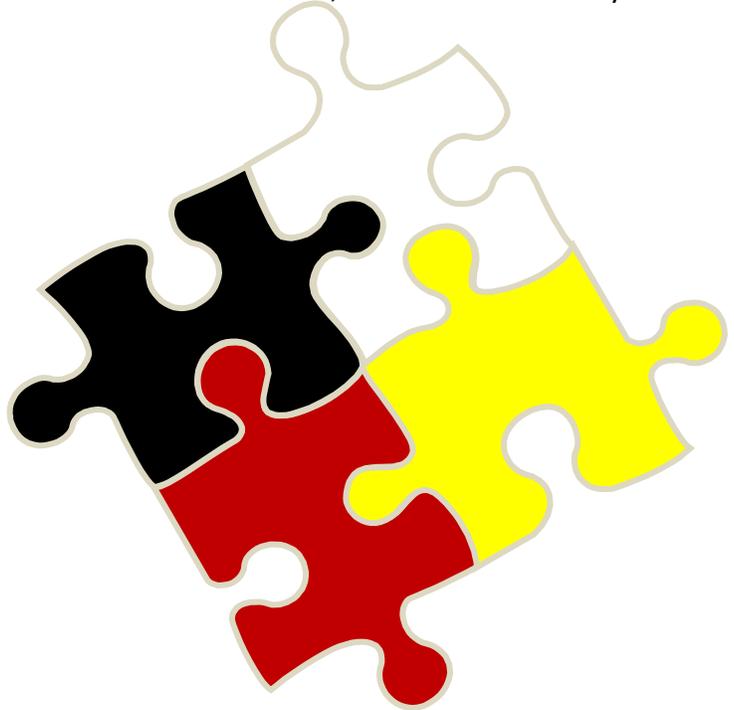


PERCEPTIONS OF ALZHEIMER'S DISEASE AND RELATED DEMENTIA AMONG ABORIGINAL PEOPLES IN ONTARIO

**FINAL REPORT JANUARY 2014: SIX NATIONS COMMUNITY
REPORT**

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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 Six Nations as well as relevant information from the academic literature. There were 22 participants in total from Six Nation. 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

- Many participants viewed healthy aging as a holistic process, 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.
- Participation in social and cultural events, as well as maintaining meaningful relationships, and being socially involved with friends, family, and the community were also seen as having a positive impact on old age.
- Following a traditional lifestyle by taking part in the ceremonies, as well as eating healthy foods and being out on the land were considered important to aging well. Participants talked about the connection between taking part in cultural activities and

health and wellbeing, in terms of being physically, mentally, emotionally, and spiritually engaged.

- Some participants were concerned that the traditional roles of Elders within the community were changing. A couple of seniors felt that there was a declining sense of responsibility and power.
- All participants mentioned the number of services available in the community, such as, home care, meals on wheels, local pharmacy, as well as numerous workshops and information sessions on a variety of health issues, and a seniors social club where seniors can get together to visit and play cards. All of these services were believed to help keep seniors in their homes, with their families and as active members in their community.
- Possible barriers to healthy aging include access to affordable healthy foods, general financial health (having to live on less), loss of freedom associated with inability to drive or secure transportation, diet and lifestyle, 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 and cognitive decline. They also brought up that some seniors may further isolate themselves by not asking for help when they need it out of fear of being seen as a burden to their family members.
- Some participants felt that risky behaviours, such as reckless driving or excessive drinking were barriers to healthy aging.

2) Understandings of Age-Related Dementia

- Participants had some knowledge of biomedical explanations for Alzheimer's disease and other related dementias due to the Alzheimer's Society coming to the community and offering workshops and information sessions. However, even with the information offered, 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.
- Participants felt that there was no word in their language (primarily Cayuga) that would translate to 'dementia' as it understood by Western medicine but there are words for particular behaviours such as "forgetful", "confused", "memory loss" . Participants also shared words in their language that describe the experience of dementia from their cultural understanding: 'returning to childhood'. In English people used words such as "forgetful", "elder's sickness", "getting old", "reverting back to childhood", "second

childhood”, “deteriorating”, “sickness in the brain”, “memory loss”, and “old timer’s/some timers disease” when talking about Alzheimer’s and dementia.

- The terms Alzheimer’s disease and dementia were not widely accepted. Participants in the focus group, as well as the geriatric care specialist stated that elderly people in the community typically do not say the words Alzheimer’s or dementia, unless they are joking around. Even if a diagnosis is given, elderly community members will still use the words “forgetful” or “very forgetful” to describe their memory loss, as opposed to labeling it as dementia. Some seniors felt that there was more of a stigma attached to the words dementia and Alzheimer’s disease. There seemed to be more fear over losing one’s independence than memory loss itself.
- Many of the participants from Six Nations 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 and drug abuse
- Many of the primary and secondary prevention strategies for dementia suggested by participants in Six Nations are similar to what is suggested by the Alzheimer’s Society of Canada but with a local relevance; for example: these included eating healthy (primarily land/traditional foods), physical activity including walking and taking part in cultural activities such as lacrosse, having opportunities to be socially active and engaged in the community, engaging in activities that keep the mind active such as puzzles, listening to music, stories and language tapes.

3) Diagnosis

- Symptoms experienced by participants included: **Mental** – forgetfulness, confusion, compulsive behaviour; **Spiritual** – communication with the spirit world; **Emotional** – frustration, irritability, anger, fear, sadness; **Physical** – impaired mobility, falls, difficulty speaking and writing and sensory loss.
- The majority of the caregivers stated that their loved ones were tested and diagnosed, with three caregivers stating that their loved ones had Alzheimer’s disease, while one caregiver stated that their loved one was diagnosed with vascular dementia. The participants with dementia did not say if they had a formal diagnosis or not.

- Focus group participants and the geriatric care specialist believe that Aboriginal people are diagnosed at a later stage than non-Aboriginal people. The reason for this is partially attributed to family caregiving obligations and the view of dementia as normal in aging, denial of any behavioural changes, but also to patients not liking or being able to connect with the physician, resulting in patients not seeking care until much later on.
- The geriatric care specialist talked about the importance of taking the time to build a relationship with Aboriginal patients before administering any type of test. In addition to building a relationship, they would also try to modify the assessment tools to make them more culturally relevant. Other participants did not state if these methods were used on them or their loved ones or offer alternative suggestions for more culturally relevant cognitive assessment tools.

4) Treatment

- The findings suggest that Aboriginal people are seeking treatment for dementia at a later stage in the illness than non-Aboriginal people. This may stem from an acceptance of memory loss as natural.
- Prescription medications were used by some participants to treat symptoms associated with dementia. One participant specifically mentioned that their loved one was taking Aricept. Participants discussed some of the benefits of taking prescription medications, such as controlling mood swings and helping them sleep.
- Participants talked about the role of culture and ceremonies in contributing to health and wellbeing in the elderly, but did not know of or report the use of traditional medicines specifically to help with dementia symptoms.

5) Dementia Care

- All participants in this study reported multiple complex chronic conditions in addition to dementia. Care for dementia in this context is highly complex.
- Though the acceptance of memory loss and confusion is primarily thought of as something that comes with getting older, most agreed that there is a point when symptoms get more severe and outside care and support is needed. Fortunately the community has a lot of services, including a long term care facility, to help care for people throughout various stages of dementia.
- Most often Aboriginal people with dementia in this study were being cared for at home by family members or in the long term care facility in the community when symptoms

became more advanced. The community has a home care program for families who need additional support or for seniors who choose to live on their own.

- Most participants reported having some knowledge of Alzheimer's disease and related dementias. Participants stated that they learned about the symptoms through searching the internet for resources, while others attended community information sessions and workshops put on by the Alzheimer's Society. It was believed that more information on dementia, through the use of pamphlets or community newsletters, would help to further raise awareness in the community.

6) Dementia Related Programming and Information

- Participants stated that the Alzheimer's Society holds informational meetings and workshops in the community on the different stages of Alzheimer's and dementia. In addition to the informational meetings and workshops, some participants suggested that pamphlets and newsletters be sent out to community members to raise awareness in the community. One senior also suggested a place where people could go to privately ask questions without being signalled out in a group setting.
- Caregivers expressed a need for more information on the illness and its progression. It was felt that this would help them understand the symptoms, the progression and would let them plan for the needs of their loved one over the years.
- Some participants recommended that health care staff providing services to people with dementia could benefit from additional training on dementia symptoms, disease progression and appropriate caregiving – this was emphasized to be especially important to workers who are offering respite care for dementia patients.
- Focus group participants expressed the need for a separate wing / area for dementia patients in the long term care facility. They also suggested that more home care staff should be hired to go and visit with the elderly people in the community.
- People with dementia, as well as some seniors, stated that they did not participate in community activities or go to the community centre as much as they wanted to because of a lack of transportation. Having a community van to transport elderly people to and from the community centre would allow elderly community members to take part in any dementia specific programming.

7) Culturally Safe Dementia Care

- Participants stressed the need for culturally appropriate care for Aboriginal people with dementia to include policies and programs that would continue to keep Aboriginal seniors with illnesses in their home community.
- Cultural differences in communication styles are a barrier to the delivery of culturally safe dementia care for Aboriginal people. Participants spoke about the importance of being able to connect with their health care provider, as well as having the provider be able to communicate in a manner that they understand. This type of trusting relationship requires time to develop and is contingent on continuity of care.
- Delivering healthcare services and especially doctor patient interactions in the language of the patient was identified as important for getting accurate information and achieving an appropriate comfort level for the Aboriginal person with dementia and their caregiver. Related to this is the need for complicated medical information to be delivered in simple understandable language.
- There is much to be learned about appropriate health promotion activities from traditional knowledge keepers, faith keepers, and Elders. We heard that participation in traditional activities could have many benefits, for example, faith keepers and others were required to memorize ceremonial speeches, extensive repertoires of songs and that participation in singing, drumming and other ceremonial activity would promote cognitive health. These ideas are echoed in other senior informants who note that listening to Indian music or language tapes, taking Indian medicine for ailments, and participating in ceremony are good for “finding things out about yourself” and leading a healthy life.

RECOMMENDATIONS FROM THE ADVISORY COMMITTEE BASED ON KEY FINDINGS

The research team met with the advisory group to review the findings, as well as discuss next steps, and recommendations on August 18, 2014, at the Six Nations Health Centre, in Ohsweken. The discussion during the meeting revolved around the following key areas: diagnosis, prevention, training, and education. The advisory group wanted to ensure that these key points were captured and translated into recommendations that the community could use to continue to raise awareness about dementia.

The advisory group agreed with the findings around diagnosis and acknowledged that community members are typically diagnosed in the later stages of dementia. They agreed that more information is needed to raise awareness of the signs and symptoms associated with dementia. The advisory group commented that many people in the community may not seek out a diagnosis because they know there is no cure. In order to address this concern, the advisory group recommended that awareness raising campaigns include information on the benefits of early assessment and diagnosis. The advisory group also stressed the need for culturally appropriate diagnostic assessment tools. They also suggested that the language should be taken into consideration and incorporated into these screening and assessment tools.

In addition to increasing awareness and developing culturally appropriate screening tools, the advisory group stressed the need for more information around prevention. Promotion of health and wellbeing at all stages of life was discussed at length by the advisory group. The recommendations ranged from encouraging language use, creating community functions where seniors and youth could come together, to teaching lifecourse interventions. The advisory group also wanted more information on secondary prevention strategies and recommended more information on ways to slow the progression of the disease be made available. They also recommended that all health promotion materials should reflect Six Nations culture.

Other key areas that were brought up by the advisory group and supported throughout the findings, was the need for more training and education. The advisory group shared that a significant amount of health care workers working with the senior population in the community have training in Gentle Persuasive Approaches in Dementia Care. Additional cultural safety training, which would address colonial history, past traumas, and Indigenous beliefs, would benefit all health care providers in the community.

Recommendations were also directed towards providing additional training and support for family caregivers. The advisory group recommended that a similar type of cultural safety training be available for families providing care, as some of the younger generations may not fully know the history or understand the impacts of historical trauma. They also recommended additional support be given for family care givers who are victims of family violence and now looking after their loved ones. They thought that the family violence program in the community could possibly provide caregivers with this additional support.

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 (ARD) 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 ARD 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 ARD? What are culturally appropriate types of health promotion materials concerning ARD? 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 ARD in their communities. In March 2007, Mnaamodzawin Health Services Inc. and Noojmowin Teg Health Centre organized a roundtable forum on ARD 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 Six Nations 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 Six Nations 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, judgement and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person's ability to function at work, in relationships or in everyday activities"

Alzheimer's Society Canada

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

Risk Factors for Dementia

Modifiable

- Age
- Heredity

Modifiable

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

healthy lifestyle choices as a means of reducing the risk of developing dementia. A healthy diet, aerobic exercise, cognitive stimulation, and active social life are all considered to be beneficial in preventing the onset of dementia. Preventing head injury and seeking adequate treatment for other medical conditions (i.e. diabetes, high cholesterol, and high blood pressure) are also factors that can aid in the maintenance of brain health (Alzheimer Society 2010).

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.

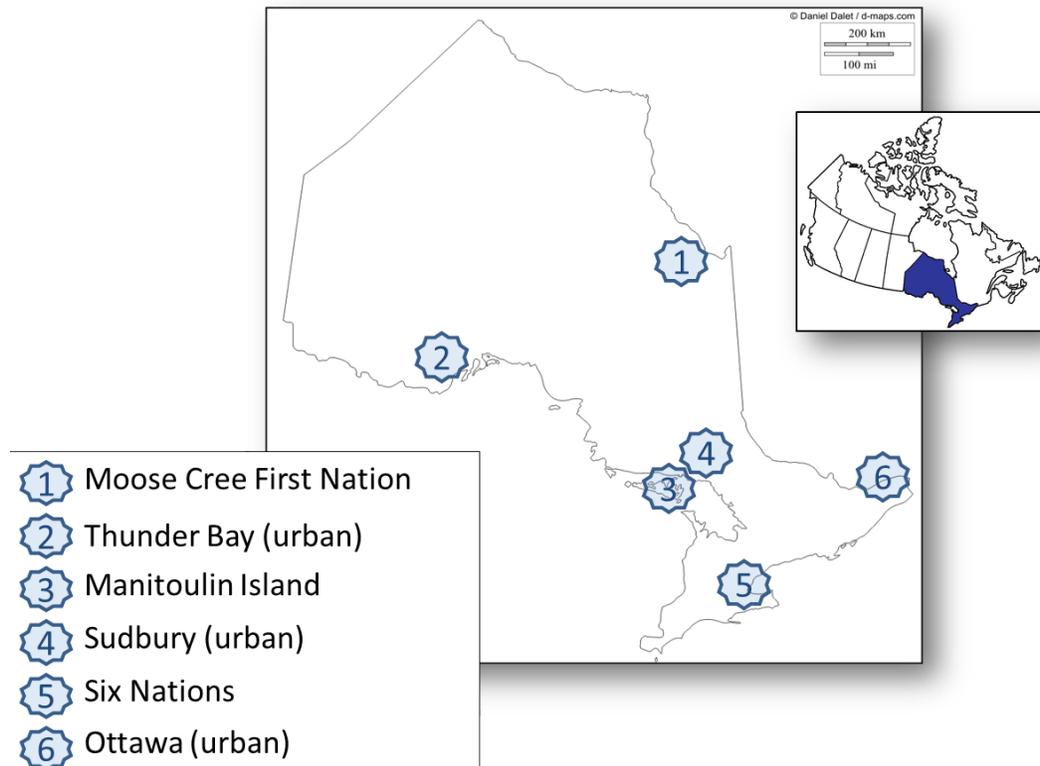
METHODS

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.

In Six Nations the investigators obtained approval for the research through the Band Council's Ethics Committee. We worked with administrative and program staff at Six Nations Health Services on the development of the methodology and research implementation. A local research assistant, Trisha MacDonald, conducted interviews with community members. We presented preliminary findings to the community in May 2011 at a community research forum. 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.

Figure 1: Research Sites



Community advisory groups were struck for each research location usually including health directors, staff, and community volunteers, or sometimes formal 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 Six Nations 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 Six Nations to recruit participants. Potential participants were identified and first approached by a long term care or home care nurse with knowledge of a person's symptoms. They were asked if they would be interested in being contacted by a researcher to participate in the study.

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

Research Site	Six Nations
Interviews	
People with Dementia	5
Caregivers	5
Older Adults	5
Total	15
Focus Groups	1
Number of Focus Group Participants	5
Key Informant Specialist	1
Key Informant Traditional Knowledge Holder	1
Total Participants	22

People with dementia were generally undiagnosed in our sample. Early interviews with physicians suggested this would be the case. Therefore our approach was to allow the person with dementia and/or their caregiver to define memory loss or dementia based on the symptoms they were experiencing. Without any information available on the possible incidence of dementia in Aboriginal peoples our approach was to not limit participation to those with an official physician’s diagnosis. Our only exclusion criterion was that participants could not be in late stages of dementia where it would be too difficult for them to participate in a meaningful way. Our inclusion criteria required that anyone in the ‘person with dementia’ category must agree that they are experiencing symptoms of memory loss and/or confusion. Symptoms people were experiencing included forgetfulness and repetition, a loss of a sense of time,

suspiciousness, inability to manage activities of daily living, and unsafe behaviours including wandering, forgetting to turn off appliances, or manage health issues. People with dementia ranged in age from 69-86, there were five females and no males. All people with dementia were community-dwelling. That is, they lived in their own home, the home of a relative or in the community run long term care facility.

Caregivers in the sample were all adult children looking after their parents. Although caregivers were not asked to disclose their age, some did express how old they were. All five caregivers we spoke with were female.

Seniors who were interviewed could be included if they were 50 or older. In our sample they ranged in age from 66 to 92. There were two males and three 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 one traditional healer and one physician specialist. Focus group participants were personal support workers within the community.

DATA ANALYSIS

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

LIMITATIONS

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

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

As previously stated, getting rich data from some of our participants who were at various stages in their dementia proved difficult.

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. Participants did not discuss healthy aging in relation to the absence of illness or disease. Collectively, they felt that healthy aging would include staying in the community, preferably in their home or with their family members, having access to health and social services, being socially involved and participating in cultural practices.

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 visiting with friends and family, engagement in community events and cultural practices, and being able to use humour to get through difficult times. A lot of the participants talked about their family, particularly their grandchildren and great grandchildren and how much joy they brought them.

I think the seniors should get together you know and talk a lot. Good, good discussions don't hurt anybody even if it's not true, yeah [laugh]. Yeah and they turn around and say what the heck he's babbling about. Yeah when they have a conversation you say a few things it makes the person laugh you know, it makes you feel cheerful you know. (Senior TM04)

In addition to visiting with family and community members and using humour to boost one's spirits, participants also talked about the importance of being outside and being physically active. One caregiver talked about the activities her loved one did that helped them maintain a positive outlook as they aged.

She um worked outside a lot um like she would pick tomatoes, pick strawberries and stuff like that. So she would go out in the yard and pick up weeds, pick dandelions like you know go around picking up dandelions up picking up stones from the ground and we would go outside like I said before looking at the trees and the bushes, she looked, liked to look at the birds and she

enjoyed talking to people to some extent. Until she became tired of doing that or um yeah, any outside activities she liked to do. (Caregiver TM02)

Other participants shared their beliefs around being physically active and healthy aging in terms of following traditional lifestyles and participating in cultural activities. A couple participants talked about the amount of work it took to follow a traditional lifestyle, in terms of growing food, hunting, trapping, fishing, as well as cutting wood. A few other participants also talked about the physicality of participating in cultural activities, such as playing lacrosse or dancing powwow.

Well, I never thought of myself as a senior really [laugh] but um, it's not bad because they have a lot of things for you to do. Like there's a lot of things you can, activities you can get into. If you're into that, but I myself and um I do the powwow trail, so it's, like I stay active that way. (Senior TM02)

I mean um, uh, like there's sort of the whole cultural thing with um being physically active as well. Um, like we have a, a whole series of healing rituals that are in the form of games so lacrosse is one of them, um, so you know, there's a healing ritual form of lacrosse that's played at people's homes out in the backyard, you know, which there's no age restriction or limit to it, I mean. Yeah, so as long as you feel well enough to get out there, you can do it [chuckles] you know. And even as an older person, you don't have to move around a lot, just catch the ball and throw it to someone else and you know. (Traditional Knowledge Keeper WW01)

Aside from mental, emotional, physical, spiritual or cultural practices, all participants from Six Nations mentioned the number of services available in the community and how they contributed to healthy aging. These services range from dieticians, home care and meals on wheels to a seniors social club, and help keep seniors in their homes, with their families and as active members in their community. A number of seniors felt that the number of services available in the community helped them maintain their health as they aged.

Well I think there are a lot of opportunities for seniors on, on the reserve here, like there's the Long Term Care has all kinds of activities for seniors. Like meals on wheels [laugh], meals on wheels and um I, we haven't joined the um, what is it the Silver Fox club yet but there are a lot, they have dinners and and ah your meds are free [laugh]. There's lot of opportunities to being a senior. (Senior TM01)

Well I think it's great being a senior in this type of community there are so many services and things to do and I know they aren't available in other communities. We get meals on wheels and I'm so happy cause I don't like cooking and Silverfox is you know an a social outlet. (Senior TM05)

BARRIERS TO HEALTHY AGING

Barriers to healthy aging for Six Nations participants were related to a number of issues including access and affordability of healthy foods, diet and lifestyle, depression, isolation, and neglect, along with perceived changes to traditional values and roles.

Perceptions around health and aging well can encompass different meanings as one grows older and starts to see the impacts on their physical bodies. While individuals may understand what is needed to support healthy aging, they may not necessarily have the means to actively live a healthy life. One senior talked about the cost of eating healthy and how some people may not be able to afford fresh produce.

And I think it would be their finances to because some people can't afford to eat healthy. They have to eat what they can afford. And like fresh fruits and vegetables are very expensive, yeah and then like they have the food bank but the food bank it canned goods and stuff you know that are not good for you. (Senior TM02)

In addition to not being able to afford healthy foods, some people may not necessarily enjoy eating healthy foods all the time. For individuals who grew up eating certain foods or learned how to prepare foods using ingredients that we now know are not good for us, transitioning away from those foods may prove challenging, especially if these comfort foods are associated with positive memories.

Staying healthy it's, it's hard. Especially the way we used to eating you know, fry bread and salt pork. That's the old way anyway. We grew up, that we didn't throw the grease away we put it on our potatoes. (Senior TM02)

Of course some people may not necessarily see the correlation between their current actions and the impacts it could have on their health later on in life. A couple of seniors said that even though individuals may know that certain actions can have a negative impact on health later on, they do not believe that it will happen to them. One senior talked about the risks that people take while driving, in terms of being reckless, not paying attention, and speeding, believing that nothing bad will happen to them. Another senior commented on how this type of recklessness and denial could be applied to the impacts of alcohol or substance abuse on the body.

I think people think it's not going to happen to them. Like in, for instance people if you drink a lot of alcohol. People don't realize what the damage they're doing to their liver and their brain. What's going to happen to them when they get older, you know. (Senior TM01)

Healthy aging? I don't think were healthy aging. I don't think we are. I mean diabetes is run rampant around here um alcoholism and drugs and ah I don't think that's healthy. (Senior TM05)

Other barriers to healthy aging that were brought forward by participants in Six Nations include loneliness, depression, isolation, neglect, as well as perceived changes to tradition and Elder's roles. A couple of seniors expressed that they believed roles and 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.

Yup. And a lot of times to ah I find the even my children um, like, when I was young you didn't talk back to your elders and now um I find that children will like talk back to their elders like say well you know I gotta do this, you know I gotta do that you know and it's you know really they don't, they don't show respect like that they should. And it makes the elders feel really bad I mean for your child to scold or you know and that. Um hmm. Yeah because if they are going to act like that you know you're not gonna bother with them. (Senior TM02)

This is kind of abstract it's, you lose your power, you know, in in the community, you lose your power because um you know in the community people are respected because of who they are, what they do, or who they know and ah as you get older you lose this power. (Senior TM01)

This perceived loss of respect or status may impact how an elderly person interacts with family members or other people in the community. For example, if an elderly person did not feel respected or appreciated, they may start to distance themselves from family members or other people in the community. An elderly person may also distance or isolate themselves if they feel they are imposing on others by repeatedly ask for help. A couple of seniors talked about how some older individuals might not ask for help because they don't want to be a burden to their family or other people.

And the a lot of times to an older person might now want to say anything for fear that their um ah what would say a burden. You know a lot of them won't say anything, won't complain that they, they even have maybe have something that's sore on them or something and they won't say anything, I know there's, there was a lot of people like that. (Senior TM04)

And like I said the old people don't like to impose either, cause they figure if, I know I do and I know a lot of other people do to. If you ask, if you ask somebody something once that should be enough, they know you have a need and they know you want them to help you or you want them yeah to help you. But um, you know if they don't well they just figured well you know he's not gonna help me, cause they don't want to be constantly asking. (Senior TM02)

This type of behaviour could significantly impact the health and wellbeing of individuals, especially if they are lacking basic necessities, such as food, shelter, or even healthcare. One senior shared their thoughts on how elderly people could become neglected if they don't ask for or accept help or assistance from family or community members.

Um, they are with people that are really outgoing but we have some elders that don't like to bother people and they get neglected quite a bit and um, I know some people that live and horrible conditions and have nothing, not to much to eat but they won't ask for help so it, I know their family's should do more for them but um even if they would you know let somebody else know because sometimes the parents won't let the children you know help them but if somebody else found out like I don't know there's gotta be a better way to do things cause there are a lot of elders that are neglected. (Senior TM02)

This type of isolation can create or contribute to feelings of loneliness and depression, all of which has been cited as barriers to healthy aging by Six Nations participants. For people who do not have steady access to transportation, getting around the community or going out to visit may be very difficult. One person with dementia commented that she doesn't really utilize many of the services or get out in the community and socialize since her driver's license was taken away. She commented that she would like to go and take part in the seniors' activities and visit with others if she had the means to get there, but since she lived alone and did not have someone to drive her there and back, she couldn't really participate. A couple of seniors talked about the impacts of loneliness and not having family or other community members around to visit with.

Um, what else, I think being lonely, I don't know what I'd do if I lived alone, you know. (Senior TM05)

One senior commented that the situation may be worse for elderly people who can no longer take care of themselves, don't have family members around, and have to move into a nursing home.

I feel sorry for the people that are in the nursing home and don't have a family. Nobody hardly ever, ever comes to see them just sort of by themselves eh. After, after ah while a person in the nursing home just kind of give up and not want to participate. (Senior TM04)

TRADITIONAL LIFE AND HEALTHY AGING

As described in the previous section, the questions concerning healthy aging also discuss traditional lifestyles and cultural continuity during the aging process. We found that participants valued cultural practices such as ceremonies and traditional medicines, along with

taking part in cultural games, and powwows. One senior credited their strength and outlook on health and aging to their belief in the traditional teachings and was at peace knowing that they would one day join their loved ones that have already passed on in the spirit world.

Many participants also viewed listening to traditional stories and music, as well as visiting/socializing and speaking the language as being an important contributor for healthy aging. While a few participants felt that certain values had changed from when they were younger, participants for the most part felt that elders were still respected and cared for.

Plus on the whole I think our community leads towards respecting elders, towards respecting older folks cause usually when you go someplace they always let the elders go first and ah there is that um that um elders are respected. (Seniors TM01)

A couple of participants talked about the importance of being a part of the culture and learning about and taking part in the ceremonies throughout the year. One senior spoke about how people use traditional ceremonies and medicines to help heal illnesses, while a traditional knowledge keeper talked about the interconnection between ceremony and wellbeing in terms nourishing the body, mind, and spirit.

Because I think um people would um if they're involved in ceremonies and spir...spiritual activities then they go on Indian medicine. They take Indian medicine for ailments, like my friend she takes um Indian medicine for her arthritis and I, yeah I think that it says why do you think that is and I think because, because they, when they find out things about themselves through the ceremonies then they act on them and try and...most people do I think anyway try and correct what is wrong and do what they have to do to um make it, fix it. (Senior TM01)

I guess because, um, you know, take ceremonially for example, I mean, each ceremony throughout the year um, first of all, connects a person to his natural cycle so you have to be aware of what's happening in nature, I mean you know, uh, which is difficult to do today, because you know, just because of the way, the lifestyles that we lead, um, but never the less, um, you know, people maintain that connection, you have to in order to determine when your ceremonies are to take place. So I think that's one area, just being aware of your environment, you know. (Traditional Knowledge Keeper WW01)

The connection between traditional ceremonies and healthy aging can also be seen through the physical, mental, emotional, and spiritual preparation one needed to take in order to participate in or conduct certain ceremonies.

Yeah [short pause] yeah so those are some of the, you know, the activities that a Faithkeeper, on top of that the Faithkeepers are actually responsible for maintaining the Longhouses physically

so, you know, that means yard work [chuckles] that means cleaning up after everyone is gone, you know, it means actually preparing sometimes for, there's certain ceremonies where the male Faithkeepers actually do some of the cooking, you know, so, and that's, you know, remembering all of them things as well you know [chuckles]. Um, there's certain ceremonies where, the ceremonial food that we actually used at one time was like deer meat, we still, you know, we still do get it um, and when deer meat is used, the men cook the meat, you know so that's another part. But the actual cleaning up and all those kinds of things, those would be the main duties of the Faithkeepers on top of, as I mentioned, you know... Yeah, and that means actually like I said, knowing the speeches, knowing the songs and of course not every Faithkeeper does all of those things right, you know, I mean some take it more seriously than others. (Traditional Knowledge Keeper WW01)

PREVENTING DEMENTIA

Six Nations 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.

Keeping the mind active was viewed by some participants as a primary method of prevention. Participants talked about keeping their minds active by engaging in activities like reading, doing puzzles, as well as crossword puzzles.

That's the one thing, the two things I do all the time. I have puzzle books and I'm always reading and reading. (Person with Dementia TM 02)

Another person with dementia enjoyed reading the bible and felt that reading parts of the bible everyday helped to stimulate the mind. While other people with dementia mentioned that they had a hard time seeing and couldn't read as much, but did enjoy singing, dancing, and watching T.V.

Participants also talked about the importance of actively engaging in cultural practices to prevent dementia. Many participants enjoy listening to music, traditional stories and language tapes, in addition to singing, beading, dancing and participating in ceremonies.

Um, I sing, I walk, ah I do the bead work, that keeps me busy. I listen to music, I listen to tapes and I have the Mohawk language tapes and then its, I have a lot of native music. (Senior TM02)

Engaging in cultural activities can help stimulate the mind and the body, especially for those who carry the songs, stories, and traditional knowledge to conduct the ceremonies in the traditional languages. A traditional knowledge keeper shared that some of the older

generations used to speak multiple languages and noted that the parents and grandparents of the older generation spoke upwards of seven languages. This participant also talked about the roles of the Chiefs and the Faith keepers and how they need to be able to remember and recite the protocols and the ceremonies.

Um, first of all, and I mentioned leadership and like, you know, because we have Chiefs and Faith keepers and that sort of thing, um, who, who'd have to rely a lot on memory for, to complete ceremonies. I mean there's not a lot of written material, it comes in a, it's an oral tradition, I mean, you know, so all of the ceremonies and how they are all carried on uh, rely heavily on a person's ability to remember things, you know, so I think that plays a big role in, in, you know, sort of, those, those peoples having um, you know, good, good mental health. (Traditional Knowledge Keeper WW01)

The ability to retain and recite such a tremendous amount of oral history, along with the protocols, practices, and prayers associated with each ceremony, in multiple languages, would act a protective factor in delaying the onset of dementia. This is also supported by research that suggested the more active a person's mind is throughout their lifespan the greater 'cognitive reserve' they have when they age which appears to delay the onset of dementia. Speaking more than one language also has this effect.

Within the focus group, participants expressed that traditional people or those active in the Longhouse were typically healthier and lived longer than those who were not a part of the Longhouse. They also commented that they very rarely see traditional people in the nursing home. Many participants also pointed out that people who are active in the Longhouse or who follow the traditional ways are less likely to consume alcohol or drugs and are more likely to be active, eat traditional foods, and be around other people.

Because it seems to me that those that follow the ways are not as prone to ah have so much dementia. I think so and it's, it's with the constant um, ah, being together and talking to together and um reinforcing the ways. (Senior TM02)

LOCAL PERCEPTIONS AND UNDERSTANDINGS OF DEMENTIA AND MEMORY LOSS

LOCAL PERCEPTIONS OF DEMENTIA

Six Nations participants seemed to have more medical information about Alzheimer's disease and dementia than some of the participants at the other sites in this study. Health Services in Six Nations has a working relationship with the Alzheimer's Society and runs workshops and other programs aimed at raising awareness. A few caregivers shared that they looked up

information about Alzheimer's and dementia on the Internet. One person with dementia said that they read about memory loss and forgetfulness before they started experiencing memory loss. One of the seniors also read quite a few articles about Alzheimer's disease and believed that it was important to reread information and look up new developments every once in a while. Even though participants were more aware about the signs and symptoms associated with dementia, they still predominantly believed that memory loss was a natural part of aging. The 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.

NATURAL CHANGES WITH AGE

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. According to one traditional knowledge holder, traditionally no stigma was attached to the memory loss or confusion that comes with aging.

I think they see it more as a natural, yeah, of course I can't speak for everyone, I'm just going by my own experience but, you know, in, in, like I mentioned uh, you know, coming from what the Code talks about, um, it's more of a natural thing, it's not looked at as a disease, you know, some people go back that way and, and this is how they're going back to the Creator I guess is how you could look at it, you know, so, um, yeah it's not, it's not seen as a disease. (Traditional Knowledge Keeper WW01)

One person with dementia talked about their experience with memory loss and viewed it as part of growing older. They also asked their doctor about their issues of memory loss and were told that certain memory issues and forgetfulness are a natural part of aging.

I talked to my doctor but he wasn't too concerned about it. He said it was just an aging process or something like that, so I just you know, I didn't worry about it or nothing I just figured it was part of growing old. (Person with Dementia TM02)

SECOND CHILDHOOD

Discussions around traditional and cultural understandings of aging and forgetfulness, confusion, along with other symptoms associated with dementia, were explained as going through a second childhood. The traditional knowledge keeper shared that individuals who

were going through this stage were more connected to the spirit world and becoming closer to the Creator.

From what I've been told, it has to do with, uh, the fact that, uh, you know, you're going back into this stage where you're going sort of childlike again, um, and children actually, they say just came from the Creator so, you know, they're still sort of connected, you know, they still got this connection to the spiritual world I guess you could say, to the Creator, and when you start, as an, you know, as an aged person going back to that, you're going back to that state that you were in when you were first born so you're getting closer to the Creator again. (Traditional Knowledge Keeper WW01)

One caregiver shared that any visions or hallucinations were accepted as a blessing in that the person was starting their journey back to the spirit world. It was understood that in being closer to the spirit world, the person may see or converse with others that have long since passed on.

Um, to be able to, to have that connection and we talk about the points of, of life and that when you get close to the, the portal or the time of change the birth, death area, the closer you are to both birth and death the more your able to see and experience so we don't dismiss it we accept it and we use it and were actually happy when that happens. (Caregiver TM04)

LABELLING / STIGMA

Memory loss is seen as a natural part of aging as long as it is not labeled. Once a label, such as Alzheimer's disease is attached, then people start to worry that others will judge them. There may also be a certain amount of fear that exists in not fully knowing how symptoms associated with dementia or Alzheimer's will impact them or how others will see them.

It's, well they see it as a natural part of aging, they refer to it as aging and um, if the word Alzheimer's comes in I think that's a very scary word for them. There's stigma there, you know. (Geriatric Specialist WW02)

The specialist stated that even with the increased awareness and education surrounding Alzheimer's disease and dementia in the community, some of the community members still will not say the words Alzheimer's or dementia.

Um, but with the education that's given, they're able to understand, you know, a little bit more of that, um, but I think it has to come with the education that's given for them to understand because they don't understand, you know, like "I'm, I'm forgetting things", you know, they don't think "Oh my God, like I may have Alzheimer's, I may have dementia" and stuff like that and

that's why they say, you know, "I'm just more forgetful" and stuff like that, they just don't say the Alzheimer's word or the dementia word. (Geriatric Specialist WW02)

Some of the older generation may not use the terminology, Alzheimer's disease or dementia, for a number of reasons, including not wanting to attach a western biomedical definition to something they see as a normal part of aging in their culture. Even if these individuals acknowledge that there is a western biomedical definition for what they are experiencing, they may prefer to follow their own cultural beliefs, practices, and ways of knowing when it comes to their health and wellbeing. Some individuals may also believe that these symptoms may eventually go away and do not want to call attention to themselves. By saying "I have dementia" or "I think I have dementia," people may feel like they are giving up.

DENIAL / LOSS OF INDEPENDANCE

Some individuals, on the other hand, may be in denial, and not want to except that they can no longer care for themselves. One caregiver shared how their loved one struggled with losing their independence.

Um, um, it's not a denial it's that, it's not a denial of the problem it's a denial that um she's lost her independence, that's what she struggles with. She totally admits to being confused easily and forgetting but she hates the fact that she can't stay by herself or or she thinks that she relates it to being thought of as stupid. (TM CG 04)

The thought of losing one's independence and having to rely on others can be very scary for some individuals. One senior believed that some people may go to great lengths to hide illnesses from their family members or other people in the community out of fear or embarrassment in having to ask for help.

I would think their, they've, they're trying to keep up appearances. They might realize that they're forgetting things and ah they don't recognize people and so they try to keep up appearances because they don't want to be, they, people will, they think people will think they're crazy or something so they try to keep up appearances and at first they might um refuse care or help from family or the comm....community support services you know. They might refuse it but then they have to, they have to succumb and let the, let their family or the community supports services help them and I think that makes feel helpless. They're probably um...embarrasses them. (Senior TM01)

PREVELANCE AND INCIDENCE RATES

When asked about the prevalence rate of dementia in the community, care workers estimated that 25% of elderly people in their case loads have Alzheimer's disease or other related dementias.

P----- Well I don't like I'm not working out in the community as much as you guys around, around them where I just work with them as of from the brain injury. P----- I'd say 25 percent. Quarter of them. Not to many of them left. (Focus Group TM01)

The geriatric care specialist has worked within the community for over thirteen years and has come across a number of patients with memory problems and issues around cognitive impairment.

Okay um, I'm going to go with [pause] in the thirteen years, probably, that I actually have come in contact with and I'm going to go ballpark area is around maybe 200. (Geriatric Care Specialist WW02)

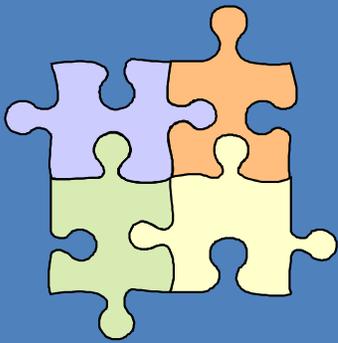
Well just looking at um, L----- case load and even when I had my um, case load, I would have um, anywhere from 40 to 50 on my case load of elderly and more than half of that were um, had a cognitive impairment dementia. (Geriatric Care Specialist WW02)

The geriatric care specialist also believes that the community will see an increase in the rates of Alzheimer's disease and related dementias as more people become aware of signs and symptoms associated with dementia.

Yeah, it, yeah, I think, I think we are starting to see an increase because I think there's more awareness and they're trying to do a detection at an earlier age to give the supports [inaudible] so I think yeah, we are seeing a little bit more of um, of that, um, more of the mild cognitive impairment, um, like I said before, I had um, the youngest one I had was in his um, late 50's but that was alcohol related dementia and stuff like that, um, but I think we are seeing it a little bit more now in the community, um the earlier stages of it because of the awareness um, in the community in regards to that, more education and that, more programs, um, throughout the reserve and that and then we're looking at the aging population come in, so yeah we are seeing that. (Geriatric Care Specialist WW02)

PARTICIPANTS UNDERSTANDINGS OF THE CAUSES OF DEMENTIA

- Natural
- Age
- Processed foods
- Lack of cognitive and social stimulation
- Trauma, stress, and grief
- Other illnesses
- Western medicines
- Alcohol, and substance abuse
- Heredity



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 – concurrent illnesses, trauma, and stress.

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

PHYSIOLOGICAL

Family history/genetics:

Participants did not mention genetics or family history as a possible reason for their loved ones' memory loss. A possible reason why family history may have not been widely cited, may have to deal with the fact that forgetfulness was seen as a natural part of aging. Although one participant believed that Alzheimer's disease was inherited.

Well its inherited from your mother and ah, and it, my sister, step-sister, my sister in-law, biological, read a book on Alzheimer's disease and she told me this, this one thing about it you had, you had to be like a mother or [inaudible] the family can get it, there was 4 of them. Only one in the family can get the Alzheimer's so it's inherited from her mother, her mother get all the names, and all the kids, we thought that was funny, that's where I got into that, I didn't think it was funny. (Senior TM03)

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:

- Parkinson's disease
- Diabetes
- Acquired Brain Injury / Traumatic Brain Injury
- Kidney disease
- Complications of diabetes leading to a stroke – resulting in vascular dementia

One caregiver noticed issues with their loved one's memory after they had a stroke and took the steps to rule out other health issues.

At first I think we thought it was just the stroke and um, then I thought well maybe her blood pressure was out it seem, as I was getting that checked thinking maybe that had something to do with it but it was that was always good. Um, and I guess that's when um the changes that we noticed in her that's when we took her to her family doctor and she did couple tests.

(Caregiver TM01)

Participants also talked about **physical injuries and head trauma** as a cause of dementia and memory loss. One caregiver attributed their loved one's memory loss and related symptoms to a childhood head injury.

Well, mom would tell us, um, she would tell us that she, when she was a young girl, ah, she fell down some stairs at school, Okay, and she had injured her head. Her, for about 2 or 3 days her eyes were fixed and all she could say was momma, momma. And I know that dementia can be caused by a head injury and I believe that's where the um, dementia came from. I know that her parents my grandparents didn't have it and they lived to be in their 80's and none of her sisters or brother ever had it. And so that's where I'm thinking, there's nothing like this, no family history of it so I'm thinking, thinking that's where might have originated. (Caregiver TM02)

Prescription medications:

Concern was expressed that the side effects of certain medications can include memory loss and general confusion. Some participants felt that the use of prescription medications would cause or worsen dementia. One caregiver shared that the medication their loved one was taking had a lot of side effects that led to them being diagnosed with Alzheimer's disease. Once the medication was adjusted, they were back to their old self.

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.

Well I think losing my dad was a really huge traumatic event for her and just getting older and losing more and more people. Um, just basic stress I guess and inability to deal with stress I guess not the stress itself or having it but the inability to release it and move through things. (Caregiver TM04)

One caregiver believes that Alzheimer's disease is associated with unresolved trauma and people not dealing with their issues. Coming to terms with loss and dealing with traumatic events in our lives can take a tremendous amount of strength and energy. If a person does not have the means or support to deal with their issues, they may adopt certain coping strategies to manage the impacts of stress around the issue, which may lead to certain behaviours that can harm the health and wellbeing of the individual.

I'm an aboriginal person and the way that we think about things is completely different so I talked to myself about it. I mean I use my own senses of what I think Alzheimer's is and to me I think its um, ah it's a generation of people who didn't think about dealing with issues so they carried them with them instead and it's instead of dealing with reality they're use to lying to themselves so when they get older and all of these little lies that they've told themselves have begun to breakdown then they, they don't know what to do with them. So I mean, I talk to people about healing and wellness like on a daily basis those are the people I know. Those are the things that we talk about. (Caregiver TM04)

Other factors that were believed to contribute to the progression of symptoms related to Alzheimer's disease and dementia included isolation and loneliness. One caregiver shared their beliefs around what contributes to the progression of dementia.

So, at first I thought it was because she lived alone after she finished work and no, and I, we had family over there but they didn't bother with her much. So I think to me I don't know what's true but I think that would have brought it on faster. I, I don't know. (Caregiver TM05)

In discussing some of the causes of dementia and Alzheimer's disease, one senior talked about seeing a presentation where there was a black mark on the brain one of the participants from the focus group felt that concussions and head injuries could lead to dementia and Alzheimer's disease later on in life.

I read somewhere that um, people who had Alzheimer's later in life it usually stems from some type of fall from their past. They hit their hit real hard or something to do with a concussions ...

Or a concussions or something like that ... that later on down the road the result of that can lead to Alzheimer's. (Focus Group TM01)

Processed foods, alcohol and substance abuse:

Some of the Six Nations participants stated that a poor diet may have an impact on memory loss among Aboriginal people. While a few participants felt that excessive alcohol use and drug abuse potentially caused dementia.

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
- Getting old
- Reverting back to childhood / second childhood
- Deteriorating
- Sickness in the brain
- Memory loss
- Old timers disease / some timers

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

KB: They kind of joke about it. PN: Um hmm. They make jokes about some and I find that with a lot of them like you know when they forget something like and they can't remember right away they do make a joke out it and they laugh about it. (Focus Group TM01)

You know when you say that Old Timer's disease it sounds, it sounds not as severe and um (yeah that word) hurtful as Alzheimer's and dementia. (Senior TM01)

WORDS FOR DEMENTIA IN THE LANGUAGE

Some words and phrases from the participants' Aboriginal languages were shared about aging related memory loss and confusion. There were no specific words for dementia or Alzheimer's. One traditional knowledge keeper we interviewed suggested that there were ways of speaking of memory loss and forgetfulness in the languages, and ways of distinguishing between stages of forgetfulness (that is more serious cases). The traditional knowledge keeper did share Cayuga words and their respective meanings that may be used to describe symptoms associated with dementia:

Uh [pause] you say uh "sáh-sa" Well it would translate as "how he remembers" and then, [short pause] you know, "sáh-sa" means he remembers and then "soknigoheh [00:25:14]" would mean when he starts to forget, being kind of forgetful. (Traditional Knowledge Keeper WW 01)

"Soknigoheh skon" when a person starts to become more forgetful, like you know, they forget all the time, "soknigoheh skon." So those are some of the things. (Traditional Knowledge Keeper WW01)

Um, that's what I was just trying to think and that's the only word that I can come up with is uh, "soknigoheh skon" and that mean's you know, there's another term that I've heard uh, where they say [speaking in the language 00:26:45] I guess you could say [speaking in the language 00:26:47] which would mean that they're going into their second childhood. (Traditional Knowledge Keeper WW01)

DEMENTIA SYMPTOMS

When caregivers, individuals with dementia, and seniors were asked to describe the dementia symptoms they most commonly experienced, they quite naturally fell into four categories in Six Nations: mental, spiritual, emotional, and physical symptoms.

MENTAL SYMPTOMS

People with dementia, along with the caregivers, expressed that forgetfulness was one of the main symptoms that people with dementia were experiencing.

When asked how their dementia or memory issues affected them, a couple of people with dementia shared that they had difficulties with planning ahead; as they would often forget what they were planning for. Forgetting to turn off the stove, losing or misplacing items, as well as forgetting the names of certain objects, was also discussed.

I just be, I, I'd get up and come out here to get something and I forget what I'm going to get and I have to stand there for a minute to think about what I came out to. I think a lot of people has done that though. (Person with Dementia TM04)

Um, the forgetfulness is specific, it's with to do with names of things. She can describe to you what the thing is but she cannot tell you what the name like the specific thing is called. (Caregiver TM04)

One caregiver shared how her loved one's symptoms progressed to a point where they could no longer remember or recognize other family members and started exhibiting unusual behaviours. The continual progression of the disease can be extremely hard on families, especially if they do not regularly see the person with dementia.

Um. And I think when she didn't recognize um, family members that was kinda hard too. She's doing things that you know she normally wouldn't, wouldn't do ... I don't think she's aware of it. Of what's, cause she, sometimes she looks dazed out I guess and like when she didn't recognize um my brother and sister, that was hard. (Caregiver TM01)

This caregiver explained that they share the caregiving duties with two other family members and take turns watching after their loved one in their loved one's own home. They feel that it is easier than trying to move their loved one out of their home into unfamiliar surroundings. This caregiver also shared that someone has to be there at every meal time to ensure that their loved one does not hurt themselves trying to cook something.

We just try to make it easier, easy for her like, cause she still wants to try and make breakfast, she's, she can't cook no more that's definitely out. I was, it was my turn that one and I got there, I phoned her and said I'm on my way I'll be there by 5 because they eat at noon and 5. 7, noon and 5. [laugh] No it was lunch time and um I was just coming up stairs and I could smell hamburger so I thought oh somebody must have started, here she, I just come around there and she was um had her hand, she was frying hamburgers and she was gonna use her hand to take it out of the pan. (Caregiver TM01)

Many participants also talked about how people with dementia could often recall long term memories, but had difficulty with their short term memory and could not recall more recent events.

Ah, she forgets a lot and it's mainly ah things not to long after you talk about it but she remembers years ago and up to a certain year you know where, like she has two, had two sisters, one passed away and the other one is sick in Hamilton and um she remembers all of that and things. (Caregiver TM05)

Many participants also talked about how people with dementia often lived in the past. This would most likely coincide with the person's long term memory being more prominent. This caregiver explains how their loved one would talk about their childhood and where they grew up.

Ah, not really, it just that, because she's lived, she lived in her past. She kept talking about going home, even after living in her current home for 60 years that didn't become home, she would say this isn't my, my house. She was thinking of her home that where she would talk about um where she grew up. (Caregiver TM02)

This caregiver shared how their loved one would be adamant about returning back to her childhood home and how they would have to drive her around the area up to three times a day in order to keep her from wandering off.

She would, like I said, she would be talking about going home and she would become very insistent about it and she would even um, if, if allowed she would even begin to walk down the road going towards her home and therefore to prevent that because I couldn't really tie her down or do anything like I would drive her. We would go in the car and I would drive around the area where she once lived and she would look for it She couldn't find it and I would have to do this about 3 times a day. (Caregiver TM02)

As the symptoms associated with Alzheimer's disease and other related dementias progress, people with dementia may start to exhibit more and more compulsive and habitual behaviours. One caregiver mentions how their loved one needed to do certain chores and eat at specific times every day.

Um, she still has habits that, that she's done forever I think just like eating, she's gotta eat right at noon, she's done laundry every day, she still wants to do that even if she puts like 2 things in the washer. So were trying, trying to wean her off of that I guess. But we still want her to do things like we don't want to take everything away from her, while she can still do stuff like that. (Caregiver TM01)

One specialist talked about a couple of cases they have seen where the patient was no longer able to understand English, but spoke entirely in her native language.

There was a couple cases when I was working full time at the lodge as a nurse there, that um, people, this one lady with Alzheimer's and that, as it progressed, she did go back to her Native language and that she no longer understood the English and I thought that was so fascinating. (Geriatric Care Specialist WW02)

SPIRITUAL SYMPTOMS

Participants explained that in their culture hallucinations or visions were accepted as normal for people who reached an advanced age or who were closer to the spirit world. One person with dementia shares the teachings they received around growing older and seeing spirits.

You see in my religion I'm longhouse and ah we have spirits. There are things we see that other people don't see. And it's just a natural thing for our religion, like the old Indians. And ah, I've had those kind of things happen to me but they were always put off by the elders in my family as a part of growing and you know, they were hallucinations or anything it was just a part of growing up. (Person with Dementia TM02)

One caregiver understood that her loved one was getting closer to passing into the spirit world and expressed her frustration over having to explain cultural beliefs to health care professionals only to have them brushed off as being a symptom of dementia.

And it's something that it's a sign of dementia and for me that is clearly not a sign of dementia. That's an expected behaviour and it's expected in little ones and in older people and I found it irritating and demeaning to have to explain it and for them to just dismiss it as a sign of dementia. Because I expect her to be able to see um, people who have gone on, I expect her to be able to see things that aren't accepted in the main stream. (Caregiver TM04)

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. When participants with dementia were asked what kind of symptoms they experienced and if they felt like their emotional state has been impacted, most of them said that they did not feel that their mood or personality had changed. One participant with dementia mentioned that they have always been a cross person, quick to react angrily, and did not feel like their personality has changed with their memory loss. Another participant felt that their personality changed in they had to kick a family member out of the house because they did not pay rent for over four months. This caused them sadness because they could no longer see their great grandchildren.

Many caregivers, however, did notice a change in their loved ones' behaviours and moods and gave the following examples.

Um, my mom's kinda getting cross and she was never ever like that. She's not like that with me though but I see her with other family members that, that she can snap on them now and she never use to be like. Um, I think that's the hard part is just knowing that, that's not her. (Caregiver TM01)

Her change in mood, not her personality really but ah the mood is I think more of when she gets tired. She gets over tired cause she won't go to bed until we go to bed ... See with the, even the personality I think because ah she's just over tired and kinda crabby. (Caregiver TM05)

One caregiver shared that their loved one was tremendously anxious and needed to know where they were at all times in order to feel safe and secure.

If I was in the bathroom, I would, she would knock on the door [laughter] or at sometimes I would even leave the door open so that she could see me since it was just her and I there. And at night I would leave my bedroom door open and the light on, not my light but the hall light so that she could see you know that so she would always be able to see cause that seem to be a something that she needed to have. (Caregiver TM02)

Participants also commented on how frustrating it would be to know that one's memory was not as good as it used to be. One caregiver shared that their loved one denied having any memory issues and become angry when it was brought up. Another participant expressed that the person with memory issues may be angry at their situation and taking it out on the people around them.

Like we would tell her that she needed maybe to see somebody about her thinking but she would say no there's nothing wrong, so she did deny it and she would become angry and ah, she would refuse to receive any type of help that we might had suggested. (Caregiver TM02)

Yeah cause you see people, you'll come across people that are angry and um they're not angry at you they're angry because of their situation and they realize that something is happening to them and it, they're embarrassed and anger. Anger is another, I forgot to mention that. That's another feeling that comes up. (Senior TM01)

One caregiver spoke of how their loved one with dementia started to withdraw from family get-togethers and would leave the room and go sit by themselves. One of the reasons may have been because of the noise, or that the person with dementia did not remember the people in the room anymore.

Like when she didn't recognize um my brother and sister, that was hard, but, made, it, like I was sad when that happened cause I was there and she kinda like just withdrew from all of us and just went and sat in her room all by herself. (Caregiver TM01)

PHYSICAL SYMPTOMS

Physical symptoms experienced by those interviewed included dizziness, loss of balance and coordination, including the ability to write, as well as loss of the ability to process speech.

Even with her balance, just bunch of little things that, her coordination yeah, even her speech. (Caregiver TM01)

Participants also discussed the decline in personal hygiene and physical appearance as a common symptom associated with Alzheimer's disease and other related dementias.

So, we, she tried to get her to wash her hair today she said I'll help you and do it at the sink cause she doesn't like to get into the tub, she does sponge baths and ah but she, all she'll say no I'll do it myself but we know she can't do it herself. So sometimes we can talk her into if we're out shopping talk her into getting her hair done at a shop sometimes it's, that works better. (Caregiver TM05)

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 SIX NATIONS

The participants in this research may or may not have had a formal diagnosis of Alzheimer's disease or a related dementia. The majority of the caregivers stated that their loved ones were tested and diagnosed, with three caregivers stating that their loved ones had Alzheimer's disease, while one caregiver stated that their loved one was diagnosed with vascular dementia.

Yes, we did take her to um Brantford to get, to get some kind of a help and as I understand it Alzheimer's is a type of dementia, um and she was diagnosed with Alzheimer's in 2002 ... Um, Dr. ----- she's a neurologist; she's currently at in the Brantford General Hospital. (Caregiver TM02)

Health care workers cite instances of dementia, vascular dementia and Korsakoff's (alcohol related dementia) in their clientele. The geriatric care specialist stressed the importance of being aware of the signs and symptoms associated with Alzheimer's disease and other related dementias and felt that this awareness could result in earlier assessments and possible diagnosis. The specialist also felt that this would allow the family members the time to read up on what kind of supports they would need to effectively deal with any behavioural changes.

I think it was very important in the community to get that early diagnosis and stuff like that, um, due to the fact that the family were able to um, to keep the loved one at home longer if they had the supports available and also the knowledge of it. Mostly with when you start to get into the behaviours of um, with the Alzheimer's and stuff like that, aggression or just different behaviours that are seen, um, it's easier for the family to be aware of it at an earlier stage, that way they are able to care for the individual longer at home. (Geriatric Care Specialist WW02)

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 Six Nations participants, a dementia assessment usually occurred when the person who was experiencing memory loss or confusion (or their loved one) approached their family doctor. In most cases, the doctor would have the patient take a "memory test" (cognitive screening) designed to check their cognitive ability. Questions on these tests can include asking the name of the current Prime Minister, specific dates of well-known events, and drawing a clock.

So um, I know it had to do with ah her slowly losing the ability to drive, it being noticed by my brothers and my sisters and then her losing her license. They did an actual test on her. (Caregiver TM04)

Three out of the five people with dementia mentioned that they were given a memory test and were asked some questions by the doctor, but did not elaborate on the types of questions or if they felt that more appropriate questions could have been asked. Similarly, four out of five caregivers said that their loved ones were tested, with only two of the caregivers saying that their loved one was given a combination of a verbal and written test.

Her family doctor, they just kinda did like a memory test just asked her bunch of questions, um, more or less asked us about her, the changes that we noticed. (Caregiver TM01)

MISDIAGNOSED DEMENTIA

There was one case where a caregiver felt that her loved one was misdiagnosed with Alzheimer's disease and felt that the symptoms that her loved one was exhibiting were simply side effects from the medication. Once the medication was adjusted, the symptoms went away, but the diagnosis was not removed.

No um what happened there was um, his medication wasn't adjusted. Yeah, it got all kinda and it messed him up so then they diagnosed him with Alzheimer's and soon as his medication was straightened around he was ok again. So and he's been this way ever since. (Caregiver TM03)

UNDIAGNOSED DEMENTIA

There was a sense from participants in the focus group, as well as the geriatric care specialist, that there were more cases of undiagnosed cases of Alzheimer's disease and other related dementias in the community. The geriatric care specialist thought that some family members tend to normalize their loved one's behaviour or memory loss and therefore do not seek medical care until the symptoms become much more advanced and problematic.

Living with the dementia in the community, um, I don't think you really see, the families are so connected and close here that um, they um, tend to, when I'm going, when I'm doing some assessments, family will be there and they'll be jumping in because mom's not answering quick enough and then um, at that point I usually, you know, come out here and talk and then I'll explain to them, well this is why I want them to answer, you know, stuff like that, so trying to educate them. (Geriatric Care Specialist WW02)

Some people admitted they avoided accessing physician services because they did not like their family physicians and/or they did not like the physician they saw for their initial consult and so did not come back for their follow-up. Other participants reported not having a family physician. One person, who was having problems with their memory said that they brought it up to their family doctor, only to have the doctor tell them that it was a part of growing old. Shortly thereafter, the family doctor retired and the person has not sought out a family physician since then. A couple of other participants with dementia said that they did not feel comfortable talking with the physician they went to see and have not gone back.

CULTURALLY RELEVANT ASSESSMENT

Getting a diagnosis of dementia for Aboriginal patients is anything but straight forward. There are often language, communication, and cultural issues that must be overcome in order to properly diagnosis dementia. The geriatric care specialist tries to get at some of these issues by taking the extra time to talk with their patients and build a relationship, understanding that some Aboriginal people may not feel comfortable discussing health issues with people they do not know or trust.

That's the thing, that's where it comes down to, you don't just go in and um, "Hi, my name's, you know, so and so, I'm going to do some, um, testing on you, see how your memory is, to see if you have dementia." It's how it's worded. What I do in that first initial assessment, I'm doing my nursing history, the first visit, we will go through all the stuff and I would say something like "I noticed when we were doing this you had a little bit of forgetfulness, you know, you had a little difficulty focusing on this" you know, to get them talking about it. And then I would ask them, are you agreed, like I can come back next week, and that and we can sit down and go through some tests and I'll explain a bit about it. When I come back, um, usually they do remember my face, um, sometimes, you know they can't remember my name, but um, then I'll go sit down probably for about 10, 15 minutes and, you know, "you remember last week when I was here" and you know, I'll say a few things and that, "is it alright if I do the testing." Never ever have I just jumped right into it, um [short pause] possibly when I first started, I prob, you know, I might have but um, you're not going to get the results. They stop, they literally stop, they won't talk. (Geriatric Care Specialist WW02)

When I'm doing either a mini-mental um, or my other assessments, um, kind of change it, looking at the Native culture in regards to um, the individual. I usually would sit with them for an hour to two hours [inaudible] just get the basics and that, and then I would come back later to do either mini-mental, the MoCA, or extended dementia scale, um depending on the severity, I've seen, when I first did my first nursing assessment to see how far along they are in their um, cognitive impairment. (Geriatric Care Specialist WW02)

In addition to taking the time to build a relationship with their patients, this care specialist would also try to modify some of the assessments to make them more accessible for the individual, taking into account their values, beliefs, along with any other factors that may impact comprehension and understanding.

Then I would um, if I'm doing like um, uh, a mini-mental, I would look at changing certain things in regards to um, you know, listing um, and if house call late, I may change it, may change that to um, things that they are familiar with in the culture like a wolf, you know, stuff like that that they are familiar with, trying to keep it that way. Also with uh, spelling world backwards, I felt

that was um, a lot of it could do it, and that, but when I had the difficulty, I would bring in other stuff if I knew they were traditional, or if I knew they were Christian based in the community, I would bring in certain things as a Christian, you know, like um, Lord or church and have them spell that backwards. (Geriatric Care Specialist WW02)

Asking about the Six Nations, you know, going through the Six Nations, name the Six Nations in regards to that, um, uh, changing things from identifying the, in uh MoCA, they have like a, I think it's a camel, um, a rhinoceros, and um, a lion, changing them because I um, I would do my own pictures, make them larger, working with the elderly, made larger just because things are so small, and I would have a picture of like a wolf, bear, you know the clans of the nation and that so stuff like that, changing it that way. (Geriatric Care Specialist WW02)

TREATMENT AND CARE-GIVING

TREATMENT

The Six Nations participants were asked to discuss the different approaches used in the treatment of dementia, specifically around Western / biomedical medicine and Traditional / Indigenous medicines. While some participants shared information about the types of medications they were taking, a lot of participants did not know of specific traditional medicines that were used to help with symptoms of dementia.

WESTERN MEDICINE

Following assessment and diagnosis the most common treatment option for Alzheimer's disease and dementia is the use of pharmaceutical medication. The specialist stressed that in most cases Aboriginal people seek medical help later in the dementia disease process compared to non-Aboriginal patients which limits treatment options:

I think that comes down to um, later detection in regards to, yeah, because if, I always go back to that, if it's caught early, if the um, warning signs and the family are educated a lot more on the warning signs of that and it's brought in, with the medications that we do have now to slow the progression, with the teaching and stuff like that, I think there's that little bit longer, that we would be seeing compared to when they're actually, they come in, they're at more of the advanced stage and you know, you got three years, three, four years. (Geriatric Care Specialist WW02)

A couple of caregivers spoke about the effects medication had on their loved ones and how they had to often go back to get their medications or dosages readjusted. One caregiver

commented on how her loved one was like a zombie after the doctor changed the medication. Once they took the person off the medication, it took about six months for them to get back to being themselves. Another caregiver said that their loved one was prescribed Aricept, which is used with Alzheimer's disease.

Finding the right medication for a person can have a tremendous impact on their day to day lives. One personal support worker shared a story of the positive impacts of a medication change on a person with dementia.

But they put him on medication and it was through this ah they, they were treating for Alzheimer's and they put him on this new medication and you would not believe the difference in that guy within two years. Yeah, he, like he could, when I first went there he, he'd go out for a walk and he would just wanna go right down the road, just keep right on going and the, by the time second year he go for a little walk get down to the end driveway, he'd turn right around and went right back to the house. He could talk and tell you about the stories he liked to watch Y&R. He would tell you all about the stories. (Focus Group TM01)

TRADITIONAL MEDICINE

Six Nations participants included followers of Christianity and traditional Haudenosaunee teachings. Some participants noted that those individuals who were of a traditional orientation (or the Long House faith) might experience or think about Alzheimer's and dementia in different ways.

While participants did not speak at length about the use of traditional ceremony or medicines for dementia specifically, we did find that historically there were ceremonies that were specifically aimed at Elder health (or illness) and that Elders were given teas derived from Red Whip (red willow).

Some participants shared that they hosted or took part in other traditional practices to maintain or improve their health and wellbeing.

Yeah, so we have a feast for that and it seemed like ah after we had put that through for him that it, it kind of settled him down and you know it just like a few short days after to that the doctor he had gone back to the doctor again and they readjusted this and that and It seemed like it worked out good for him. I don't know whether it was the pills or the feast or what maybe a combination of both maybe. (Caregiver TM03)

The traditional knowledge keeper did not believe that there was a specific ceremony that was used for dementia or Alzheimer's disease, but did talk about one ceremony that could be used to help with forgetfulness and symptoms related to nervous system disorders.

Uh [sigh] [pause] no, not, not specifically. Uh, I think one of them, actually when uh, just thinking of it, the um, the eagle dance is actually something that uh, is used, not specifically for a person being forgetful but when they are having memory problems or um, mental problems, difficulties um, yeah, that's, that's one of the ceremonies that's prescribed for that. (Traditional Knowledge Keeper WW01)

Um, well the eagle dance is uh, you know, it's, it's the ceremony dedicated to the uh, the eagle, you know what they say is that [short pause] they actually, these sort of uh, diseases I guess uh, whether it be Parkinson's or be a person being forgetful or even, even nervous, you know, a nervous condition, um, that uh, eagle spirit I guess has the ability to, to heal that and so what they'll say is that uh, you know, they, they go through the, the healing ceremony, there's a tobacco burning at the beginning, uh, people who belong to it are invited um, and there's, you know, certain ceremonial foods that are cooked. Um, dancers are, are, singers and dancers are brought in as well and uh, so when you begin you have the tobacco burning ceremony and then the speakers who are invited to attend. (Traditional Knowledge Keeper WW01)

CARE-GIVING

WHO PROVIDES CARE?

The caregivers in this study were adult children looking after their parents. All five caregivers interviewed were women, four of which cared for their mothers and one provided care for her father. Some of the other participants including, people with dementia and seniors were cared for in a long term care facility in Six Nations, while others had the assistance of home care. A couple of seniors commented that the community tends to take care of each and look out for one another. When community members see people who may have troubles with their health or with their memory, they will go and talk with them and figure out if they can help them in any way.

Um, ah a lot of people um know that, that's what that there's you know, everybody knows everybody pretty well so you, you pretty well know if somebody's having trouble remembering things. So everybody just, see most people have patience with them and kinda figure out what they, what they want or um if somebody needs to be called to come and get them or or something that, they seem to be treated I think with, with respect and dignity. (Senior TM02)

Many participants greatly valued the services in Six Nations in helping them or their loved ones stay in their homes and in their community for as long as possible. For the most part, home care workers, drivers, and support staff were members of the community and were well known by the participants who used these services. Participants stated that they felt more comfortable asking questions about their health and receiving care from people that they knew and who treated them like family.

WHY DO FAMILIES PROVIDE CARE?

In most cases, the family has decided to take on caring for their loved one out of love and familial obligations, as well as a desire to have them stay in their homes for as long as possible. One caregiver explains the reason why they decided to become the main caregiver:

Um and it's not even um, a question of ease it would just like it's not a question. It's not a question whether I would do this for my mom or not it's just the way life is and I think that might be different then the bigger outside world. You know the last thing that we want to do is send them to a nursing home whereas that seems to be the first ah avenue for people that aren't, aren't family oriented. Um, the other thing is um, my brothers and my sisters and specifically my niece, they want mom to come visit they want her to be with them so we do it together even though I'm the one living here ah. TM CG 04

EXPEREINCES WITH CARE-GIVING

Care-giving tasks

Caregiving tasks were dependent on the stage of dementia the person was in. Caregiving participants talked about helping their loved one with household chores, getting around the community, driving them to appointments and communicating with doctors, and cooking meals. People who are in more advanced stages of dementia need additional help with grooming practices, bathing, and getting dressed. One caregiver gave up her fulltime job so they could take care of their loved one.

Yeah for myself to I suppose cause I find myself just saying well what if dad could ah, what if, wouldn't it, I sit here a lot of times and think wouldn't it be nice if somebody came, took dad for a ride cause he likes to go for a ride, took him for a ride and I could go to sleep. That's the first thing I would do is I would just lay down and go to sleep. Ah, well actually it isn't difficult it's just committing your time yourself. Like I gave up my full time job I gave up everything so I could come and look after him. (Caregiver TM03)

Challenges

There were many challenges related to care that were talked about by all participants. Some participants with dementia were saddened by their loss of independence. Many expressed that they were not able to get out and socialize in the community as much as they wanted to because they either did not have a car or their license was taken away and they could not drive. 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.

It definitely did affect my relationship with her not understanding um what was happening to her fully and it would make me angry and I would argue and that's one of the things that one shouldn't do with a dementia person is to argue with them but I didn't know that and so I would become upset and angry and we would get into it. And for example um I mentioned that she would misplace her purse and she would accuse me of taking it or hiding it or taking the money and that would upset me too not understanding where she was coming from or why and that would make me angry and so my not understanding it may have even made her worse in arguing with her cause I didn't know that I shouldn't be arguing with her. (Caregiver TM02)

Um, so that was a challenge learning patience. Trying to understand where my mom was at. Which challenging mainly cause I didn't have that information you know a lot of that information I didn't have on the onset. (Caregiver TM02)

Taking care of a loved one at home can be challenging, especially if the caregiver also works outside of the home. This situation can become increasingly difficult as the person's condition progresses. One caregiver spoke about the challenges they had in getting their loved one ready in the mornings.

Um, yes, when um, when I have to get to work in time and I have to tell her 7 or 8 times so I think this is really my stuff it's not hers. Like sometimes ah I forget that she has dementia of a sort and I need to be more patient so really it's a you know it's all of those types of things it's like mom I need you to get ready, mom I need you to get ready, mom I need you to get ready and then she gets mad and then I get upset because I'm just trying to get her out the door or getting her up in the morning or all of those things. (Caregiver TM04)

This caregiver also talked about the challenge of taking their loved one to various medical appointments, especially if the appointments are outside of the community.

Anything that makes it difficult? I guess just the fact that they are all over the place. To me I feel like every, I'm always running her to a different appointment for eyes, for her teeth, for a check up for this and a check up for that ... So, the fact that I have to take her all over like to Hamilton for specialists and to Brantford for specialists and those things is kind of a pain. (Caregiver TM04)

Family based caregivers shared many stories of the challenges they faced as part of this role that they took on. Taking on caregiving responsibilities can cause a lot of stress and frustration, especially if the person does not have the knowledge or support to help them. If there are any unresolved issues from the past, that could also impact the caregivers ability to care or to cope with what is happening. One caregiver mentioned the toll that caring for their loved one has on their own health.

And one other thing that I might mention is that toll, that caring, that caring for a dementia person can take on one's health. It does even without realizing it, it takes a lot out of a person and I know that um we've centred on the person with the dementia but I think if anybody's going to be caring for a person with a, with a dementia and as it becomes more experienced on the reserve I think that will be happening more people will be caring for their loved ones in the home. (Caregiver TM02)

This caregiver also had challenges in arranging respite care with people who had experience working with dementia patients. They commented that the respite worker did not have the knowledge or experience to work with people with dementia.

Decisions around long term care

Caring for a person with dementia can be very demanding. As the condition progresses, the person with dementia will need more attention and care, sometimes resulting in needing twenty-four hour care. Caregivers at this point may need to make additional arrangements to ensure that their loved one is safe and getting the care that they need. For some caregivers, this means quitting their jobs to take care of their loved one. For other caregivers, this may mean looking at long term care centres. For some caregivers in Six Nations, the thought of putting their loved one in a long term care facility brought forth a lot of mixed emotions.

I heard rumours that he was going, putting him in the nursing home so I just thought I'll put a stop to that and move in with him. (Caregiver TM03)

As long as I can I would rather have her in her house where she's happy, where's she comfortable, this is her house. As long as it's possible for us to take care of her here we will and it would have to be like extremely difficult for us to make the decision. There have to extreme behaviours in order for us to make the decision to put her into care. (Caregiver TM04)

One caregiver remarked that her loved one was becoming too hard to look after by herself. In addition to not being able to fully care for her loved one's needs, the caregiver also spoke about the physical, mental and emotional toll that it was taking on her.

I had spoken to the nursing home prior to that, a few weeks before that before her injury about putting my mom into the nursing home because um she, it was just becoming to mentally and physically hard to handle her by myself at home. And from what I know of dementia, her symptoms will get worse it's not something that's curable at this time. And I know that she won't recognize me in time or know, know who I am. I know that her speech will eventually go, and I know that this disease will eventually lead to death. (Caregiver TM02)

Placing a loved one in a long term care facility is a difficult decision to make and often takes a toll on the primary caregiver and the rest of the family. One geriatric care specialist talked about the guilt that families often have around making this decision.

I was called in many times, it was um, usually there was a lot of behaviours being disclosed and at that point the family caregiver's stress and stuff like that was so much and trying to educate them at that point, [inaudible] that that behaviour is so strong in the home, it was very hard, and then it got to the point where, you know, have to be placed in long term care where then the family, the guilt too, was put back on them. (Geriatric Care Specialist WW02)

Some people do not want to put their family through the guilt and frustration of trying to make a decision surrounding long term care and will make their own care arrangements instead. This was the case with one person with dementia from Six Nations, who made the decision to place them self into a long term care facility so their family member would not have to make the decision surrounding caregiving duties.

Like my children didn't put me in here. I put myself in here because my daughter has a bad heart and I didn't want her having to you know doing everything for me so I thought I'd be better off here. (Person with Dementia TM02)

Strategies and Coping:

While many of the caregivers talked about some of the difficulties that arose in caring for their loved ones, they also talked about some of the strategies and coping mechanisms they used to deal with any of the challenges that came up. One caregiver said that they prayed that they would become a more compassionate person in caring for their loved one.

And ah, yeah I believe that, one other thing to that I had prayed about in fact was that I would become a more compassionate person because I felt I was harsh, like I could just feel that hardness and so I had prayed that the Lord would help me to become more compassionate and

through this he has. It's been a long haul, haul, you know. It's been hard. But patience comes through hard things and I believe he's given me that more compassion than I had before.
(Caregiver TM02)

Another caregiver talked about the importance of bringing the family together. Scheduling family functions, where the entire family could together and visit, allowed the person with dementia to socialize and interact with family, while giving the main caregivers a bit of a break.

We try have um, where the whole family's there at least once a month on a Sunday. We tried, we been doing that for a while. She seems to enjoy that. (Caregiver TM01)

This same caregiver said that she and some of the other people that helped care for her loved one would keep a journal every day to keep track of her loved one's moods and changes in personality. This strategy would also be helpful for reporting any changes to their family physician.

Um, well I still learn I guess as, as we go along with it. Just different things that she. Oh we keep a journal ah like [laugh] I guess it's a journal at home every day we write in there, whose ever there, what kind of day she's having or if she did something just so whose ever is there next can see what kinda day she's had and we write down if she did something out of the ordinary just so we got a record as just to see how she's, if it's getting better or worse. (Caregiver TM01)

BENEFITS OF CAREGIVING

Although there are many challenges associated with providing care for a person with dementia, there were many benefits of being in a care-giving position. Many caregivers felt good about being able to provide care and uphold traditional cultural values related to kinship roles. Further benefits that relate to family care include being able to rebuild and renew relationships, as well as being able to take care of their loved ones at home for as long as possible.

Ah, I think what made it easier or more natural is that being aboriginal that's one of the traits is family care. And it became an automatic sort of thing to is because it's even though we made have had a fight so that traditional feeling was still there as being family and so that, that made it easier. (Caregiver TM02)

And the rewards, there has been rewards in, in that and that it has brought us closer together as a mother and daughter. We weren't that close before in fact we fought a lot [laughter] you know, just verbally of course. Um, but since I've had to be the care, the one that did the caring um it changed my attitude towards her and it brought us, both of us closer since she had to rely

on me too it just brought us closer as a mother and daughter and then yeah having someone to depend on me and needing me help to change my attitude. (Caregiver TM02)

COMMUNITY AND MEDICAL HEALTH SERVICES

Six Nations has a wide range of services in the community including a health services department that offers programming for children, youth, adults and seniors. Services that are available in the community that were mentioned and are of particular importance to Six Nations participants include: a long term care facility, a pharmacy, a diabetic clinic, as well as mental health services, meals on wheels, home care, dieticians, social workers, and counsellors. Seniors in the community talked about the importance of having services and service providers in the community that understood the needs of Aboriginal people. A couple of seniors and people with dementia seemed to appreciate having a pharmacy that was staffed with individuals who were known within the community, easy to talk to, and who could effectively explain medications and the possible side effects.

I, I think they are. Because of well for one thing, because we have a pharmacy on the reserve and that I think a lot all seniors and elders should be really thankful that we do have we do have our own pharmacy and you can go there and you know they understand Indians. (Senior TM01)

Another senior spoke about their experience with homecare and expressed how much they valued the homecare workers who lived in the community and knew how to talk to them and take care of them. Building this type of relationship takes a tremendous amount of trust, respect and understanding.

They're very informative too and you can ask them anything. They're quite truthful with you. And it's more like on a um, like a family basis where people talk to you and if they need to scold you they'll scold you. Like it's on, it's you know it's like family talking to family, they're trying to tell you something for your own good. You know it's not like the outsiders say I've had some experience with outside health professionals and they come in and they don't talk to you they tell you like they. More or less say demand that you do something. You have to do this, you have to do that. And not you should and then explain why you should. They just say you have to do this. So it's, it's a lot better getting care here. (Senior TM02)

SERVICE NEEDS AND RECOMMENDATIONS

Even with the Alzheimer's Society offering workshops in the community, there was an identified need for more information about dementia from all types of participants. Caregivers

and seniors expressed a need for this information to raise awareness within the community, as well as help them anticipate and deal with the condition itself.

As it becomes more experienced on the reserve I think that will be happening more people will be caring for their loved ones in the home. It would be helpful to help that care, that caregiver to know what they may experience in going through something like that. Um, especially if that caregiver has had their own issues in the past. (Caregiver TM02)

Seniors and personal support workers suggested pamphlets, information sessions, workshops, and dementia groups as a means to raise awareness in the community and offer support to people with dementia and their caregivers.

I would think to send out um health letters. You know like the Council has information they send out about Council business maybe every so often send out a pamphlet or something about this information... about dementia and alzheimer's. Plus maybe on some, have a speaker come you know, have a, to the community centre and have a speaker come or a group of speakers and have it so that people could ask questions of them. Um hmm. Cause I think people are afraid to ask questions about it but they really, they would have to be encouraged really encouraged you know to answer questions. So would be better if they had like little booths around maybe. People could go sit down and talk to somebody. (Senior TM01)

In addition to having information for people with dementia and their caregivers, some participants felt that more information and specialized training was needed for healthcare workers and respite care. One caregiver expressed that the personal support worker did not have enough knowledge of dementia or training of how to care for dementia patients to effectively offer respite.

But the knowledge, the extent of the knowledge is not there. The experience is not there. So I found that like my mom when the personal support worker's would come in to try and give me, give me respite time a lot of the times I had to stay there just because the PSW didn't know how to handle mum. She would kick them out. (Caregiver TM02)

In offering specialized training for healthcare workers and respite care staff, it would be good to include a component as to why culturally appropriate materials are needed. When asked if resources were culturally appropriate to Six Nations or what they could use to make sure that resources are culturally relevant, the one personal support worker did not believe that culturally relevant resources were needed.

I don't think so because it affects everybody in the same way it's that um, what is it if I remember correctly that electric charge that goes through synapse in your mind, that starts to

deteriorate, its like that electric charge can't get passed from one to the other and when they slowly start shutting down that's the um, later stages it goes into the Alzheimer's from what I remember anyways so.(Focus Group TM01)

One senior suggested a more holistic approach in terms of providing seniors with a space to not only socialize, but a dedicated room where seniors could exercise, build up their strength, and learn more about preventative measures. Providing transportation to and from the community centre would also allow elderly people who may not be able to drive or arrange for a ride, to get out and socialize.

Or even if they built these um, these seniors complexes like if they had a recreation room in them. Well I think that exercising it might, you know helps, helps with delay that. (Senior TM05)

Focus group participants expressed the need for a new nursing home that is large enough to have a separate wing for people who are at various stages of dementia. They felt that the current nursing home was not large enough and did not have a separate space for dementia patients. They also suggested hiring more home care workers to go and visit with the elderly people who lived alone.

CULTURALLY APPROPRIATE APPROACHES AND CULTURALLY SAFE CARE

It is important for healthcare professionals to learn about the colonial history and how this continues to impact Aboriginal people today. Aboriginal people in Canada have faced numerous assaults on their identity through the aggressive assimilation policies of the Indian Act, including the forced removal of children from families through the residential school system. Indian Residential Schools were a place of terror for many Indigenous people. The legacy surrounding the schools has had a great impact on former students along with their families and communities. In addition to the colonial policies, many Aboriginal people were also subjected to racist ideologies and discriminatory attitudes. For some people with dementia, these memories and past traumas may start to resurface as their cognition starts to decline. One caregiver shared that as their loved one's symptoms started to progress, they started to make more references to some of the experiences they had when they were younger, especially if they were in a situation where they felt uncomfortable or like they were being judged. The caregiver felt that these experiences were from when her loved one was much younger, perhaps when she attended the residential schools.

I would say yes to some extent um, being a native person or aboriginal as you know aboriginal people, children were put into the residential homes. And I think there have been signs um I know that she would have experienced racism even though during the years up to the time of the

illness at home she never really expressed a whole lot of that but as the dementia came and has been there now she's talked, like we would go to Hagersville to get groceries or Brantford to go shopping and she would say these people don't want us here. You know, lets go back home. They don't want us here. So I think that's came from her past perhaps from the residential home. (Caregiver TM02)

One specialist recognized that many off reserve services and healthcare providers fail to acknowledge the impacts of historical trauma on Aboriginal people which most likely means that culturally competent care is not being offered as well.

Well I think that, and then I would also go back to uh, the trust that they don't have in non-Natives in regards to um, past things in history that have affected them and stuff, so they're not going to question because mostly if you're looking at residential again, you know, you do this, do this, do that, you don't question, you don't do anything, you just, that's that. So I think that is a main card with um off reserve services not being um, culturally competent in regards to understanding actually the whole history of um the Native population and trying to incorporate that into their sessions with them. (Geriatric Care Specialist WW02)

Cross-Cultural Communication:

The geriatric care specialist stated that physicians need to be aware of the language they use when communicating with patients and that the patients need to ask physicians to clarify terms in plain language when they do not understand.

So it comes back to when they were first seen, whoever gave them that diagnosis, the education wasn't input and you got to see with um, again with um Natives going off reserve to be assessed um, their trust in non-Natives and the information that's maintained because it comes back to what they understand and that so if they go into an office and they're saying all these big words, they'll nod yeah, yeah, but they don't understand. Even families accompany them and that, so when I was working in the role as a psycho-geriatric nurse, I would accompany some of them to their appointments to make sure, you know, everything's being said, once we leave there, then I would sit down and go okay, this, this and that. (Physician Specialist WW02)

Doctors and specialists need to be aware that their patients may not be able to understand them and will have to rephrase their questions.

Yeah um, sometimes I have to remind the different specialists that they have to phrase their questions differently, that um, they need to deal with her and not necessarily with me. Ah because once I start rephrasing their questions to her in a different manner then they take it as a queue that they need to just ask me and they kind of forget that she even exists as a human being and then I find myself being asked to speak on her behalf instead of help her and I don't

like that. And I have to remind them well ask her the question, rephrase the question to her not to me. (Caregiver TM04)

It was also suggested that 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.

In addition to learning about the colonial history, healthcare professionals need to recognize that each community is unique and that the care and services offered should reflect this. Physicians also need to realize that some patients may need more time to build a relationship before they fully disclose any health issues they are having. A couple of Six Nations participants with dementia mentioned that they did not like their doctor. One person with dementia felt that their doctor did not listen to them and simply passed off any of their concerns regarding their memory lapses as a result of aging. Another person with dementia said that they had a hard time opening up to the doctor and as a result never returned after the initial visit.

In summary,

Participants shared their ideas about approaches to care that would better suit their culture and needs. Others identified improvements that could be made at the level of the clinical interaction such as improved cross-cultural communication through health care worker training and at the program level through the use of Aboriginal language and culturally appropriate activities, food and exercise. This information, together with the findings concerning Aboriginal peoples understandings of dementia, can further inform culturally safe dementia care for Six Nations community members.

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