what he wants to do but your mother will be stimulated it will keep her going. But no h-h-his dad no I can’t take mother out, can’t can’t, no one can see mother in this way. This is not mother, the way that they know her, you know and so he kept her home and she ended up having an accident, fell down and broke her ankle and ended up in the hospital and never came out of the hospital.” (Focus Group WF03)
moving them around, even to the room to the next room in the same unit it causes more confusion because they are already confused (slight chuckle) so you can’t be bouncing them around like popcorn here, leave them in one spot.” (Focus Group WF03)

Most of our participants agreed that there is need for more home based care. Providing personal care workers and/or home care workers would go a long way toward improving outcomes by making independent living more feasible.

“I like this home care, I’ve been in and out of the hospital and I’m tired of seeing hospitals and this is a good experience for me, this is the first time they do this home care for me. I had one before, but it didn’t it wasn’t like that yeah for for changing my dressings and stuff, but this program is pretty good.” (Person with Dementia WF04)

Caregivers also expressed a need for respite. Most were happy to be caring for their loved one though they recognized that it can be overwhelming physically, mentally, and emotionally. Respite, even if only a few hours a week provided an opportunity for these caregivers to recharge.

Social interaction or just to have some company to ward off loneliness were identified as needed by our participants. In addition to home care and personal care workers some services that were suggested to alleviate this were support groups, community groups, and Aboriginal specific programs and groups. The various healthcare workers described how care needs to be more interactive for those with dementia and getting people out of the house and away from the television is necessary. The need for services to be delivered in the local Native language was also expressed. It was felt that this would be beneficial for maintaining the mental capacity. This was confirmed by one of the people with demetia we interviewed who felt that when they used their language they had less trouble remembering than if they were thinking in English.

There was an identified need for more information about dementia from all types of participants. Those with dementia and their caregivers expressed a need for this information to help them anticipate and deal with the condition itself. Many of the participants, especially family caregivers and those with dementia talked about how they had little knowledge about their condition and had been provided with little to no support to gain this knowledge. Sometimes this lack of knowledge led to difficulty coping with their dementia and sometimes it led to fear based on not knowing what was happening to them or to their loved one.

“Well, I have it does bother me for like when I forget loss my memory and I have to think over what, where and how to start it and things like that but you know it worries me sometimes, what’s wrong with me or like what’s I don’t know it’s my age right now or I don’t know like some people have their what do you call that
thing ADRD, we don’t know when it affects you.” (Person with Dementia WF04)

Those in healthcare claimed to need more information about how to assess, care for, and treat those with dementia. They thought that this information was lacking at present.

**CULTURALLY APPROPRIATE APPROACHES AND CULTURALLY SAFE CARE**

The study revealed that there is clearly tension and dissatisfaction when older Aboriginal people access health care services in Thunder Bay for dementia care. Participants shared experiences of racism and fear associated with clinical interactions and a lack of knowledge on the part of health care providers of their culture. For the most part this resulted in a reluctance to seek care.

For many Aboriginal peoples, having to cope with dementia may mean moving from their community to Thunder Bay to access specialized services or nursing home facilities. For many this resulted in the experience culture shock and isolation from friends and family.

“... they have been uprooted from their home and placed in there and nobody knows, they don’t have their language, they don’t have their culture, they don’t have their food, even their caregivers are all waab-shke-wag (meaning white person) so you have no one that looks like you, cause as soon as they see us coming there’s a big smile on their faces.” (Focus Group AK02)

As suggested during one focus group, it would be ideal to have senior care facilities provided within Aboriginal communities so that Aboriginal seniors could stay in their community and access specialized services while being able to be where their social network of family and friends is.

Another idea that was suggested that may help Aboriginal seniors to feel more at home was to provide traditional food options. A service that provides some traditional foods for these seniors is provided by the Thunder Bay Indian Friendship Centre but there is need for more of this.

“So sometimes when we have moose meat or rabbit, fish, we will bring them here to eat cause that’s what she’s saying, they want their wild game because it’s not inspected and all this stuff and their not allowed to bring in all that wild game and that stuff is what they want is their wild game so we usually bring them bannock, wild rice, berries if but if we get wild meat like rabbit or moose meat we bring them there, like the last time we had that moose meat, salt pork.” (Focus Group AK02)

**Cross-Cultural Communication**: is one area that could use considerable improvement. Using plain language and avoiding medical jargon when communicating with Aboriginal patients was suggested as one method to improve communication. Participants suggested that it would be preferable to have medical services delivered in the patient’s Aboriginal language but where this is not possible professional translators are needed to ensure that there are no misunderstandings between patients.
and healthcare workers.

MG..... They told us to watch out she was aggressive she was a hitter ... we are going in the group and she never touched us once but she said that that white lady grabbed her like this ... instead of come on we have to get you up, I guess she grabbed her like that and was pulling at her so she went like that to her, and she had a sore arm, she said her arm was sore, oh yeah she said that white lady was grabbing her, in her mind she was getting grabbed at and so she went like that.

AM..... ah self defense.

MG..... yeah, in their mind she’s aggressive. (Focus Group AK02)

Beyond plain language and the use of an Aboriginal language where possible, sometimes there is need for communication assistance from either family or an Aboriginal navigator within the healthcare system. An example of this, as provided by some participants, is that Aboriginal seniors may not ask questions.

“If I am in the room I would sort of, if my mom would explain, like I’d let her do the talking because it’s her her her situation and if I felt she was having some trouble explaining it then I would add on or elaborate or whatever or sometimes would ask question that my mom would not even think of asking, it’s one thing I notice with her, my mom is probably the same with other Aboriginal people, they don’t ask questions.” (Caregiver WF04)

This is similar to what was described in the section on culturally relevant assessment where Aboriginal peoples may not feel comfortable talking to or sharing personal information with healthcare staff that they have not established a relationship with.

**Provide Culturally Congruent Care:** One way to ensure that communication improves is to bring more Aboriginal healthcare workers into senior care homes and hospitals. Some of those interviewed did not believe that Aboriginal peoples are appropriately represented within care facilities in Thunder Bay.

“I think too that you need to recruit Aboriginal people I think that you need more Aboriginal people in these facilities because if you look at the population of this city, but none of our people are working in these areas.” (Focus Group AK02)

I was also suggested that hiring Aboriginal peoples in capacities other than healthcare positions such as cleaning and cooking services would provide a resource for Aboriginal patients to talk to and healthcare workers to learn from.

“I keep telling these Nursing Homes well why are you not hiring Native people
well you could develop programming, you could have conversations with these people you could find out more and the answers we get is that they don’t apply, as far as I know my people know how to cook they know how to clean I am sure they can be personal support workers because they’ve all been caregivers for their own children they’ve mothers, their families themselves.” (Focus Group AK02)

In Summary, it was clear that interactions with the health care system have been less than ideal for Aboriginal people with dementia and their caregivers in this study. Participants shared their ideas about approaches to care that would better suit their culture and needs. Some of these issues can only be addressed at a systems level, for example, strategies to keep Aboriginal elders in their home communities rather than being transferred to Thunder Bay. Others identified improvements that could be made at the level of the clinical interaction such as improved cross-cultural communication through health care worker training and at the program level such as Aboriginal language use and appropriate food and exercise. This information together with the findings concerning Aboriginal peoples understandings of dementia can begin to inform culturally safe dementia care for Aboriginal people in Thunder Bay.
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