

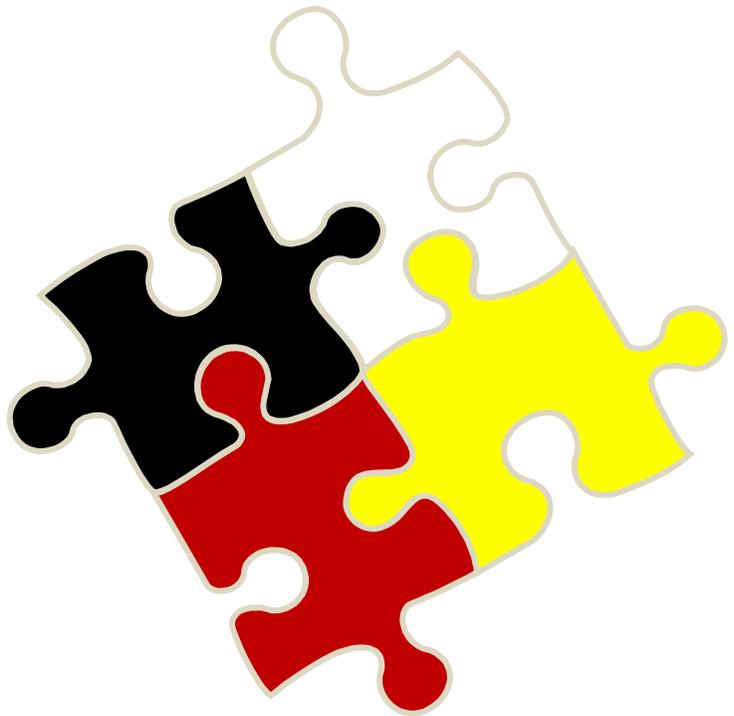
PERCEPTIONS OF ALZHEIMER'S DISEASE AND RELATED DEMENTIA AMONG ABORIGINAL PEOPLES IN ONTARIO

SUDBURY COMMUNITY REPORT, FEBRUARY 2014

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EXECUTIVE SUMMARY

The purpose of this research was to engage Aboriginal peoples with dementia, their 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 (ARD) 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 Sudbury as well as relevant information from the academic literature. There were 18 participants in total from Sudbury. 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 agreed that healthy aging should be viewed holistically, involving the physical, mental, emotional, and spiritual aspects of a person. Being physically active, eating healthy foods, staying mentally active, as well as maintaining spiritual faith were seen as key to aging well.
- Taking responsibility for one's own health and self-care emerged as a key component to healthy aging. Engaging in activities that utilized the mind and body were seen as important to maintaining health and wellness. Part of self care also involves taking responsibility for one's own health and making changes to diet and lifestyle in order to maintain their health as they age. Some participants stressed the importance of staying informed about preventative measures and being their own health advocate.

- The ability and opportunity to participate in social and cultural events and maintain meaningful relationships with friends, family, and the community are thought to have a positive impact on old age. Connections with children were viewed as especially significant. People who had strong family and community connections were seen to be more resilient than those who did not have those connections.
- Participants stated that taking part in cultural activities, reconnecting with the land and following the traditional teachings were associated with health and wellness in older age.
- The study revealed barriers to healthy aging for the older Sudbury Aboriginal population including: access to affordable healthy foods, lack of financial resources, loss of mobility and independence, affordable and accessible transportation, and reported changes in cultural values and roles of seniors in the community, the latter believed to result in depression and neglect.
- Many participants, including caregivers, people with dementia, and seniors, believed that loneliness and isolation were one of the biggest factors for ill health in old age with both being related to depression and cognitive decline.

2) Understandings of Age-Related Dementia

- The study revealed a general lack of knowledge concerning Alzheimer's disease and other related dementias. Memory loss/forgetfulness was often viewed as being related to aging rather than illness.
- Memory loss and confusion (dementia) were most often discussed in a traditional way as a normal part of aging. Words such as 'natural', 'normal for that stage of life' and 'second childhood' were used to describe this as a natural process associated with getting older. Although this was not universal, some participants, including caregivers and healthcare workers, also spoke about people with dementia, along with family members being in denial over the symptoms, while some participants were fearful of what a diagnosis could mean. One participant stated that a certain amount of memory loss was a blessing in disguise for their loved one.
- The results suggest that there is no word in Aboriginal languages (Cree, Ojibway, as well as Oji-Cree) that translates to 'dementia' as an illness. However, there are words for particular behaviours such as "forgetful", "confused", "memory loss", and "thoughts are mixed up". Participants shared words in their Aboriginal languages that describe the experience of dementia from their cultural understanding: 'returning to childhood'. In

English, the participants used words such as “forgetful”, “sickness of the mind”, “getting old”, “reverting back to childhood”, “second childhood”, “losing it”, and “memory loss”, to talk about Alzheimer’s and dementia.

- The terms Alzheimer’s disease and dementia are not widely accepted. Participants conveyed that elderly, along with middle aged people typically did not say the words Alzheimer’s or dementia unless they were joking around. It was suggested that it is not used in direct reference to an individual exhibiting signs of illness.
- Many of the participants from Sudbury who understood memory loss and dementia as natural also offered non-natural explanations of why symptoms may have come on when they did. These explanations included those that are:
 - physiological: such as having other illnesses (multi-morbidities), head injury, prescription medications, and to a lesser degree family history
 - psycho-social: such as stress, grief, trauma, unresolved trauma, stress, depression, loneliness, isolation, and alcohol abuse
- Many of the primary and secondary prevention strategies for dementia suggested by Aboriginal participants in Sudbury include keeping the mind and body active through puzzles, games, crafting, walking, speaking or listening to their Aboriginal language, strength and balance training, as well as getting outside and reconnecting with nature.

3) Diagnosis

- Symptoms experienced by the Aboriginal participants included: **Mental** – forgetfulness, confusion, hallucinations, compulsive behaviour; **Emotional** – frustration, irritability, anger, fear ; **Physical** – dizziness, impaired mobility, shaking, falls, difficulty swallowing, seeing, hearing and speaking and writing and decline in personal hygiene and fine motor skills. A physician participant cautioned that apathy (lack of interest in anything, lack of motivation) is often the first sign of dementia in her experience. Most of the participants with dementia, as well as those caring for someone with dementia, reported that a formal or accurate diagnosis of dementia had never been made.
- Informants were not able to tell us the rates of dementia in their clientele, although some Aboriginal health workers speculated it may be around five percent and be higher among males than females. A physician participant noted that it is more common for female spouses to bring their husbands for assessment than men bringing their wives.

- Few participants had direct experience with cognitive screening but those who did, along with health care workers who administer them, recognized that they are not appropriate or accurate for Aboriginal people.
- Overall there was no consistent way dementia was being diagnosed in our research sample. Caregivers reported difficulties getting a diagnosis in some cases because physicians were not concerned about the symptoms. In other cases diagnosis was made purely on the basis of the physician's opinion and in others on performance on cognitive assessments. Even among physician participants it was agreed that there is no agreed upon way to assess for dementia leading to varying practices. Misdiagnosis was a concern expressed by people with dementia and their caregivers.

4) Treatment

- Key informants stressed the need for physicians, patients and caregivers to discuss treatment plans in order to connect caregivers with the appropriate services to help care for their loved ones.
- Prescription medications were used by some participants to treat emotional symptoms associated with dementia (e.g. mood). Some participants reported using traditional smudging and or other spiritual means to treat hallucinations. No one reported being on cholinesterase inhibitors to stabilize or slow memory loss. The importance of taking the time to explain the medications was stressed.
- Participants stressed the role of culture and ceremonies in contributing to overall health and wellbeing in the elderly, but did not know of or report the use of traditional medicines specifically to treat memory loss.

5) Dementia Care

- The research confirms that dementia care for Aboriginal people in Sudbury is complex. Participants with dementia or caring for someone with dementia reported multiple complex chronic conditions.
- A preference for care in the home by family was expressed by most. However, many participants suggested that there is a point when symptoms get more severe, that outside care and support is needed.
- The services provided by the Friendship Centre, including Life Long Care, played an essential role to the health and wellbeing of community members, especially elderly people who utilize the services.

- There seemed to be a general reluctance by some participants to utilize non-Indigenous programs and services, as these services did not appear to address the holistic needs of Aboriginal participants.

6) Dementia Related Programming and Information

- We found overwhelmingly that participants had very little knowledge about Alzheimer's and related dementias. There was widespread support for programs and services to provide more information on the illness and its progression. Participants linked this need for knowledge to a need for planning for care
- Participants suggested that communication about Alzheimer's and dementia in community may be more effective if it were presented in shorter presentations, in easy to understand plain language, or in alternative mediums, such as plays and videos, with more culturally appropriate content.
- The results indicate that some issues have arisen because power of attorney and decision making have not been addressed by Aboriginal families. There is a need to understand how to appropriately discuss and facilitate the legal process of power of attorney with Aboriginal seniors in Sudbury.

7) Culturally Safe Dementia Care

- The need for health care providers to have a shared understanding of colonialism and how colonial policies continue to impact Aboriginal people today was evident. Participants shared stories of how experiences in Residential Schools and during the Sixties Scoop affect how dementia and dementia care is experienced by their loved ones. Learning about this history can help healthcare providers improve care through a better understanding of the intergenerational impacts. Learning about this history can also help healthcare providers understand that Aboriginal people are very diverse and they may or may not follow traditional cultural teachings.
- Cross-cultural communication, time, and continuity of care were all reported to impact the quality of care in this study. Participants spoke about the importance of building a relationship with their health care provider and having enough time at appointments to effectively communicate. Allocating more time for patients could also give physicians the added time to look for more subtleties associated with early dementia, as well as discuss treatment options, especially if the patient is accessing care in different places, such as in their home community and in an urban setting.

- The urban landscape in Sudbury consists of a blend of those who are Aboriginal who have access to federally funded services on their home reserves (status) and those who do not have status and fall under mainstream health services. The diversity of scenarios around potentially available services results in confusion on the part of physicians and health care workers trying to support patients in the urban context. There is also an added burden on Aboriginal people and their families when trying to access services and negotiate the various insurers and jurisdictions. This results in systemic inequity for patients and their families.
- Participants felt that families and care-givers could best help the person with dementia by keeping them in a familiar environment and support them in doing familiar tasks (folding clothes, washing dishes) and taking them places they have previously enjoyed (church, the bush). Some suggested scrapbooking with the person with dementia to help them keep track of names and faces. In many cases participants talked about the importance of getting on the land and doing land-based activities (e.g. fishing) as a way to stay active in an appropriate way and to bring back positive memories. It was widely recognized by participants that this may or may not slow the illness but it was an appropriate approach to care.
- Delivering healthcare services in the language of the patient was identified as important for getting accurate information and achieving an appropriate comfort level for the Aboriginal person with dementia and their caregiver. Related to this is the need for complicated medical information to be delivered in simple understandable language.
- Participants identified a need for educational material and sessions that are more appropriate to Aboriginal people and reflective of their culture.

COMMENTS FROM THE ADVISORY GROUP

The Advisory group met for a final time on April 2nd, 2014 to review and discuss the findings. There were no formal recommendations made during this meeting but the discussion did emphasize some on-going key concerns and emphasized some important directions moving forward.

The group reiterated the importance of creating a culturally appropriate screening and assessment tool for dementia. There was a discussion about how this might be accomplished and what could be learned from the KICA tool developed for Indigenous peoples in Australia. In relation to this there was the acknowledgement by some members that health care workers may be reluctant to diagnose dementia because there is no cure and nothing they can concretely offer patients following the diagnosis.

The second key point the group wished to emphasize was the need to focus on primary and secondary prevention strategies that are grounded in Aboriginal culture – for example how language use and ceremony might play a role in delaying or preventing symptoms of dementia.

Finally, the group is keen to hear back from the researchers once all community reports are finalized to see if there is some consensus about what next steps should be taken to continue work on this issue.

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 Sudbury 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 Sudbury 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 solutions to diagnosis and care.

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).

What is Dementia?

“Dementia is an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgment 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

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

Risk Factors for Dementia

Non-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

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).

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.

METHODS

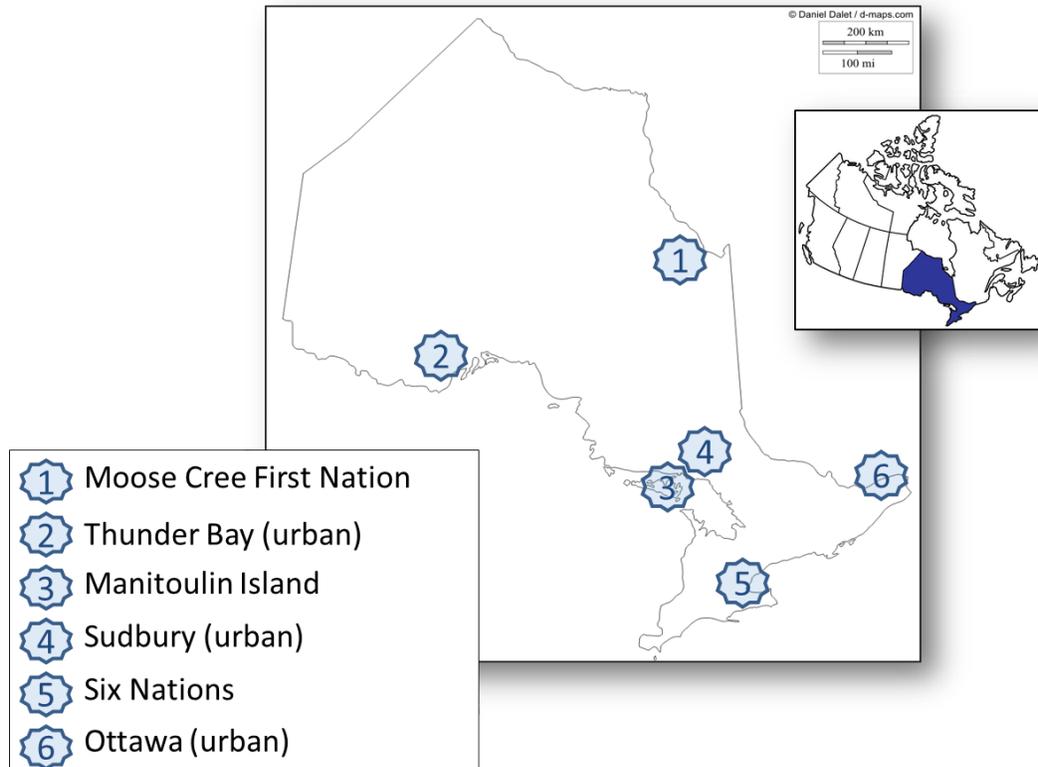
COMMUNITY-BASED APPROACH

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.

Provincially, at all sites, community health centres and/or Friendship centres provided support to identify key informants to help guide the research and participate in early interviews where community-specific challenges and circumstances were discussed. Local health centres also aided in the recruitment of community-based researchers for the project. Across the sites, six 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.

In Sudbury the investigators worked with the Executive Directors and key staff at the N'Swakamok Native Friendship Centre, Métis Nations Ontario Sudbury Site, and the Sudbury-Manitoulin Alzheimer's Society beginning with telephone consultations in the Fall of 2009 and a subsequent meeting with partner organizations in February 2010. The Shkagamik-Kwe Health Centre was also consulted but declined participation. The N'Swakamok Native Friendship Centre and Sudbury-Manitoulin Alzheimer's Society 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.

Figure 1: Research Sites



Where possible, community advisory groups were struck for each research location usually including health directors, relevant staff, and community volunteers, and sometimes the Health Committees. 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 Sudbury 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 Sudbury 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. All participants provided informed consent prior to being interviewed.

Research Site	Sudbury
Interviews	
People with Dementia	2
Caregivers	5
Seniors	5
Total	12
Focus Groups	1
Number of Focus Group Participants	4
Key Informant Physician	1
Key Informant Specialist Physician	1
Total Participants	18

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. With assistance from program staff at N'Swakamok, two people with dementia were identified for interviews – falling short of our target of five. These two individuals lived in Sudbury in their homes and were over the age of 70.

Caregivers in the sample included wives, adult daughters and close friends. There were 5 female caregivers.

Seniors who were interviewed could be included if they were 50 or older. In our sample they ranged in age from 58 to 79. Senior participants were Métis, Ojibwa and Odawa/Potawatomi and had been living in Sudbury between 6-58 years. There were 5 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 and 1 physician specialist. Focus group participants were coordinators of health and wellness programs at the N'Swakamok Native Friendship Centre of which there were 3 females and 1 male.

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

It was challenging to find individuals with a clear clinical diagnosis of dementia, so the findings represent people who are experiencing symptoms of memory loss and dementia, but have not necessarily been clinically diagnosed with the disease. It was difficult to recruit people with

dementia to the project in Sudbury and therefore our sample includes just two people with dementia.

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 analysis will have the numerical power to include a fuller gender analysis.

The research assistant hired and trained to conduct the interviews in Sudbury left the project after completing two interviews. Our inability to locate a suitable replacement delayed our work.

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. Sudbury participants described healthy aging primarily in terms of their ability to continue to contribute to and have a role in the community. Participants did not discuss healthy aging in relation to the absence of illness or disease.

ENABLERS FOR HEALTHY AGING

For many of the participants aging well is not defined as a lack of disease, but as having a wide network to draw from for physical, mental, emotional, spiritual health. Some participants felt that healthy aging was a result of taking care of oneself throughout their lifetime. This included having access to health care, affordable healthy foods and activities where people could come together to visit, as well as maintaining their independence.

ah good medical care, good social activities, healthy food, healthy accessible food and don't live on top of the mountain, I am just joking cause if you don't have a vehicle you can't walk up. (Senior AK01)

I think ah eating properly and ah getting exercise, maintaining um relationships. (Senior AK05)

Taking care of their physical body was important for the Aboriginal participants in Sudbury. One participant talked about how maintaining a healthy body and mind through exercise and self care was important for maintaining health and wellness and that this was something that does not stop when getting older.

I think that is one of the best things that I did ah you know when I was younger I tried to take courses but that was some way kinda taking care of yourself you know to paint just to relax and do something physical too like a yoga like I paint, joined the drum group I like that cause I find that gets me out sometimes I feel tired after a long day and to have to prepare something to cook and the comradeship is good you know I get out to see people besides work and I paint I just enjoy that so much and the yoga. I don't like to do research myself, you know I just like being in the library. (Senior AK03)

In addition to being physically active, many participants also talked about the importance of keeping their mind active as well. One senior talked about the different activities they did to stimulate their mind, including doing puzzles, reading, listening to books on tape, as well as listening to different programs on the radio in both French and English.

Another participant discussed the importance of staying informed and taking control of their health by making changes to their diet and lifestyle in order to maintain their health as they age. Taking responsibility for their actions and being their own advocate when it comes to health and wellness helped one participant lower their blood sugar levels, which helps decrease some of the risk factors associated with diabetes.

Some participants stated that they kept busy with craftwork, knitting, and quilting, as well as cooking, gardening, and going out to movies or visiting with friends. For one senior keeping busy was a good way to ward off depression and dwelling on problems.

For many participants, visiting with family, particularly seeing and interacting with their grandchildren brings great joy to their lives. One participant stated that they wanted to live longer so that they could continue to watch their grandchildren grow and be a part of their lives. Maintaining close family relationships, particularly between grandparents and grandchildren may encourage grandparents to take better care of their health so that they can remain active in their grandchildren's lives.

Visiting with friends and family, engaging in community events and cultural practices, and being able to use humour to get through difficult times were also seen as an essential role to healthy aging. Several of the participants also stressed the need for social interactions to be about helping each other and helping the community at large. For some of the seniors this meant being able to donate money to local fundraising efforts, creating items to be raffled or auctioned off, as well as visiting or assisting more elderly seniors in the community. Having community events and being able to contribute to the health and well being of the community at large may serve an additional purpose of having a sense of belonging and being able to make a difference in the lives of others. This may be especially true for people who may not have family nearby or who have moved from their home community.

Well you know what when I moved here I never seen so many um people take part in fund raising you know... yeah that was nice you know and we phoned in and donated some money you know and ah and things like that I like to take part with as much as I can you know. (Senior AK02)

While the participants' beliefs, actions, and interactions with friends, family, and community can be seen as essential to healthy aging, they can also be seen as keys to

maintaining one's independence. This was supported by one of the physicians, who commented on the resiliency of Aboriginal people, especially those who are able to maintain their independence in the face of multiple morbidities because of their connections to family and community. Seniors who are actively involved in their community may have a better sense of where to go to access services.

BARRIERS TO HEALTHY AGING

Barriers to healthy aging for Aboriginal participants in Sudbury were related to a number of issues including mobility and transportation issues, loneliness and isolation, as well as access to affordable housing, healthy foods, and social activities for preventative care. Some participants also discussed racism and stereotypes, changes to the traditional values and roles of seniors within the community as additional barriers to healthy aging.

For some participants, growing older brought about certain challenges related to loss of mobility and loss of independence. For people who have multiple morbidities, this loss of mobility can lead to increased dependence on others, which could be problematic for some people who do not like asking for help.

You can't get around too well and you can't carry your own groceries. You have to have somebody to help you and me I don't ask for help I'd rather pay my way or do it myself. (Senior AK04)

Previous experiences of vulnerability, dependency, and racism can play a large role in how people think about and react to getting older and needing extra assistance. One senior who has mobility issues shared their concerns over being judged because of their unsteady gait.

I'm going to have to use my walker pretty soon. Well yeah when I do go out during I'm walking I have a cane which I should be using because I'm a little staggering you know and I have to keep my eyes on the road where I am going. If I look around I get you know and I said oh boy I said um I don't want to look like a drunken Indian woman walking down the street. Yeah, I don't want people to misjudge me because they won't they can't understand these things you know. They look at you and oh another drunken woman and I hate that to be judged but they don't understand. So anyways, I take my time and you know ah that's what worries me. (Senior AK02)

Unfortunately, these stereotypes of the "drunken Indian" continue to exist throughout Canada. These preconceived notions and stereotypes are dangerous and can greatly impact the level of care and attention a person receives, which in turn can act a huge barrier to healthy aging. For example, symptoms resulting from a stroke include weakness, such as loss of strength or sudden numbness in the face, arm, or leg; trouble speaking, which can result in slurred speech, sudden confusion and trouble understanding; vision problems; headache; and dizziness,

including loss of balance, may not be fully looked into if the person holds on to these stereotypes and simply sees the person as a “drunk Indian”. We have recently seen the fatal impact of these biases in the case of Brian Sinclair.

Additional barriers to healthy aging include loneliness, living alone, and isolation. One senior shared their views on being alone, stating that people are not meant to live alone and that isolation and loneliness can lead people to withdraw from everyday activities. This senior also mentioned that having to be around people after being isolated for a period of time can cause a great amount of stress and anxiety and can lead the person further withdrawing from activities and interacting with other people, which will have a negative impact on one’s health and wellbeing.

the more alone a person is without mental stimulation here every day or people stimulation I mean there in your everyday life and where your living the more you’re gonna be prone to getting dementia and Alzheimer’s cause your brain is like any other part of your body if you don’t use it you lose it. (Senior AK01)

Other barriers to healthy aging that were brought forward by participants include changing cultural values and Elder’s roles within the community, which could result in elderly people being ignored, neglected or abused. One senior felt that leadership was not doing enough to uphold the roles of Elders in the community and should include seniors in the decision making process, especially in any decisions that would directly affect seniors in the community. The lack of consultation could result in services or programming that is not appropriate or useful for seniors.

A couple of seniors felt that certain values have changed from when they were younger and that the level of respect that was traditionally shown to elderly people was not being upheld today. One senior commented that as a child, it was their job to go and visit with the elderly people in the community in order to make sure that they were okay. In the process of visiting with the elderly people, the child would mostly help with certain chores and learn things along the way. This senior felt that this does not happen today either because the youth do not want to learn from the Elders or that they do not know how to ask for help. This is thought to be especially difficult for people who are second, third or fourth generation residential school survivors who were raised in a time of cultural disruption or dislocation who now struggle to pass on cultural values to their own children.

The legacy of Indian Residential Schools has greatly impacted survivors and their family members over multiple generations. Some participants shared their concerns about the impacts of intergenerational trauma and how this can in turn impact elder safety, especially if the person taking care of the elderly person is not particularly healthy themselves.

So that's a whole consideration what do we do when we have unhealthy caregivers with poor coping skills well that's why we have elder abuse that's why we have the money missing you know that's why her cupboards were pretty much empty and she hardly had any clothes you know. (Caregiver AK01)

But I think that hard part is ah when you are being abused by family or by young people I found that pretty ah ah difficult for a lot of people they didn't know how to say no to their kids and their kids had addictions and they would ah rip their family off like ah elders especially the isolated one no one to protect them they would mug those people that's a hard thing in a lot of communities still. [They go] after their medicine stuff like that. Sometimes it's not safe for them when their cheques come in and stuff they're more high risk for them the people that want that kind of money eh. (Senior AK03)

For many seniors, having their cheques or medication go missing can greatly impact their health and their ability to pay for necessities such as food, housing, hydro, as well as any medications or medical supplies that may not be covered. A couple of seniors commented on the challenges they face due to lack of finances and stated that while they may understand what is needed to support healthy aging, they cannot always afford it.

I showed them I said listen cause my income last year was less than 11, 000. She said oh my god you have no money for food, I said now your figuring it out. There's no money for groceries, there's no money for a lot of things. I just pack everything on my credit card pay out a little bit then put some more on it. (Senior AK01)

One senior mentioned that many Aboriginal people may not have a pension beyond the Canadian Pension Plan. If they did not work for a company that provided a pension or additional benefits, they may find themselves in a difficult position as they age. This senior also mentioned upon her ex-husband turning 65, both of them will be cut off from his benefits and she will not have access to any medical benefits. Since she is Métis, she is not covered under Non-Insured Health Benefits and will need to find a way to cover any medical expenses or medications that are not covered by the Ontario Drug Benefit program (ODB). Once she is 65, she can apply for a Seniors Co-Payment Program, which will lower their co-payment to two dollars each time they fill a prescription. Unfortunately, syringes, other diabetic supplies, eyeglasses, dentures, hearing aids and compression stockings are not covered under the ODB, which means that a loss of benefits could have a devastating impact on a person's health and wellbeing.

TRADITIONAL LIFE AND HEALTHY AGING

Many of the participants in Sudbury stated that their traditional teachings and cultural practices helped them with healthy aging. Some of the participants followed both Christian and Aboriginal teachings and stated that their beliefs gave them strength and helped them live a good life.

I am very spiritual and very religious. I am culturally inclined in the Francophone community, in the Native community I practice the Ten Commandments, that's hard to do. I even practice celibacy and I practice the Seven Grandfather Teachings. I am a traditional Pow-wow dancer and I go in ceremonies, talks and socialize and stuff like that I know I should put exercise more but it's on it's way. (Senior AK01)

One senior stated that a lot their strength came from being a part of Creation and knowing that they have the support of their ancestors. Knowing that they have this support helps them in reaching out and connecting with others. Being involved in the culture as well as any cultural events and activities helps create a sense of belonging and community. Taking part in cultural activities also allows different generations to come together to promote traditional values and pass on the traditional teachings to the younger generation.

Participants also talked about the importance of going back out on the land and the traditional teachings and ceremonies that are associated with the land. For many participants being outside, eating, praying, being around the fire brings back many positive memories and can help rejuvenate them. One participant stated that they continued to take their father out fishing because they knew it was something that he enjoyed, even though they had to modify the activity a bit by fishing from the shoreline instead of going out on the boat due to his limited mobility. This example is a great reminder that taking elderly loved ones back out on to the land, even if the activity is modified slightly to accommodate any mobility issues, can greatly add to their overall health and wellbeing by engaging them physically, mentally, emotionally and spiritually.

PREVENTING DEMENTIA

When seniors, people with dementia, and their caregivers in Sudbury were asked what they did to prevent dementia or slow down the symptoms related to dementia, many of the responses fell into quite naturally into four categories, physical, mental, emotional and spiritual. These four categories, while separated out in this report are very interrelated in terms of engaging the body, the mind and the spirit. The interconnectedness of the activities that the Sudbury participants discussed is captured in the medicine wheel.

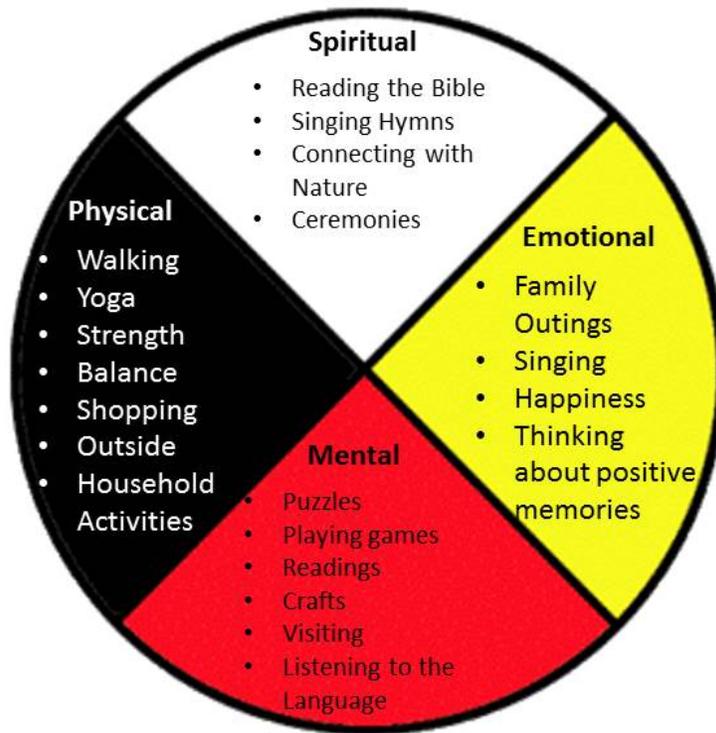


Figure 2:
Thoughts on Dementia Prevention for Aboriginal Participants in Sudbury

Sudbury participants shared a variety of activities that they engaged in to stimulate their mind and body and aid in the prevention of dementia. Beliefs about healthy aging are also very relevant to the prevention of memory loss. For many of the participants, stimulating the mind, whether it was through playing games, doing puzzles, crafting, reading, and visiting with others was a good way to prevent cognitive decline.

The distractions keep the electricity in the brains going, doing puzzles ah playing a game with somebody a game of cards, a game of chess, even talking. You're alone you're not going to talk to yourself. (Senior AK01)

Let's see, I guess I read and ah I try to watch the news and know what's going on and um it's to ah keep my mind working good. Oh I try to feed it properly too and rest it, talk to people so you have time to think when you're too rushing you get confused too easily and make sure that you're not in the house all the time, but sometimes it could be more comfortable eh. Just more comfortable not to go out but ah it's good and you go visit people you know. (Senior AK03)

One person with dementia recognized the importance of challenging their mind and stated that they would like to go back up North to be immersed in the language, where many of the

community members use a combination of Cree and English. This person commented that they were able to still understand the language and knew what was being said even when the two languages were used together and felt that it could help improve their memory. While this activity may not necessarily improve the person's memory, it may help delay further deterioration as suggested in the research around cognitive reserve.

In addition to keeping their mind active, many participants also talked about the importance of keeping their bodies active. Many of the participants stated that they and their loved ones enjoyed walking and felt that it was a good way to keep their body moving. A couple of seniors also commented on the importance of staying physically active, with one senior stating that they enjoyed taking part in activities that helped improve strength and balance, while promoting self reflection and relaxation.

I think so I think so you should be you should at least walk 20 minutes a day maybe I have been doing that since after my heart attack even if it is too cold I can hardly breathe in the cold so and when I go into town I go to the mall and I walk around. (Senior AK04)

I only learned as an older adult about yoga and ti-chi but I love it you know. You don't have to go like Jane Fonda to be healthy and hurt yourself, yeah, cause they don't hurt you when you do those exercises. Yeah and if somebody is skilled and helping you do that program the focus is getting to understand yourself with those, that type of physical activity it focuses on you to relax and to focus strengthen it's not all it's not competitive you know. (Senior AK03)

For individuals who are trying to prevent Alzheimer's or dementia, or even trying to slow down the progression of the symptoms, being physically active can decrease certain risk factors associated with vascular dementias. This is supported by the physician specialist who stated:

That's a grade A recommendation, a level 1 recommendation in the guidelines that people who continue to exercise with Alzheimer's disease tend to decline less quickly from a functional cognitive point of view than those who don't. (Physician Specialist KJ02)

In addition to keeping one's body and mind active, many participants spoke about the importance of tending to their and their loved one's emotional and spiritual wellbeing. A couple of participants spoke about the importance of keeping their loved ones engaged and including them in any outings, even if they are only going out for a short period of time. Taking part in different activities, including those that the person used to enjoy doing in the past, may help bring forth positive memories. One caregiver talked about how her loved one enjoyed singing hymns and could remember all the songs that she used to sing when she was in the choir.

She likes gatherings once in a while, not as long as she use to. And the other thing that she really enjoys she went to my brothers, when was that now, and they were singing. My brother and his wife sing hymns and he said she remembered all those songs so she had fun singing cause she use

to sing in a choir and that too eh so that's another thing that she enjoys would be singing.
(Caregiver AK03)

Some of the participants also shared their beliefs around spirituality and how it helped them in their day to day lives. One participant stated that they read the bible and that helped them feel better. Another participant followed Christian and traditional teachings and used these teachings to help guide them in their lives. Both participants with dementia shared that they used spiritual methods, such as smudging and praying, to help alleviate dementia symptoms. One senior commented on the power of reconnecting with being outside, going to the bush, touching the water, and how that can help heal a person and tend to their body, mind and spirit.

A couple of participants shared some examples of what they found to help keep people who already had dementia active as well as lift their emotions and stimulate their memories. One caregiver encouraged their loved one to keep active through writing simple tasks on a list. This acted as a reminder of all the different things that their loved one could do to keep their mind and body active, while also helping out with some lighter household chores, such as folding clothes and washing dishes. Another example that was discussed among the participants in the focus group revolved around the creation of a scrap book for people with dementia in order to help them keep track of names and faces of family members that they may not see as often.

For the most part, many of the participants in Sudbury were aware of the various activities they could do to help them with healthy aging and the prevention of dementia. In addition to eating well, exercising, and keeping the mind active, individuals need to talk with their family physician if they are having memory problems or confusion. One participant, who was quite active, stated that they never thought about taking to their doctor about aging:

I never thought about going to see a Speaking in the language – doctor, speaking in English – about aging and things like that about trying to prevent Alzheimer's I never thought about that or memory but I know that it's happening enough for me that I want to talk to my doctor about it you know like what should I be doing what are the suggestions on that and I am going to read up on those medications too to see you know maybe that's some the reason surge up in my lack of memory check things out first to see what is really going on. (Senior AK03)

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.

I3: ta-nen-don they don't know that there's just a thing as dementia you know back then but it's just a reminder of how we would forget that's just the way they would talk about it the elders anyways; I2: yeah cause it's they didn't know what it was; I1: yeah they didn't know about this disease back then they didn't know about Alzheimer's they just knew it like forgetfulness and that you're like a child again that's why they said that cause you do like when you get to that stage you don't know when you're going or you don't know you know that's why they are like a child again so somebody has to take care of you that's why they said that. (Focus Group AK01)

The traditional view of this as being a normal part of aging may be changing however as there were some stories of fear and denial. Part of the fear and denial may have to deal with a lack of knowledge about Alzheimer's and dementia in the community. A large portion of participants stated that they did not have enough information about Alzheimer's or dementia, with three out of five seniors and four out of five caregivers saying they needed more information.

I would say no in the beginning there we never we never knew nothing about it and it's still the word dementia and Alzheimer's. I don't know the difference between that is there a difference and they tell you if you want to learn more about that you can go here and there but I never did do that I was just told certain ways a person has it and how you treat it when they are telling you something. (Caregiver AK03)

One participant with dementia shared that they did not know what Alzheimer's or dementia was. The other participant with dementia felt that nobody really knows the full extent of Alzheimer's or dementia, including doctors.

You know I don't think those doctors really know much about Alzheimer's. They know something about it and that's it you know. (Person with Dementia AK02)

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. Some of the caregivers stated that they thought that their loved one was simply getting old and that was the reason why they were forgetting certain things.

And especially her daily routine stuff that she didn't even know how to start or what to do ...as long as I knew my mom she was always a good crafter, making quilts, sewing when she forget she couldn't even thread the needle at the end. Yeah, well I was, we just thought well mom's getting old (laughs) that's it. I guess that what you go through when you get old I said. (Caregiver AK05)

A couple of seniors mentioned that they were having trouble with their memory and at times would forget simple tasks or names of things. One senior mentioned that their memory loss

worried them a little bit, while the other senior found their memory loss to be more of an inconvenience. Although memory loss was clearly a concern, both seniors seemed to believe that memory loss was a normal part of getting older.

Well the thing is as I age I noticed that the my memory this is something I worry about my memory you know I'm ah I don't know if it's because I am trying to remember about too many things at one time. You know and I forget things and um that worries me because well maybe I'm going not crazy you know because of my age I guess. (Senior AK02)

um as long as it doesn't impact my life too much I find I right now I lose so many things that I can't get to work on time at times not every day but enough or when I am doing my housework I am going to get soap and I don't even know why I am in there or I am going to get something down in the freezer and I don't remember what I went down for even I will check the freezer to see if it will click my memory right now it is just kind of inconvenient I try not to get embarrassed by it but ah because people tell me they are all struggling with that you know. (Senior AK03)

Focus group participants shared that they heard similar sentiments of memory loss being a normal part of aging from their clients. They stated that people who were experiencing memory loss would comment that they were getting old and that's what happens when one ages, often joking that they were having a "senior's moment".

One participant stated that they did not recall people having any memory issues back when she was younger, in that many people did not live all that long to have serious cognitive problems. For people who did live long enough and did have more serious health issues, including symptoms associated with dementia, they were typically cared for by family members or placed in a long term care facility. This person also alluded to the fact that if family members were present, they would take the time and attention to make sure that the person was "well taken care of", whereas if the person had no family ready to help out they would be shipped out to a care home where people would not know what was going on. This suggests that any memory loss would simply be dealt with and not really talked about.

Although participants viewed some memory loss and confusion as a normal part of aging, symptoms started to be viewed as problematic when they began to interfere with their daily living. One physician specialist shared that some family members tend to normalize their loved one's behaviours until it gets to a point where there is obviously a problem.

A lot of people by the time, you know, they come to the family physician and again this is general, generally speaking, you know, they said, well I just thought it was aging, so there's all sorts of you know, what our expectations of aging are mixed into that, so you know, I'll often have people say, well for the longest time I just thought he was getting old right, um, until I realized, and then at that point, you know, we like to start treatment for dementia earlier than

later because we know the best benefit is really in the early stages and so that point, kind of the cat's out of the bag. (Physician Specialist KJ02)

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. One person with dementia shared that they heard about people with memory loss reverting back to childhood and understand the long term memories would be stronger as they grew older.

Don't they use something like ah he has or she has back to her childhood again. Like the person had lost all her memories in her future the future life and she was going backwards into her childhood that's I remember that. (Person with Dementia AK02)

Some participants recalled examples of loved ones going back to their childhoods, and spoke about how the person would ask for their mom, look for their siblings, play, as well as need additional help with certain things that children need help with. In addition to exhibiting certain behaviours, memories from the person's childhood were said to be the most prevalent.

For individuals who went to residential schools or who were in the foster care system, certain actions or places may trigger different types of memories. A couple of participants shared their experiences in dealing with people who have symptoms associated with Alzheimer's and dementia and who went to residential school or who were in foster care. They stated that when the person with dementia heard people raising their voice or arguing, they would revert back to that scared little child that was taken from their families.

Yes yes so you've got to talk to him like he is, what he needs Speaking in the language – he scared Speaking in English – it's like, I know how our foster care kids are like when their moved around or transported they are scared they are going to be taken to some place and never brought back you know that whole experience they have that's what they go through fear mistrust. (Senior AK03)

I2: and for some of them it's like they were in Residential School and the thing about raising your voice thing they might of heard that in the Residential School and that's scary and it's scary cause it brings them back to that time or just before. (Focus Group AK01)

DENIAL / FEAR

While a certain amount of forgetfulness and confusion were largely seen and accepted as a natural part of aging within the community, some participants expressed that people may actually be in denial and not want to acknowledge that their memory is getting worse or that their loved one may have Alzheimer's or dementia.

But at the very beginning she would, ah she wasn't admitting to anyone that she was having memory loss, she would just laugh you know. (Caregiver AK01)

They didn't tell me, I was talking to her mom and she didn't tell me and I don't nobody wanted to talk about it ah especially the husband he didn't want to talk about it he was very um I guess what do you call it ah.. He was hoping that everybody else looks after her but he didn't really want to be responsible for what was happening to his wife cause I don't think he knew how to cope with it and he didn't have maybe a ah information about what it is and all of a sudden it's happening right in front of him and to him maybe it was a shock he was trying the best he could. (Caregiver AK02)

People who are starting to experience memory loss may try to deny their symptoms out of fear of being labeled as having a certain condition. One caregiver shared that their loved one denied having anything wrong with them once they knew that the specialist they were going to see was located in a certain building that was associated with mental health issues.

Well it did cause ah where she actually went to this place in Peterborough it was kinda stigmatized cause it was called this building was called oh it be like in Sudbury the sanatorium so it was already labeled that if you went in this building there was something mentally wrong with you, so that was one of the things she hated going into that building it was called "Nickels Building" in Peterborough but it wasn't always but it wasn't just for that but it was mainly known for people that had a mental something mentally wrong like Alzheimer's not Alzheimer's but ah ah what's the other one Schizophrenia. She always took people there so she knows knew those things so she hated that when we took her there to be interviewed by a doctor. So she was saying there was nothing wrong with her. (Caregiver AK03)

Part of the denial may have to deal with fear or a lack of knowledge about Alzheimer's disease and other related dementias. One senior stated that the lack of information about Alzheimer's and dementia concerns her and probably most other people she knows in that they do not know the signs, the symptoms, or the progression of the disease, including what people could do help prevent dementia or slow down the progression of the condition. This sentiment was echoed by the focus group who shared that people may not talk about their memory loss or asked to be tested because they are afraid of being diagnosed, especially since there is no cure for Alzheimer's.

One person with dementia expressed fear over becoming a "walking corpse" once they were diagnosed with Alzheimer's. They also were also fearful that their symptoms would progress at a very fast rate.

It was scary, um because I thought I would go fall right into Alzheimer's forget about everything forget who my relatives were my daughter-s my son my grandchildren I thought I was going to forget them right away. Um that time no no there was with me that time that was right when I

came out I left the extend-a-care see I got it this time. Yeah it was so sad I was so sad thinking about all those things you know they thought I had dementia but they had give me pills and that or medication for that I was fine. (Person with dementia AK02)

ACCEPTANCE / BLESSING IN DISGUISE

While dealing with memory loss, along with changes in personality can be a frightening time for some individuals and their family members, some participants accepted the changes in their loved one's personality and memory loss as being normal and in some cases a blessing.

but I'm not fearful I accept that this is normal progression it's a progressive disease it is not something that we cannot ah we might be able to make it we might be able to promote activities and have a more fuller life but we can't stop it from my understanding is that we can't stop it. (Caregiver AK01)

you know the only thing that I could think of when you said rewards it's not a reward but it's um when somebody dies and they dwell on that and when they get, when their memory is when they start to lose their memory. Not memory, but memories is that it's actually sort of good that they forget that cause then they are not worried. Cause she was worried a lot worried a lot. Like when my dad died and my brother died it was always with her and when this memory came she forgot about that and it was actually good for her. You understand what I mean. (Caregiver AK03)

PREVELANCE AND INCIDENCE RATES

When asked about the prevalence of Alzheimer's and dementia in the Indigenous population in Sudbury, the focus group participants speculated that rates of Alzheimer's and dementia for the Aboriginal population in Sudbury were around five percent, but this represented a best guess as they were not tracking this systematically.

One physician, along with the physician specialist both stated that they have a higher prevalence of male patients being brought in by their spouse or adult children to be assessed for Alzheimer's disease or other related dementias. The higher prevalence of male patients is interesting and raises a number of questions as to why this might be the case, including whether medical help is sought due to behavioural issues or if issues related to memory loss in women is not recognized by family members as fast as it is in men.

A few participants felt that the number of people being diagnosed with Alzheimer's and dementia was increasing. The physician specialist stated that the rates of Alzheimer's and dementia are increasing in all communities, including among First Nations people. Part of this reason is due to the higher rate of vascular risk factors, including obesity, diabetes,

hypertension, smoking rates, which would increase risk of dementia. The physician specialist went on to explain that there is more of a shift from a pure Alzheimer's diagnosis to more of a mix of Alzheimer's and vascular dementias.

Like most dementias are at least modified by vascular disease if not driven, so even the Alzheimer's pathology, very rarely is there a pure Alzheimer's pathology, most people, you know, we used to say it's you know, I forget, like 60% Alzheimer's you know, 30% mix, 10% pure with a smattering of Lewy body and you know, frontal temporal, we're now widening that mixed so that there's much less very pure Alzheimer's and much less pure vascular. (Physician Specialist KJ02)

UNDERSTANDING CAUSES OF DEMENTIA

Participants described many factors that they believed might contribute to the development of memory loss and cognitive decline. Memory loss was commonly understood as being a normal part of the aging process.

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, concurrent illnesses, trauma, and stress.

Here we categorize “unnatural causes” into physiological and psychosocial causes.

PHYSIOLOGICAL

Family history/genetics:

A couple of participants believed that Alzheimer's and dementia is hereditary. When asked about their family history, one person with dementia mentioned they had three uncles who had Alzheimer's. They also talked about their family and how their mother was able to see who would have Alzheimer's in the future.

I use to hear my mother talking with this other woman eh like when I came back from um from ah Toronto didn't take me long to understand what they were saying I hear them naming names who was going to have Alzheimer's in the future and and my name came up and I never told my daughters that or anything and I never thought about it until I got Alzheimer's. (Person with Dementia 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.

Participants in this study related their own or their loved ones memory loss to particular health issues. For example:

- Heart disease
- Kidney disease
- Organ failure
- HIV related dementia
- Severe unattended diabetes
- Complications of diabetes leading to a stroke – resulting in vascular dementia

Aboriginal people are often dealing with multiple chronic illnesses. Both people with dementia lived with multiple co-morbidities and all of the caregivers mentioned that their loved ones also had other illnesses and chronic diseases. It is often these co-morbidities that are bringing people into the health care system. According to one physician:

I think that the disease prevalence when I think of my elderly patients I mean type 2 diabetes and its, um, and its sequelae, you know in terms of cardiovascular disease and peripheral vascular disease, the retinopathy, the, the um, you know, the microvascular disease, the macrovascular disease as far as amputations, etcetera. I mean that is the one that's sort of out there. Um, I mean, and I would say that when I think of elderly people and their cause of morbidity and eventual mortality probably is clustered mostly around that. There will be some people that have cancers. Um and so, you know the, the primary diagnosis as being of Alzheimer's and dementia would be very low right, now in my thinking. Um, but there is the occasional person, but um, it can be sometimes a comorbidity but what's causing most of their contact with the health care system initially is the type 2 diabetes. (Physician KJ01)

Prescription medications:

Some participants expressed concern over the side effects of certain medications and felt that some of these side effects can include memory loss and general confusion. Some participants also felt that the use of certain prescription medications could cause or worsen dementia. One senior felt that prescription pain killers, along with other medications led to her mother's cognitive decline.

My mother had a form of dementia but that was caused the doctor's made an accidental drug addict out of her since many years ago, I remember seeing my mother when I was just 15 years old she would take her she had ah a broken back and it was fused together those old days they fuse it together with a silver 6 inch ah how do you say with 3 screws on each side a silver rod or pin or plate with 3 it was made out of silver with 3 silver screws on each side so she was constant pain and the doctor made an accidental drug addict out of her and that lasted till she died so part of her dementia okay could have been cause by old age and from burning out her brains from those friggen pills I find doctors ah over prescribe pills especially pain killers and in the old

days it was nerve pills and sleeping pills I find doctors should (clears her throat) prescriptions, prescriptions could cause some form of dementia too. (Senior AK01)

PSYCHOSOCIAL

Emotional, physical, and spiritual traumas and stress:

Some of the participants believed their or their loved one's memory loss and dementia may have been caused by a **traumatic or stressful** event in their life. A couple of caregivers related the onset of dementia to **grief** and talked about how their loved one's memory loss coincided with a loss of a close friend or spouse. One participant with dementia stated that they started having trouble remembering after their spouse passed away. A caregiver also mentioned that her mother's memory seemed to decline after the death of her father.

I guess we thought just her age I guess and living alone not too much communication with my dad or without my dad there, there was always two of them before. Suddenly live alone in a great big house, I mean we would just pop in and out, we tried to have somebody there all the time but it was pretty hard with everybody working. Yeah she was very active when she was driving on her own, she was all over the place. (R: you felt that it started after your dad died) Yeah after my dad died maybe a year after. (Caregiver AK05)

Other participants felt that **depression, loneliness and isolation** can all lead to issues of cognitive decline. Many of the participants discussed the impact of living alone has on a person's cognition and stated that isolation and a lack of stimulation can lead people to decline at a faster rate.

I think a lot of it had to do with she lived alone to like ah she's 82 she lived by herself for 25 years at least cause my dad died when he was quite young he was 54 I think part of that has I think contributes to that I think if you are by yourself you are not talking to people and interacting as much eh so I think being by yourself doesn't help that and if you have that in you then I think and you're by yourself that's how I see it anyway that it will it will make it happen then slowly manifest. (Caregiver AK03)

It could be a lack of stimulation of the brain and of the environment ah but there are people who are prone to getting it if they are alone and they lack mental and personal stimulation around them they're gonna deteriorate faster. (Senior AK01)

Participants also talked about **physical injuries, abuse, and head trauma** as a cause of dementia and memory loss. One person with dementia believed that their memory loss was a result of a traumatic head injury from many years back when they were at camp. The participant stated that they were attacked by two other girls trying to steal her purse. As a result of the attack, the participant woke up in the hospital after being unconscious for two days. While one caregiver

stated that their loved one's memory loss became much more pronounced after a motor vehicle accident.

Unresolved trauma was also cited as a cause of dementia among some of the participants. Negative experiences at Indian Residential Schools that were not dealt with by the individual or their families were believed to have a continued impact on the person's physical, mental, emotional, and spiritual wellbeing. Healthcare providers, caregivers, and seniors felt that these experiences could impact on a person's memory and overall mental capacity of these individuals as they age. One caregiver believes that it was a combination of chronic illnesses, medications, mental health issues, including trauma and unresolved grief and depression that led to her loved one's dementia.

Processed foods, alcohol and substance abuse:

A couple of participants felt that excessive alcohol use can potentially cause dementia, with one caregiver stating that their loved one's memory loss was due to Alcohol withdrawal. Another participant thought that the additives and chemicals in processed foods could potentially cause Alzheimer's.

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
- Confused
- Seniors moment
- Getting old
- Losing it
- Reverting to childhood
- Sickness of the mind
- Memory loss

Some participants mentioned that people do not generally say the words Alzheimer's disease or dementia unless they were joking.

I2: I am not sure you hear a few of them talking and they find it as a joke oh yeah he has Alzheimer's eh they ah I don't know if they just don't wanna say they have it or they they make jokes about it eh (chuckles). (Focus Group AK01)

A couple of other participants stated that the words Alzheimer's and dementia are not used. People may talk about memory loss or being forgetful, but they do not use the terms dementia or Alzheimer's.

No we don't talk about it, it's never never discussed it. (Senior AK03)

Well, I've never heard someone say "Am I demented or do I have Alzheimer's?" Um, but, ah, maybe none of us wants to say that word but talk about, I don't know if it's in a different way, um, it may not be talked about at all. (Physician KJ01)

 WORDS FOR DEMENTIA IN THE LANGUAGE

Some 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. Some participants did share Ojibway words and their respective meanings that may be used to describe dementia:

Aboriginal word	English translation
<i>kai gwek zhaa yaa sii;</i>	"not right in the head"
<i>aaz wen dom</i>	Thoughts are mixed up
<i>menoshesidedum</i>	Worried (about memory loss)
nin mow zi win	Forgetfulness
ki je-ga ba goi ya gen maa ziin	Couldn't remember anyone afterwards
<i>zhi gaa dom</i>	Confused
<i>gii o den dom</i>	Confused
<i>o-ni-de-ma</i>	Forgetful
<i>o-nin-maa-shke</i>	Forgetfulness
<i>ah aah-sas-de-ba</i>	Something wrong in the head
<i>be-go-na-ap-be-noo-ge-ing-en-sha-kat</i>	Second childhood

DEMENTIA SYMPTOMS

When caregivers, individuals with dementia, and seniors in Sudbury were asked to describe the dementia symptoms they most commonly experienced, they fell into three categories: mental, emotional, and physical symptoms.

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, among other things.

We would have a wood stove and she would put a wood in and forget to close the stove itself. Yeah it was getting really dangerous for her to live alone. (Caregiver AK05)

Ah yeah she had a um loss of memory forgetting where she put stuff where she had ah for one example I could give you one good example is when she had taken the money and put it in the dryer and I didn't realize she had taken this money and put it in the dryer it was all crumpled up she must of thought it was ah sock or something to dry I don't know and it was in the dryer and I um when I took the clothes out then I noticed this bundle of money was all squinched up and I said T----- how come this ah it was \$60.00 all squinched up in the dryer oh she then it hit her at the beginning she it came back to her she said oh don't tell my husband and I said okay ah what that's unusual for me to find money in the dryer. (Caregiver AK02)

Several participants shared that their loved ones would become disorientated and confused and would lose their sense of direction, not knowing where they were or how they got there. A couple of caregivers stated that they could not let their loved ones walk around by themselves out of fear that they would not be able to find their way back.

In addition to disorientation and confusion in regards to location and directions, some caregivers also shared that their loved ones at times would become confused and not know what day or time it was. This could be particularly dangerous for people who are left in charge of their own medications. One caregiver shared that their loved one would often over medicate themselves because they didn't remember taking their medication earlier on during the day.

sometimes she'll over medicate herself or before we knew that her memory the doctor say well just give her that prescription and I'll say well we can't find the pills so she sometimes she wouldn't remember so she must of took twice two or three times that's another that's a dangerous sign somebody has to give them their medication then she gets mad oh I didn't get my medication yet today cause she doesn't remember eh and she would get really mad then you have to pretend you are giving her something else. (Caregiver AK05)

Both participants with dementia mentioned that they experienced certain symptoms related to dementia, such as forgetfulness. They both also stated that they experienced visual hallucinations, while one participant experienced both visual and auditory hallucinations.

Obsessive compulsive behaviour, along with short term memory loss were additional symptoms that were brought forth in the research. Some participants shared that people they knew with dementia or their loved ones would be able to share stories of their past without any difficulty, but would have troubles remembering more recent events and people. This can be very traumatic and dangerous for individuals with dementia who fallen and broken a limb.

She broke her wrist um if you got a memory thing you're not going to remember things they so she had surgery so when she woke up her whole arm they had froze it and it sorta took out maybe about 24 hours for that freezing to come out well if you got that and you wake up and you don't even remember why you're in the hospital like they should actually kept her there instead of making her wake up us dressing her take her out and bring her back the next day again um like she said what's wrong with my arm and what she ended up doing is she ended up taking if they put a temporary cast on her and she probably had what do you call those in her wrist like um pins she took that thing off at home cause she didn't know what the heck was she didn't know what she was doing she didn't know that her arm was broke. (Caregiver AK03)

Some of the symptoms brought forth, 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.

EMOTIONAL SYMPTOMS

Living with dementia or caring for a person with dementia can produce a wide range of emotions. Many of the emotional symptoms that were brought forth in the interviews included mood swings, anger, along with depression, fear, frustration, and to a certain degree denial. A couple of caregivers stated that for the most part their loved ones were happy, but at certain times they did go through mood swings and would become angry. Participants in the focus group shared an example of a person who was in a more advanced stage of dementia and the aggression and mood swings they experienced.

but I seen like when he was starting to get aggressive and violent even you know cause he didn't know he thought it was somebody that was coming at him and or somebody coming into his home you know or didn't even recognize his wife sometimes and wondering who is that stranger was in his home and that started really fast like it progressed really fast. (Focus Group AK01)

Frustration over loss of memory and lack of control was also brought forth in the interviews. One senior shared a story of a relative that had dementia and how frustrated and angry they were over being put into a long term care facility.

I just remember I had to answer the phone some place and he was really upset that he was being treated like that he didn't want to be in the old age home, he didn't know anybody there you know like everything it's just like a little kid that you take out of a foster home and put him in another place like you know they are just totally in shock and I found that's how he was that's probably where he is developmentally. Yeah and his daughters felt bad that they didn't know how to help him, he was just furious speaking in the language – he got so upset and angry speaking in English – and he is usually a very mild mannered guy and he was just phoning everybody, I heard they had to stop taking his calls at the health centre because he was just trying to get out of there anyway he could (Senior AK03)

One person with dementia had the opposite reaction and commented that they did not get upset anymore and felt that they were incapable of anger and frustration, that it was all gone.

yeah I am much calmer and I don't get upset easily I get upset sometimes like you know when you get mad there's none of that in my head now I think it's all burnt out. (Person with Dementia AK02)

Other emotions that came forth in the interviews included paranoia and withdrawal. One caregiver stated that their loved one was constantly afraid that someone was going to break into their house, or steal something from them. Another caregiver spoke of how their loved one with dementia started to withdraw from work and social activities. In one case this withdrawal may have been linked to increase sensitivity to noise and in another case to the person's inability to remember how to sew or where to begin working on a certain craft.

In working with many different people with dementia and their family members, the physician specialist shared what they saw as some of the initial signs and symptoms of dementia and stated that apathy is a common symptom of dementia. For people who are withdrawing from activities that they used to enjoy it, it may be a strong indication that something may be wrong.

It's often the first symptom of dementia, apathy. Often the very first, it's the most common very first symptom. More common than depression, and the first sign of dementia is sometimes only that people are giving up activities they previously did, not necessarily because they can't do them, but they're less interested and motivated to do them. So that's one of my key questions when I'm doing an assessment, is there things you've given up in the last few years that you used to do. (Physician Specialist KJ02)

PHYSICAL SYMPTOMS

Physical symptoms experienced by those interviewed included dizziness, mobility issues, difficulty eating, aphasia, as well as a decline in fine motor skills, along with a general decline in appearance and personal hygiene.

One caregiver shared that their loved one would get dizzy spells quite often and would need to take medication in order to stop the dizziness. One person with dementia also stated that they were fainting a lot and thought that it might have something to do with having Alzheimer's as their doctor could not find any other medical explanation as to why it was happening.

In more than one case difficulty eating was reported. One caregiver stated that their loved one had trouble swallowing, while another caregiver stated that their loved one would sometimes forget to eat altogether. Other physical symptoms brought forward included difficulty seeing, hearing and comprehending certain issues, as well as loss of muscle control.

A couple of participants shared that their loved ones had a difficult time processing speech (aphasia). One person with dementia shared that they were also having a hard time finding the right word to use in speaking with others.

um there's a lot of times you know you're talking away you know what you're talking about and you know the words as you go tell your story or something you forget the the word because you want to say it again use that word again. (Person with Dementia AK02)

Participants also discussed other symptoms such as the decline in personal hygiene and physical appearance, as well as a decline in fine motor skills, specifically hand eye coordination.

I guess that's probably when I realized that her mind was really cause she use to make a lot of crafts and I'm the one that use to pack them and one time I remembered that guy called me after I sent those crafts I didn't really look at them Speaking in the language/English – I didn't even look at the crafts I just packed them, he said did you take a look at your mom's crafts I said no, so he sent them back, they were getting pretty poor looking. (Caregiver AK05)

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 SUDBURY

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 words "Alzheimer's disease" and dementia to describe the illness of their loved one. One participant was diagnosed with Alzheimer's, while only one caregiver stated that their loved one had a diagnosis of Alzheimer's.

They said I'm about in the middle [stage of Alzheimer's]. What ever that means, in the middle, ha but I don't believe him. I don't believe I'm in the middle cause I been doing so good. Yeah my daughter don't even believe that I am now I have Alzheimer's (chuckles). (Person with Dementia AK02)

Alzheimer's they said Alzheimer's and then they said it part of our old age she was 82 when she passed away but once she went into the Nursing home that was it her brain was she didn't even know us the last two years of her life all the kids she didn't know at all. (Caregiver AK05)

Another caregiver stated that they were told by the nurse that their loved one had dementia, but did not have any medical files to confirm the actual diagnosis.

She was diagnosed on the Reserve and I'm just having, it is a huge challenge getting the ah getting the ah actual files, like her files so I know what it is. I just have a verbal from the nurse I don't have nothing written. (Caregiver AK01)

ASSESSMENT

Arriving at an Alzheimer's disease or dementia diagnosis can take a number of different steps, from general physicians or family doctors talking with the family, giving a memory test, or cognitive assessment, to taking blood tests, imaging scans, as well as referral to a specialist. For some of the Sudbury participants, a dementia assessment usually occurred when the person who was experiencing memory loss or confusion (or their loved one) approached their family physician.

In discussing their assessment, one participant with dementia stated that they were given a test where they had to answer a couple of questions and draw a box. They remembered being given five questions and they failed all of them. They also recalled not being able to properly draw a box and that it was all crooked. Near the end of the appointment the participant stated that their doctor prescribed some pills and referred them to a specialist for further testing. The tests came back stating that the participant's "brain was shrinking" and a diagnosis of Alzheimer's was given.

Another participant shared that their loved one was taken for testing but they did not know the full extent of what was asked or what types of tests were used.

Well that's where they brought her to Sudbury for testing I think they brought her twice here. Nursing Home did [ordered the testing] Yeah my sister came for a ride with her, it was because of the on going headaches to the point of passing out that's why they brought her, so that's probably why they ordered for more testing. X-rays I guess I don't really know my sister just said testing, they just came for testing. Oh what their memory was, I doubt it it was probably just machines she was probably already too far gone by that time like once they found out yeah.
(Caregiver AK05)

Preliminary tests, such as blood work, CT scans, and mini-mental tests can be used to help the family physician decide if a more formal assessment needs to be conducted or if the patient should be referred to a specialist. Both the physician and geriatric physician specialist stated that there are no set guidelines in screening seniors for cognitive decline. The geriatric physician specialist did however recommend an informal cognitive assessment for all adults over the age of 75.

In cases where the family physician was not quite sure of a diagnosis or treatment plan, they would most likely refer the patient to a specialist, including a neurologist or a geriatric specialist. Specialist care may also be recommended for the following: when there is a lack of resources in the family physician's practice to assess and treat dementia; complex cases of dementia or Alzheimer's; physicians or family members looking for a second opinion; as well as family physicians who may not be comfortable in dealing with more advanced cases of Alzheimer's or dementia.

In explaining the assessment process in a specialist's clinic, the geriatric physician specialist outlined that they have a team consisting of nurses, nurse practitioners, an occupational therapist and a physical therapist to do a comprehensive assessment. The physician specialist also stated that they do send people for a CT scan if necessary, but notes that it is not always necessary, especially if the person has all other indicators of Alzheimer's disease or other related dementias. When asked about the use of MRI's in diagnosing Alzheimer's and dementia, the physician specialist stated that they would be interested in the updated recommendations to see if MRIs will be mentioned in the Canadian consensus guidelines. They further noted that an MRI will pick up more than a CT scan and gave the following example:

I've had people who had quite normal CTs and then when they went to do the MRI it was chock-full of white matter disease. (Physician Specialist KJ02)

MISDIAGNOSED DEMENTIA

A couple of participants felt that they or their loved one was misdiagnosed. One caregiver shared that their loved one was given a diagnosis of Alzheimer's, but were told after their loved one passed that they actually had dementia and not Alzheimer's. This led the caregiver to question the treatment plan and whether the correct medication was given or not.

All this time we thought it was Alzheimer's we didn't know cause we didn't find out till she had dementia after she passed away that's when they told us they called us in the office after way after to tell us my mom had dementia that's when that doctor showed us all those little black spots on those test so I don't know if she was on the right medication all this time. (Caregiver AK05)

One person with Alzheimer's shared that they were first diagnosed with dementia, but after the assessment, the diagnosis was changed to Alzheimer's. This person stated that they would like a follow up test, including a MRI and additional questions to see where they are at. They also felt that the mini-mental test was not a good indicator of cognitive decline.

Yeah I would like to see just how am I doing from the first test you know the test I was telling you the memory test I guess you call it and um yeah they should of asked me more questions and get some x-rays MRI x-rays to see how I am doing there to see how far off I'm gone. I don't think you can tell by a written paper a written statements there. (Person with dementia AK02)

UNDIAGNOSED DEMENTIA

A couple of participants shared their concerns about their memory loss with their family physician only to be brushed off. One participant stated that their doctor told them that forgetfulness was normal at their age and the other participant was told that they think too much and that's why they were forgetting things.

I told this to my doctor and she tells me oh we all forget, you know, but I said I know the difference. I can, I can. I know the difference between when I was younger you know, we always forget things like that but I notice the difference and ah forgetting ah I am so worried about that cause ah about forgetting things. (Senior AK02)

Um yeah that's what he told me [the doctor], don't think about it too much. I, "we know you." (Research asks about having a memory test) No not really. He just asked me the reason that I think too much back with the memories that's what he said. (Person with Dementia AK01)

Misdiagnosis and undiagnosed cases are likely partially attributable to access to physician services and continuity of care. And, under many provincial billing models physicians may only have 10 minutes allocated to patient visits which is not enough time to fully assess a patient for

many illnesses including dementia. Often, dementia is not what brings a person to the physician's office as we have learned Aboriginal people with dementia are often dealing with other serious illnesses concurrently. As one physician states, they may "*miss the subtleties of early dementia, because it's not that sort of strong impact of what brings people to the office*" (Physician KJ01). This of course may speak to a greater need for more physicians and physician training for Alzheimer's and dementia. This will be looked at later on.

CULTURALLY RELEVANT ASSESSMENT

Diagnosis of dementia is never straight forward. Aboriginal people have the added complexities around language, communication, trust, and cultural issues that must be overcome in order to properly diagnosis dementia. On participant felt that her doctor should have asked a different set of questions, more specifically, "*why do you think that there's something in your head that something is wrong.*" (Person with Dementia AK01)

Aboriginal people are also more likely to be affected by socio-economic hardships and historical trauma which also need to be considered during an assessment. This requires time to develop trust and an understanding of the person's history and circumstances. The physician we spoke with gave an example of why the mini mental test was not an appropriate assessment tool for all people and stressed that the mini mental test should not be used a final determinant of dementia.

Well, I just administered the Mini-Mental Status, I mean, this is so perfect right? I just administered it on Wednesday to this fellow who scored 11 out of 30. He has been in decline, and you know he's one of the people that's tipping into and then waiting lists and everything. But um, I mean, I've known him over years, I know he lived on the streets in Toronto, his education level is [pause], he says himself, he can't write a sentence. So, I'm going through the Mini-Mental Status and I know that, but he, he did amazingly well on spelling wor, world backwards though, you know. (Physician KJ01)

So, I, I'm 100% with you that I think that there's, there's some things that where there's, where there's culturally-based or just, um, context of the education of people. Whether it really tests what their skills are. I mean, I know he's in decline, but um, it wasn't really a, a fine test. You know? (Physician KJ01)

TREATMENT AND CARE-GIVING

TREATMENT

The Sudbury participants were asked to discuss the different approaches used in the treatment of dementia, specifically around Western / biomedical medicine and Traditional / Indigenous medicines. The physician and physician specialist discussed western medical treatment plans, stating that patients and their caregivers needed a treatment plan, medication recommendations, and support for caregivers. Participants with dementia discussed spiritual teachings to treat dementia symptoms, but did not know of any traditional medicines that were used in the comprehensive treatment of dementia or Alzheimer's.

WESTERN MEDICINE

Following the assessment and diagnosis, the geriatric physician specialist discussed how their team approached treatment plans with the patient, the caregiver, and other involved parties, such as health services on reserve, and the family doctor, if they have the staff and resources to work through the recommendations presented. Treatment plans included a case conference between the Community Care Access Centre (CCAC) and the caregiver or person with dementia to set up homecare services; medication recommendations, as well as general support for the caregiver.

In addition to setting up a treatment plan, the specialist also talked about medications that are used to help manage the symptoms associated with Alzheimer's and dementia. When asked what medications were covered, the specialist named three different medications that were covered by both the Ontario Drug Benefit Formulary, for people who do not have status under the Indian Act, and under the Non Insured Health Benefits (NIHB), for First Nations people who do have status. These three medications include Donepezil, Galantamine, and Rivastigmine. The physician specialist tried to prescribe Memantine, for more moderate stages of Alzheimer's, but found that it was neither covered by the province or NIHB, even after writing letters of support for the medication to be approved and used.

One of the arguments surrounding certain medications not being covered may have to deal with the fact that there are no guarantees that the medication that is prescribed is even taken, especially if the person is experiencing more moderate to advanced symptoms of Alzheimer's or dementia. One physician gave an example of a patient who was in the more moderate to advanced stages of dementia and had no consistent long term support, aside from the personal care worker who came by with their medications.

The physician stated that the medication was delivered to the home regardless if the patient was there. So, there was no way to ensure that the patient was taking their medication.

The geriatric physician specialist believed that they had greater success with ensuring that their patients complied with taking their medications. Part of the belief came from the fact that the patients she served were actively seeking medical help and so were committed to treatment. The specialist also stated that they spent a significant amount of time explaining the diagnosis, why the medications were being prescribed, what the side effects were and how they may help.

Having a treatment plan, including the appropriate medications may help a person manage their symptoms a bit better. The focus group felt that an early diagnosis, along with a proper medication could have made big difference in one client's life.

Yeah depending on how early you get um medication for it so if this person got medication for Alzheimer's when the caregiver or wife noticed changes then maybe medication would have been given earlier then he might of lasted a little bit longer but after a while like the second year he didn't even know who you were. (Focus Group AK01)

A couple of participants mentioned that they or their loved ones were prescribed certain medications to help with symptoms associated with memory loss. For one participant with dementia, the medication calmed them down even more.

TRADITIONAL MEDICINE

When asked if participants knew of or took part in traditional healing treatments for dementia, many of the seniors, caregivers, and people with dementia said no. Upon further inquiry, both participants with dementia stated that they used spiritual treatments for their dementia symptoms. The one participant with dementia stated that their audio and visual hallucinations seemed to stop after her daughter came and smudged her place. The other person with dementia stated that they often see visitors who have passed on, and while it did not bother her, she used prayer to get them to subside. She further stated that after her husband passed away she went to see her minister as she could still see her husband's spirit in the walking around the house.

you can see him walking in the house, (inaudible) didn't tell me, well I see what happen I said, he's gone, how long it takes, it's not real and I ah talk to minister, he you did not leave you yet he said, should start to go to Church he says and ask God to forgive you rest good, try and have some peace have some God looks after that yeah it was very hard. (Person with dementia AK01)

One caregiver stated that their loved one was taking a combination of traditional medicines for more general health and western medications prior to moving in with them, but that was stopped after they moved in with the caregiver to ensure that there were no adverse complications from mixing any of the medications with traditional medicines.

Another caregiver stated that traditional medicine and spirituality were not something that their loved one followed.

We weren't brought up traditionally eh um so that wouldn't be I don't think that would be an area that she would seek even if like in the beginning to go and see somebody. I don't think she was against it because she used to always talk about people that would go for that and she said no for treatment but if you are going to see a healer for whatever you have to believe in it so I don't think it was ah something that she was been involved in the traditional. (Caregiver AK03)

When asked straight out if participants knew of any specific traditional healing or medicines used in the treatment of Alzheimer's or dementia, they all replied no, they did not know of any specific treatments or medicines used to treat dementia or Alzheimer's. The focus group however, suggested that perhaps these teachings do exist, and that the researchers were not asking the right questions or using the right words to get at that information.

I2: they need clarification on what Alzheimer's is maybe clarification on what Alzheimer's is and what is dementia ah in the language or something I'm not even sure it's; I1: or even how they dealt with it I don't know. Like is there medicine for that like you know; I2: yeah like back then if say they are probably calling it forgetful if they have something to drink to help your mind remember again; I1: or if there was or if there was or if this was like is this something new like or we never heard of it you know. (Focus Group AK01)



CARE-GIVING

WHO PROVIDES CARE?

The caregivers in this study included adult children, a spouse, as well as a close family friend. All five caregivers interviewed were women. Participants with dementia were cared for by adult children and most of the seniors lived independently with minimal help from spouses and adult children. 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 cultural values. One of the caregivers, along with a senior commented that providing care for their family and for more elderly people is something that is expected of them in the culture, *“that we care for, you know, our elders, for me that’s just a given.* (Caregiver AK01)

Additional reasons, such as love and familial obligations, as well as a desire to have their loved ones be comfortable and well taken care of also played a role as to why families would care for a loved one with Alzheimer’s or dementia.

but for me I never once ah um say well I could of said no when her husband asked me to go and look after her. I could of say no but I went. I went because I knew her, not only because I knew her, it was just something I wanted to do just to be here like for to be there for her cause she needed somebody that was she enjoyed being having company with. (Caregiver AK02)

While most caregivers shared that they wanted to take care of their loved one at home for as long as possible, they also acknowledged that there may come a time when their loved one will need around the clock care and they will need to put them in a long term care facility. One caregiver stated that they tried to take care of their loved one at home and would switch off with other family members on weekends or holidays, but it soon became too much for all of the family members involved. Another caregiver understood and accepted that they will have to put their loved one into a long term care facility once their mobility starts to deteriorate, if not before then. They also commented that Alzheimer’s is a progressive disease and that they will not be able to stop it.

EXPERIENCES WITH CARE-GIVING

Care-giving tasks

Care-giving tasks were dependent on the stage of dementia the person was in. Care-giving tasks ranged from participants helping their loved one with household chores, maintaining the household, including paying bills, getting around town, communicating with doctors at appointments, cooking meals, to helping them with more complex tasks such as managing medications, as well as safety.

When I went just go there to look after her I was there four hours and then he'd come back and sometimes he was gone five and I will be a little bit late but I would be here and then all the time her and I got along really well and I stayed right with her and stayed right with her and made sure that when we went for walks we would come back and I would make her lunch and I would help her read and then she would rest ah maybe for half hour then she would be up again. (Caregiver AK02)

Managing medications and ensuring that their loved ones took their medications at the right time was another task that caregivers were responsible for. People in more advanced stages of dementia also needed additional help with grooming practices, bathing, getting dressed, and at times eating. Safety was a key priority for caregivers, especially since many of them expressed concern about their loved one wandering off.

Even when she first ah lost her license at the beginning stages she still wanted to take off without drive and we would have to say no mommy you can't go take the car, and she would say well it's my truck ah give me the keys (chuckles). It was very hard. It's not so bad at the end but the beginning stages it's.. We are telling her not to put too much wood in the stove she would just keep filling that stove the wood stove and I think she just agitates herself too that's what I mean just. Then walk around at night that's hard too. One family member has to pretend their sleeping which their not cause you have to watch her not to go outside the door or do something yeah. Yeah yeah it was and it's vey hard to put your ah mom or dad at the Nursing home too yeah. (Caregiver AK05)

Challenges

There were many challenges related to care that were talked about by all participants. One of the biggest challenges that were brought forward by the caregivers was seeing their loved one slowly slipping away and forgetting everything.

It's very hard cause we were all very emotionally drained I think. Sometimes I would see my sisters crying going out the door or me or somebody. (Caregiver AK05)

I find it's a slowly progressive disease it can be very ah it hurts you to see your friend going like that you know. (Caregiver AK02)

Another challenge that was frequently brought up by caregivers revolves around the lack of knowledge about dementia and the frustration expressed by family members when their loved one starts having memory issues or exhibiting certain behaviours. Being aware of the symptoms associated with dementia can go a long way in helping caregivers understand a bit more of what their loved one is going through.

I guess in the beginning just where you're not, when you don't have the patience with them and you end up arguing that's the only thing that comes to my mind. In the beginning when you're not patient and not understanding it the way you should, you know it's not her fault why she is acting like that kind of a thing. (Caregiver AK03)

Not having the all the medical records or information on their loved one was another challenge that was brought up by one of the caregivers. The caregiver wanted to get the health records so that they could access the appropriate services needed in order to take care of their loved one.

I just emailed again the nurse to say this is what I need, things are coming up and I want to get specialist in place. I'm thinking I don't even know what happened to her heart. I just know she has medication, you know. You're asking her about what's your diagnosis... all I know is that it is dementia, but there is some more than this and surely the doctor would be able to ah. (Caregiver AK01)

This particular caregiver faced some additional challenges, including anger and resentment around broken parental bonds due to colonial policies such as the 60s scoop. The caregiver explained that she was not raised by her mother and any contact between them was quite limited to phone calls and visits a couple of times a year. This meant that the traditional bonds between a parent and child were not in place and when the community nurse phoned the caregiver to explain that her mother could no longer live by herself and that she expressed a desire to live with her daughter. The caregiver stated that they felt an obligation to help and that even though there was an obligation to help, there were also some unresolved feelings and underlying resentment around why their mother was not there when they needed them.

So that attachment when I asked her for help so she hasn't had she hasn't experienced raising children but you know I was really hurt when she turned when she said no I will not come and help you you know no I can't ah maybe maybe I'll come and help you but it was always us she wanted us to move there and help her so the expectation was you know this is a really unfair expectation and so that anger resentment part comes from that you know what I asked you twice to help me and you turned me down and now you want me to be here for you and so I've had to come to terms of that as well. (Caregiver AK01)

This caregiver also had children in the home as well as worked fulltime outside of the home. In addition to taking care of her mother with dementia, she also needed to take care of her

children, deal with any questions or animosity that they were exhibiting due to their grandparent coming to live with them, as well as try to take time for self care.

The challenges, the challenges are huge, I'm constantly worrying ah you know if she's okay, you know trying to find the time to get services in because I work ah that's a huge challenge, I'm trying to make time to be here or I'm have someone here, one of my kids you know one of the teenager's who'll try and be here when I am not able to be here, I'm doing a lot of working from home right now which is hard, another challenge is that I don't have any down time, I am use to having down time and I'm not having any down time now and my children are at the point now that they can cook, they can look after themselves and even do laundry and so I am back now to having to do that for somebody else you know remembering pills, remembering to give her medication is ah is another thing because my children are no longer needy or even if they have medication they do it on their own where no I am having to, so the strain of constantly having to remember to be in that caregiver role is huge for me, it's huge. (Caregiver AK01)

Other challenges brought up by participants included a lack of culturally appropriate respite care. Many of the participants stressed that respite care is needed for caregivers to take the time to take care of themselves.

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 include improved relationships between the caregiver and the person with dementia, reuniting family, keeping loved one's with dementia at home or with family, seeing the person with dementia improve, as well as seeing the positive impacts one's care has on the person with dementia.

And the rewards, I think the rewards are you know trying to rebuild a relationship when seeing it slowly coming together, for myself and her, because you know it was a disrupted attachment I was three when I left and so as a mother would still have memories, my memory of her as a mother was repl... and I attached myself to another mother and so that relearning our roles or coming to terms with it, there's a reward in that. The simple joys like watching her do a puzzle, you know those simple things that she can do and see the little things, where will she fold the laundry or I'll walk in having been at the store I walk in and she had picked the broom and start sweeping so those little things where I've seen that she had taken what I had said and incorporated into a daily routine. So there's improvement that's the reward. (Caregiver AK01)

I didn't look for any rewards to me it was looking after a person that needed the be looked after for me that was ah that was my reward is that I enjoyed doing it to make them happy and to be caring and loving in a way to make them be themselves to try and treat them as a normal human being. (Caregiver AK02)

COMMUNITY AND MEDICAL HEALTH SERVICES

As an urban centre, Sudbury has a wide range of services in the community including hospitals, health care centres, long term care facilities, home care services and respite support, as well as additional programs aimed at helping people with dementia and their caregivers. Almost every participant talked about the N'Swakamok Native Friendship Centre and the services offered there, especially the Life Long care program.

I do know that the Lifelong Care program for the seniors that are ambulatory, they really appreciate it, you know, the services they have at the centre and also the help with transportation. Yeah. And that's been quite vital to people. (Physician KJ01)

The Life Long Care program at the Friendship Centre provides support services, translation services, accompanies clients to doctors' appointments if requested, as well as providing transportation to clients so they can access these services, along with getting to their appointments. A couple of caregivers shared that the program helped in making sure that their loved ones had all the necessary services in place to make sure they were safe and well taken care of. For example, one caregiver shared that Life Long Care made sure that someone came by to visit and give their loved one communion, while another caregiver stated that a homecare worker came and gave their loved one a bath twice a week.

Focus group participants also stated that people from the Friendship Centre will even go to the hospital to visit with Aboriginal patients who have been admitted. This can be a great service for people who are from more remote communities and don't have any family members with them, or for people who feel more comfortable speaking in their language with a friendly face.

Some of the nurses know know of the Friendship Centre and they know that there is a Native person there and they think that um because they are not having no visitors from up north somewhere then they call the Friendship Centre saying can somebody come and visit maybe you know yeah . (Focus Group AK01)

The Friendship centre also provides additional services and programming, such as sewing circles, drumming, exercise classes, as well as hosting workshops and seminars on various topics. One senior appreciated the fact that the Friendship centre runs programming in the evening for people who work during the day.

We get forgotten even at the older adult centre everything is in the daytime so you can't participate in the exercises in the evening, but at least at the Friendship Centre they are offering that in the evening the yoga and the tai-chi which is nice but nobody not enough people are going. (Senior AK03)

Some of the participants talked about the services located on the reserve where their loved one lived and how services differed between urban and rural areas. One participant stated that accessing services on reserve was easier in that the person simply needed to go to the nursing station or speak with the community nurse, whereas in an urban setting they have to reach out to more places in order to access the appropriate services. One participant, who's loved one utilized the services and supports available in Wikwemikong Unceded Indian Reserve, stated that Wikwemikong has a health centre, along with a senior citizens drop in centre, a nursing home, home care services, and many other services and supports to help them care for their loved one.

For the most part participants, who moved to Sudbury because of deteriorating health, did so because they could no longer live by themselves. When faced with moving to a long term care centre far away from their community or living with a family member in Sudbury, they went to Sudbury. While Sudbury has a wide range of medical services, some participants expressed frustration over needing to go to different locations in order to access services and would rather access services on reserve if distance allowed for it, where they would only have to go to one location.

Participants in the Sudbury area have access to a variety of specialists, including a geriatrician. According to the geriatric physician specialist, before their team recently came together, there was never a geriatrician, let alone a comprehensive geriatric services division, in North Eastern Ontario. The North East Specialized Geriatric Services serves a large portion of northeastern Ontario and takes a team approach incorporating a physiotherapist, occupational therapist, a social worker, a program educational coordinator, a program manager, administrative staff and a couple of nurses and nurse practitioners, along with the geriatrician.

Given the size of the area that needs to be covered, the physician specialist utilizes telemedicine, in addition to traveling to various areas. Due to the geographic size and the demand, there is limited access to those that are further away and more remote. The specialist also shared that they are at capacity and have not reached out to some of the other communities.

SERVICE NEEDS AND RECOMMENDATIONS

Participants had many suggestions that they felt would be helpful for the care of the person with dementia or for the caregiver. Many participants expressed a need for more information about Alzheimer's disease and other related dementias. One senior expressed that they did not know the difference between Alzheimer's and dementia and wanted to find out more information. A couple of other participants who sought out information from the Alzheimer's Society stated that it was helpful for them, but some participants shared that they did not have

the time or perhaps were not ready to go and learn more. One caregiver also called for all health care workers to have the appropriate training to work with dementia patients, including family physicians to have the appropriate training to properly assess for Alzheimer's and dementia, as a couple of people with memory loss were thought to be misdiagnosed and / or undiagnosed.

Focus group participants shared that the Alzheimer's Society came to the Friendship Centre to give a presentation, but had a hard time keeping people engaged with many people leaving after they finished eating and before the presentation was over. Even with all the information that exists about Alzheimer's and dementia, the physician specialist brought up a very good point in stating that we don't do a good job of educating people about dementia.

I think we do a very bad job of educating people around apathy and dementia as a rule, because no one talks about it and it's one of the most frustrating things for caregivers, um, but that's in that particular cultural context I do find it more difficult I think. (Physician KJ02)

This lack of quality education surrounding dementia can lead to the following questions and actions that participants in the focus group brought up:

I1: yeah and does everybody get it you know as you get older does everybody get Alzheimer's or it is just like there's a lot of information that's not put out there to them so they wouldn't know what it is yeah; I2: when you say disease they sort of step back I don't want that they treat like it's almost catchy. (Focus Group AK01)

Having little to no knowledge of the signs and symptoms associated with dementia can lead to many challenges for the person who is living with the condition and their caregivers. Part of the message that physicians and focus group participants wanted to get across is that any changes in the person's health or personality should be brought to the attention of their family doctor. In bringing to the attention of the family physician, the person can get assessed and get more information on what supports are available to them. The physician specialist shared a story of a patient who had no support system in place and was kicked out of her home because the family either did not understand the signs or symptoms associated with Alzheimer's or dementia, or did not have access to supports to help them help their loved one.

she's a real tough assess because she couldn't communicate with us um, and we couldn't find family anywhere, so we had to piece it together by calling family members um, to kind of piece together the story but yeah it was a much different story than the others I've had. She didn't show up with the support of family who were trying to help her and understand, uh, she had been, like it sounded as though when she started to dement, people shunned her and, or didn't understand that that was happening and had kicked her out. (Physician Specialist KJ02)

Some of the suggestions and recommendations that were made to address the lack of knowledge about Alzheimer's and dementia included shorter presentations in easy to understand plain language or even in the Aboriginal language with the use of a translator. The focus group also recommended presenting the material in a different way, such as having a group coming in to perform a play about Alzheimer's and dementia and having a question period after the play for audience members. They also suggested creating videos about Alzheimer's and dementia in the Aboriginal language, as well as making the pamphlets more approachable and culturally relevant. One senior stated that they didn't "do computers," and would rather someone phone and leave a message or mail out information to her.

One caregiver suggested building a network where communities can come together and exchange ideas and information around best practices. This can be done through symposiums, mini conferences, or even online social media groups or support groups for the communities in Northeastern Ontario. One senior commented that they would like a tour of an Alzheimer's ward to see how it was set up. They felt that by having a tour of the facility, including the services and activities offered may reduce some of the stigma associated with having to go into a nursing home or access dementia care.

Another senior recommended that communities come up with a plan to help the elderly who have dementia. One of the physicians went even further and recommended that the different agencies need to communicate better in exchanging information. They also recommended that family members plan ahead, ideally with their loved one, about long term care plans.

I do think there is the, the need for agencies whether their, you know, Aboriginal agencies talking to each other a little better and or. Or the agencies of care getting some, you know, if the work you're doing will create, some sort of tool of, for one thing perhaps more appropriate screening tools but access to care and the need to um, talk among family members in terms of future decision-making. And, and um, you know, and this isn't future decision-making about life-or-death circumstances, this is future decision-making, you know, when the person isn't competent and what is the best housing situation. For them and, you know, because there can be, does this person have a First Nations where they may have um, you know facilities for the elderly on reserve compared to staying in home. You just, as a care provider, we need to know who is the substitute decision-maker for that person. (Physician KJ01)

The geriatric physician specialist also spoke about the importance of families having the discussion around long term care plans earlier on, especially establishing who the decision maker is, as well as decisions and wishes around end of life care.

It's, it's really critical as people in the early stages of dementia when they still have the capacity to decide that all that power of attorney and decision-making and, and you know, their wishes is, is discussed. And I think that's where, if anything, um, there needs to be some sort of group or

service that can do that, in that sort of, in the milieu of the culture. Um, and, and also the pragmatic sense of how do you actually go about doing it? Because, certainly that I think has been one of the biggest challenges for me. If I don't know who is actually the primary, you know, alternative decision-maker when, when things come to a point where the capacity may be in question. And, quite often that hasn't been decided. (Physician KJ02)

A couple of participants talked about preventative health services and how they need to be better advertised to get to some of the harder to reach population. One senior stated that many of the preventative health services are aimed at the middle class, and people who already know how to help themselves. They felt that more accessible and affordable transportation could help get more people out to access these programs. The physician also commented on a similar experience of people not knowing where to access certain services or even knowing what services exists. For Aboriginal people who are relatively new to Sudbury and are not connected with the Friendship centre, knowing where to look or what they can access can be difficult without an advocate. First Nations people who have status will have to deal with additional jurisdictional issues and figuring out what services they are eligible for. The geriatric physician specialist spoke about some of the challenges around making sure that people who are more transient are able to receive consistent care.

And, maybe I'll just say First Nations in terms of [pause] um, jurisdictional issues around um, you know when they have an affiliation with a First Nation but maybe live in an urban setting. And, so, you know, what service bundle do they fit under? I think um, so when I do think of the one patient who lived by herself in the city but seemed to go back and forth in the early stages, she would get rides to her First Nations. It was, and stay there for a period of time because some people do that in terms of having, kind of two places. It was very hard to get that, sort of, continuity of care in which sort of service branch to plug them into, if, if any. (Physician Specialist KJ02)

The physician specialist stated that they had limited knowledge of what services are offered on reserve and would ask patients and health care staff about the different services they can access on reserve. Since services for First Nations are paid for by the federal government, under First Nations and Inuit Health, certain gaps may exist in terms of what services are available on reserve as opposed to off reserve.

CULTURALLY APPROPRIATE APPROACHES AND CULTURALLY SAFE CARE

The study revealed a clear need for the inclusion of culturally appropriate approaches to care throughout the following areas: assessment, health promotion, training and education, respite services, in addition to incorporating culturally appropriate spaces and programming into existing community centres, health centres and hospitals and care homes.

The need for culturally appropriate screening tools came forth in the assessment segment. Participants did not feel that the current tools and assessment measures adequately assessed their cognition. Modifying the questions, specifically the language used in asking the questions, is needed to ensure that patients understand what is being asked of them.

Making sure that the language was easy to understand and accessible was brought forth by participants in numerous areas. Participants commented that the current health promotion materials on dementia and Alzheimer's were aimed at the mainstream population and did not reach out or try to include Aboriginal people. Having information in the materials broken down into easy to understand, plain language that Aboriginal people can relate to would greatly enhance understanding and usefulness. Participants also stressed that communication between physicians and Aboriginal patients and their families needed to change.

The physician specialist commented that they have a harder time making sure that the information is fully understood by their First Nations patients indicating some issues around cross-cultural communication including non-verbal cues.

Trust of physicians and the health care system were also raised as issues often related to a lack of continuity of care, physician shortages, and billing practices limiting the time for the clinical visit. One caregiver expressed that they feel like their doctor does not have time for them and seems to rush them through the appointment. A couple of the participants also mentioned not being able to establish a trusting relationship with their family physician. Some participants stated that their family physician retired or moved and they have not been able to find a new family physician. Other participants stated that they did not like their family physician, either because they did not trust the doctor, or they did not believe the person looked like a doctor. The latter comment we believe is related to Aboriginal peoples suspicion that the government is providing them with inferior services.

so these new doctors came into the reserve and that's when they started having physicians there and that's what she said to me he doesn't even look like an doctor (laughs) so they just put up with these doctors that are there you know. (Caregiver AK03)

Um he didn't tell me what it is he told my sister I guess had a light stroke yeah. No maybe I start to get worried eh. but my sister told me anyway. [The doctor] told her not to tell me. No. Ever lie that doctor I said (laughs) next time I see him I'm going to tell him I said. Yeah cause my sister tell me she'd tell me anyway. (Person with Dementia AK01)

Just when they pulled us in the doctor said at the beginning that you have, they wouldn't say that in front of my mom, yeah. (R: what did they tell her) nothing. No they never talk to her about her disease. I don't know I should ask my sister sometimes but I never heard them say you have Alzheimer's to my mom just to us so we could understand her better I guess. (R: but nobody

told her what was happening to her) No not with me anyway never in front of her. (Caregiver AK05)

Without a trust relationship, the patient may not fully disclose their health concerns to their family physician or may stop going altogether. The emerging cultural safety literature suggests focused training for health care professionals on issues affecting Aboriginal people can improve relationships between providers and patients.

Participants commented that training on Aboriginal peoples' history and culture would help health care professionals understand the legacy of colonialism, including the impacts that it has on their patients. It was believed that this training could help health care professionals have a better understanding of why some Aboriginal patients have difficulty in communicating with authority figures; why certain patients may not thrive or even participate in mainstream programming; as well as have a better understanding of some of the intergenerational impacts on caregivers, extended family members and in some cases the entire community. For example, one caregiver spoke about the impacts of the 60s scoop on their family and recognized that while she wants to provide care for her mother, she is having difficulty reconciling her desire to care for her loved one with her underlying questions and resentment of her mother not being there when she was growing up and not helping out later on once they reconnected. Knowing the colonial history that led to policies such as the Indian Residential School system and the 60s scoop may help health care professions have a better understanding what is needed in order to provide more culturally appropriate care.

Recommendations for culturally appropriate services and culturally safe care included the need for more culturally appropriate services for Aboriginal seniors. One caregiver stated that their loved one would not do well in mainstream dementia programming and needed to be around other Aboriginal people that they could relate to, while doing culturally appropriate activities. For individuals moving from the reserve to an urban area, a certain amount of culture shock may occur and cause the person to withdrawal if they do not feel supported or like they can fit in. One senior recommended having a space where both elderly people and youth could come together interact in a mentor – mentee relationship, while sharing and meal, speak in the language, and pass on cultural teachings.

Hiring healthcare providers or support workers who spoke the Aboriginal languages used by members in the community could be helpful for seniors or people with dementia. Even having a translator accompany seniors or people with dementia to their appointments would be helpful for those who are more comfortable conversing in their language. Some of the participants commented that even though their loved one may not speak the language, they can still understand what's being said and enjoyed listening to the language being spoken.

One caregiver stressed the need for culturally appropriate respite and what it could encompass. Having someone being able to speak the language was of particular importance for her and her loved one. They also suggested a church service in the language for the elderly people who are strong Christians. Being able to have extended respite would be ideal. The following is a description of what one caregiver would like to see:

I think it would be, you know what would be nice is to have like a bungalow, it would have to be one floor but that you could book a time, you know like as you had someone there as a caregiver like a couple or whatever. Or even a small family you know just to ah, but then if you had like three bedrooms maybe that ah people could you know and it was Aboriginal people there you know that lived there and ran it. And that they could actually stay for a week and there would still be activities and they would keep up the cultural links that are established in the community you now. All that ah for me that's what I think it should look like is that respite would be like that and so that and they get use to their little room you know part of that becomes their room you know they can hang a picture that theirs so everyone who uses it could have a picture you know.
(Caregiver AK01)

In addition to having culturally appropriate respite, a couple of participants also talked about the need for culturally safe spaces in hospitals and nursing homes where Aboriginal people could go and smudge or take part in cultural ceremonies. Incorporating traditional foods and making them more appealing was another suggestion that was brought forward.

In Summary,

Participants shared their ideas about approaches to care that would better suit their culture and needs. Addressing historical trauma, communication issues, and culture shock, are a couple of areas that are needed to promote culturally safe care. Others improvements that need to be made at the level of clinical interaction include courses in cultural safety and cross cultural communication to help health care professionals have a better understanding of the colonial history, as well as be more aware of communication cues, this was especially important for physicians in order to develop a trust relationship with the patient and their caregiver. Other suggestions included improved cross-cultural communication through health care worker training and at the program level through the use of Aboriginal language and culturally appropriate activities. This information, together with the findings concerning Aboriginal peoples understandings of dementia, can further inform culturally safe dementia care for Aboriginal people in Sudbury.

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