

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

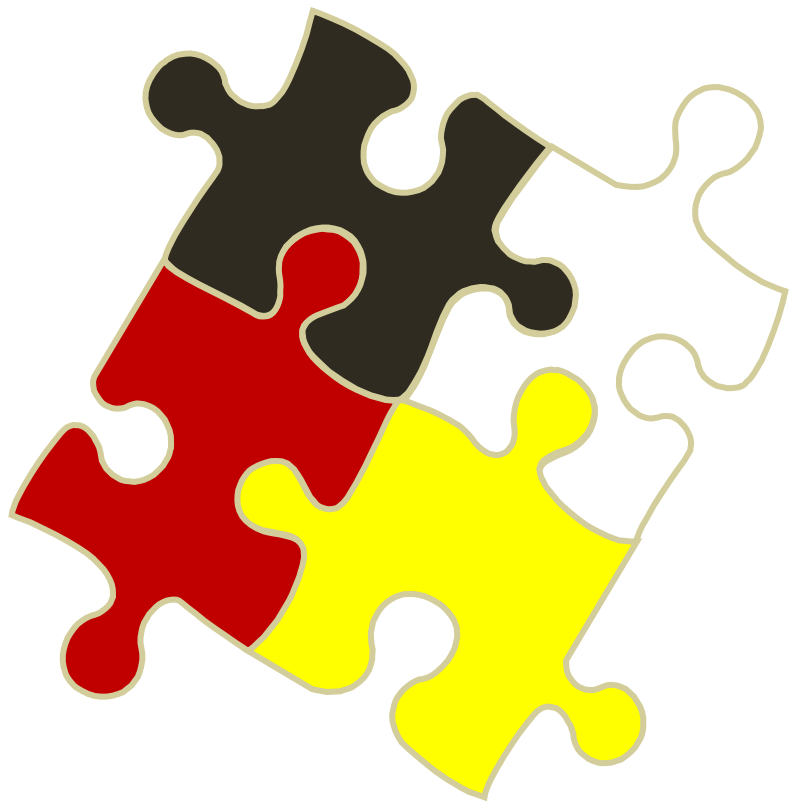
REPORT FOR MANITOULIN ISLAND FIRST NATIONS

December 2013

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## COMMUNITY APPROVALS AND PRESENTATIONS

The advisory group reviewed and approved this report in October 2013. It has subsequently been reviewed and acknowledged by the Noojmowin Teg Health Centre Board of Directors, Mnaamodzawin Health Services Inc. Board of Directors, and the Wikwemikong Health Centre Health Services Committee. The findings were presented and discussed with community members and health workers on the following occasions:

Presentation at the Wikwemikong Research Conference, Wikwemikong Community Arena, August 1<sup>st</sup>, 2013, by Dr. Kristen Jacklin.

Presentation to the Wikwemikong Health Services Committee, Wikwemikong, Ontario, June 13 2013, by Jessica Pace.

Presentation to community members at the Aundeck Omni Kaning Senior's Centre, Aundeck Omni Kaning, Ontario June 13, 2013, by Jessica Pace.

Presentation to community members at the Amikook Senior's Centre, Wikwemikong, Ontario, June 11, 2013, by Jessica Pace

Presentation to the Mnaamodzawin Health Services Management Team, Aundeck Omni Kaning, Ontario, June 10, 2013, by Jessica Pace

Presentation to Mnaamodzawin Board of Directors and Sheshegwaning and Zhiibaahaasing Communities, May 29<sup>th</sup> 2014 in Sheshegwaning by Dr. Kristen Jacklin.

(updated July 25<sup>th</sup>, 2014)

### KEY FINDINGS

#### 1) Views on Healthy Aging

- ▶ Participants generally held a shared view of what it means to age well. Participants agreed that to be healthy in old age a person would need to have good overall health in their life and be active in promoting their own health, have an active social life including good relationships with friends and family, participate in spiritual and cultural life, have a positive attitude, have a sense of purpose, keep busy and maintain appropriate autonomy.
- ▶ To achieve good health participants reported that a person needs to eat well; exercise or be active; and, avoid alcohol, smoking and other substance abuse. Being healthy and older requires staying active and engaged in life, having a role and sense of purpose, keeping busy and having adequate mind and social stimulation.

#### 2) Understandings of Age-Related Dementia

- ▶ Aboriginal people on Manitoulin Island who participated in this research overwhelmingly shared an understanding of memory loss and dementia as something natural that can be expected to affect some people on their journey around the circle of life. In describing their understanding some participants used words such as “natural”, “normal”, “part of getting old” and some participants used words such as “part of the circle of life,” the “journey around the medicine wheel,” and “return to infancy or childhood.”
- ▶ Many of the participants from Manitoulin Island 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, head trauma, amputations and prescription medications;
  - psycho-social: such as stress, unresolved grief, historical trauma, alcohol abuse
  - Indigenous: disruptions in relationships to land, bad medicine, not living a good life.
- ▶ Overall we note a general lack of worry about memory loss and dementia among people with dementia, seniors, and many family caregivers.

- ▶ Most participants agreed that dementia is a new or emerging disease for their communities. Some participants recall cases of people behaving with symptoms of dementia from many years ago but it was agreed that it was relatively uncommon.
- ▶ Many participants explain the increase in dementia as being caused by changes to traditional ways of life including an increased reliance on store-bought foods and a less active lifestyle. These participants also believe that changing roles of elders in the community over the years is contributing to more dementia, noting that elders used to have important roles in the family and community that kept their minds active.
- ▶ We found a tension between Indigenous understandings of age related memory loss and dementia (that is, natural and normal) and biomedical understandings of these processes as something 'not normal'. Based on our findings we suggested that there is an underlying acceptance of the illness as natural based on Indigenous understandings but these understandings can be layered with understandings of unnatural causes such as chemicals, medications, trauma, stress, etc.

### 3) Diagnosis

- ▶ The results suggest that Alzheimer's disease and dementia in Aboriginal people on Manitoulin Island who are not in nursing home environments, are usually not diagnosed. Explanations for not being diagnosed include an understanding of dementia as natural, and high rates of co-morbid diseases such as diabetes, arthritis, and/or amputations that are the priority for health care visits.
- ▶ Very few people in this study had undergone screening for ADRD (memory tests) and so we did not obtain a very much information concerning experiences with screening tools. A few participants, however, including people with dementia, care workers and a physician's commented that the current screening tests are not always appropriate.
- ▶ We found that how a person or family views dementia is related to when or if they seek medical care. Family members and individuals who view the symptoms of memory loss and dementia as "normal" typically wait longer to access health care services.
- ▶ The data reveal a conflict between how health care workers view the illness and how the community (people with dementia, family caregivers and seniors) view the illness. Health care workers expressed concern that the predominant understanding

of dementia as being “natural” is delaying care.

#### **4) Treatment**

- ▶ Very few participants were being actively treated for dementia. Some participants reporting being on medications usually prescribed for other emotional or psychological disorders and some were knowledgeable about medications for dementia but in general there was a reluctance to take medications due to the side effects.
- ▶ Few participants discussed traditional treatments for memory loss or dementia. Participants we spoke with were not aware of any specific traditional medicines for this illness. Some participants were engaged in traditional ceremony and used traditional medicines for other ailments and/or for overall health.

#### **5) Care**

- ▶ Overwhelmingly participants believed the most appropriate way to care for someone with Alzheimer’s disease or dementia was for family to care for them at home and for them to be in their home community.
- ▶ Participants agreed that nursing homes were not a desirable option for people with Alzheimer’s disease and dementia but also recognized that in some cases nursing home care may be the only option.
- ▶ Transfer of care to a nursing home usually occurred due to caregiver burnout, and the emergence of symptoms that the family caregiver did not feel able to handle (specifically around safety and the threat of the person with dementia inadvertently causing harm to themselves or others) and limitations in their own ability to handle the physical challenges of lifting and bathing.
- ▶ The model of caring at home and in community was noted to have many benefits. Family care-givers we spoke to reported benefits that included: the familiarity of place, the ability to provide culturally appropriate care, the ability to speak to them in the language, maintaining continuity in the families, maintenance of elder’s roles in the family and community (benefiting younger generations as well).
- ▶ Family caregivers identified issues of safety to be their biggest concern about caring for someone with dementia at home.
- ▶ Caregiver stress for our participants was primarily reported in relation to the continuous supervision that is needed for someone with dementia and the lack of respite, as well as a lack of knowledge about how the disease would progress and

what they could expect.

- ▶ Family caregivers caring for people with dementia in the later stages expressed worry about the person's safety and worry about how the disease might progress. In these cases, the view of dementia as something natural was shifting to a view of dementia as something frightening. We found the worry expressed was directly related to a lack of information on the illness.
- ▶ Nurses and Personal Support Workers (PSWs) are concerned that people with dementia are not receiving enough care hours and expressed worry over these client's safety. These workers expressed that those clients without adequate family support were most in need of additional care hours.
- ▶ Overall participants agreed that respite care and hours of home care services are not adequately addressing the needs of people with dementia or caregiver needs. Because people with dementia are being looked after into the later stages of dementia at home the home care requirements are greater than what would be necessary in non-Aboriginal communities. The complexity of the multi-morbidities people reported also requires more intense care for all of the person's health care needs. The rurality of most of the First Nations and remoteness of two of the First Nations in the Manitoulin region makes it unlikely that caregivers have adequate time to leave the community for groceries and supplies and return within the allotted care times.
- ▶ Health care staff and especially PSWs do not feel adequately trained or prepared to provide the best possible care for people with dementia. These staff also identified a need for a team approach to care that includes PSWs in the care planning. In particular we found that PSWs were not always aware of their client's diagnosis of dementia.
- ▶ Access to services varied between the First Nations on Manitoulin Island – this was most evident in terms of access to specialist services, access to nursing homes and/or housing and access to the Alzheimer's Society.

## **6) Dementia Related Programming and Information**

- ▶ Participants were not aware of any specific services for people with memory loss or dementia in their communities. Participants noted that senior's centres were available but these are usually community centres for seniors to socialize and are not designed or geared to people experiencing memory loss or dementia. Participants suggested that adult day service programs, friendly visiting programs

and services geared to men would be of benefit to people with dementia.

- ▶ Caregivers and seniors expressed the need for educational information about dementia in the communities. They expressed that these materials should be designed for Aboriginal people and be available in their language. These participants also felt that caregiver support groups would be a benefit.

## **7) Culturally Safe Dementia Care**

- ▶ Overall, the data informs the beginning of a culturally safe model of care for Aboriginal people with dementia on Manitoulin Island. Key elements of culturally safe care for participating First Nations include: ensuring access to care, policy and program support for a family care model, honouring the importance of elder's roles, addressing structural inequalities such as poverty and jurisdictional issues affecting access to care, enhanced patient-provider clinical interactions through cultural training.

## RECOMMENDATIONS FROM THE ADVISORY COMMITTEE BASED ON KEY FINDINGS

1. Undertake a review of service and communication gaps among health care providers and look for mechanisms to better connect support services for Aboriginal dementia care.
2. Work collaboratively with First Nations and Aboriginal health organizations on Manitoulin Island to establish culturally relevant support groups for community members caring for people with dementia, recognizing that Aboriginal care-givers are generally younger than those in mainstream support groups and access health services through federally and provincially funded programs.
3. Work collaboratively with First Nations and Aboriginal health organizations on Manitoulin Island to develop support groups for seniors with dementia focusing on the findings from this research that suggest support should focus on: creating or re-establishing a sense of purpose, emphasizing cultural roles as knowledge keepers and story tellers, encourage appropriate autonomy, include Aboriginal language, provide social opportunities appropriate to both men and women, and facilitate connections between generations.
4. Support a the family and community care model for people with dementia by enhancing opportunities to provide biomedical and cultural knowledge and information to the community and family care-givers on Alzheimer's disease and dementia.
5. Pursue research that more closely examines the connections between other chronic diseases of aging (especially diabetes) and age-related dementias.
6. Explore opportunities to enhance funding for more PSW positions and for dementia and/or geriatric training for PSWs.
7. Improve service coordination across jurisdictions within the region to improve resources available for dementia care with an initial priority on securing more resources for respite care.

## INTRODUCTION

### BACKGROUND

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

The need for this type of research was highlighted in January 2007 when First Nations Health Authorities in the Manitoulin District supported the need to address Alzheimer's Disease and Related Dementias (ADRD) in their communities. In March 2007, Mnaamodzawin Health Services Inc. and Noojmowin Teg Health Centre organized a roundtable forum on Alzheimer's Disease and Related Dementias (ADRD) concerning Aboriginal peoples. Aboriginal representatives from around the Province, as well as government representatives, physicians, researchers and members of Alzheimer's Societies in Ontario were invited to attend a roundtable in Sudbury, ON, to discuss what is felt to be an emerging health issue for Aboriginal peoples. There was a general consensus that Alzheimer's disease and dementia were becoming a health concern 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 Wikwemikong, all UCCM communities, and M'Chigeeng as well as relevant

information from the academic literature. We present western understandings of ADRD 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 participants' understandings of the causes of dementia and what dementia means in their communities. We also present 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 the First Nations on Manitoulin Island 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 ADRD

Within the biomedical model, ADRD 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 another illness or medications and can be successfully treated. By contrast, irreversible dementias, such as Alzheimer's disease, vascular dementia, frontotemporal dementia, Lewy Body dementia and Creutzfeldt-Jakob disease are caused by progressive neurodegenerative diseases that cannot be cured (Alzheimer Society 2010).

The primary non-modifiable risk factors for developing Alzheimer's disease are age and genetic risk factors. 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

***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

# Risk Factors for Dementia

## Non-Modifiable

- Age
- Heredity

## Modifiable

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

developing dementia (Alzheimer Society 2010). The Alzheimer's Society of Canada (2010) recommends healthy lifestyle choices as a means of reducing the risk of developing ADRD. 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).

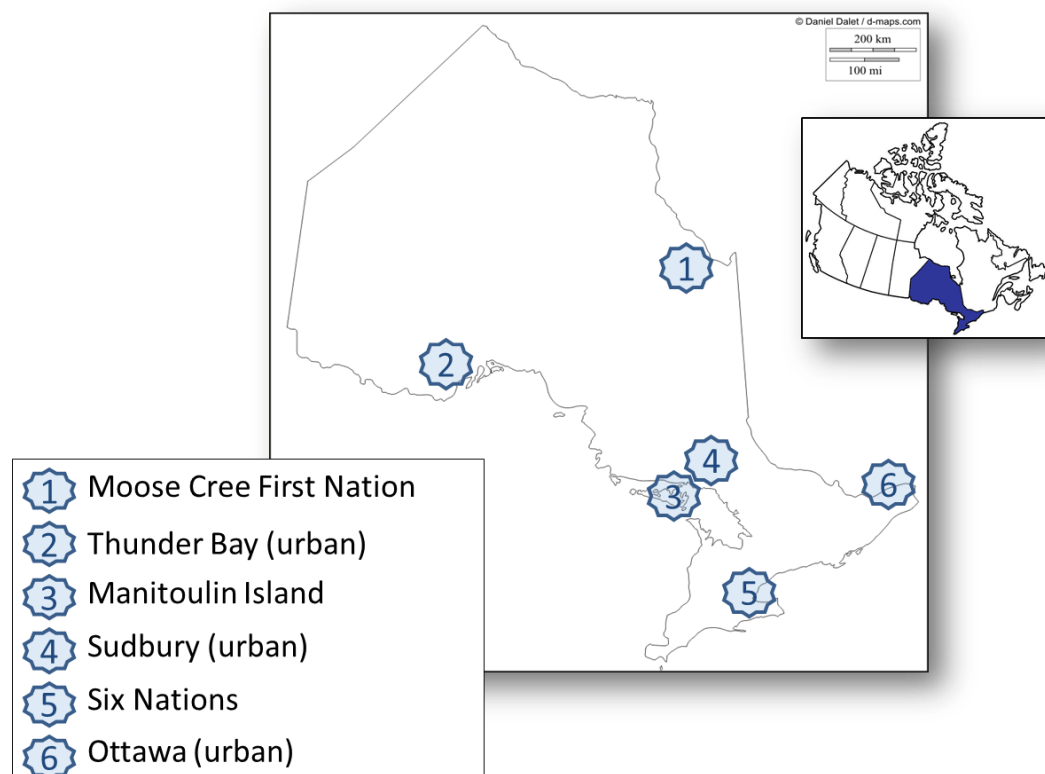
Clinical treatment for ADRD includes diagnosis, disease management and care for the person with dementia. After the onset of symptoms a diagnosis may be made by a doctor using a combination of the person's clinical history, cognitive testing (memory tests/screening) and, in some cases, diagnostic imaging (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 each author's affiliated organization and community-based ethics review boards on Manitoulin Island and Six Nations. All participating First Nations provided a BCR 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.

**Figure 1: Research Sites**



On Manitoulin Island our work was carried out in partnership with The Wikwemikong Unceded Indian Reserve (WUIR BCR 3614) and the Wikwemikong Health Centre (Health Services Committee #2009-08 motion 09-055); Noojmowin-Teg Health Centre (Board of Directors Motion #458-09); and Mnaamodzawin Health Centre and The United Chiefs and Council of Manitoulin (BCR 487). The research received ethical clearance from the Manitoulin Anishinabek Research Review Committee (MARRC) December 15, 2009. Our work was also supported by the Alzheimer's Society Sudbury-Manitoulin.

Community health 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), the CBRs were encouraged to participate in analysis of the interviews via an interview summary process and through participation in team meetings.

Community advisory groups were struck for each research location usually including health directors and community volunteers. The role of the advisory group is to review the data analysis as presented in draft reports and presentations to ensure the information is an accurate reflection of the community and to ensure that any local knowledge in the reports or publications is presented respectfully and accurately. The advisory group also provides guidance on the best methods of dissemination of the research results in their communities.

#### THE INTERVIEW SAMPLE

Data reported here is from the research conducted on Manitoulin Island 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; (3) ethnographic fieldwork. This study used a convenience sample. A PhD student (Jessica Pace) and local community based researcher (CBR) (Karen Pitawanakwat) worked with local research partners in Manitoulin Island First Nation communities to recruit participants. Potential participants were identified and first approached by a LTC 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 a variety of types of people to ensure that a complete picture of the dementia experience could be reported. We recognize that interviewing people with dementia for this type of information is challenging. In general, interviews with people with dementia were less successful in obtaining some of the specific information reflected in our interview questions, however we did learn a great deal through these interviews that help us contextualize their experiences. Although the information is limited, we have consciously worked to ensure their voices are adequately reflected in this report. Focus groups conducted with community health staff were thirty minutes to an hour long and a meal was provided. All participants provided informed consent prior to being interviewed.

**Table 1: Research Sites and Participants for Manitoulin Island First Nations**

Research Site	Wikwemikong	All of UCCM and M'Chigeeng
<b>Interviews</b>		
<b>People with Dementia</b>	5	5
<b>Caregivers</b>	5	6
<b>Seniors</b>	6	4
<b>Total</b>	16	15
<b>Focus Groups</b>	2	1
<b>Number of Focus Group Participants</b>	10	7
<b>Key Informants</b>	3	8
<b>Total Participants</b>	29	30

People with dementia were generally undiagnosed in our sample. Early interviews with physicians in the region suggested this would be the case. Therefore our approach was to allow the person with dementia and 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 First Nations 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 or forgetting to turn off appliances or manage health issues. People with dementia ranged in age from 62 to 81, there were 4 males and 6 females. All people with dementia were community-

dwelling. That is, they lived in their own home or the home of a relative.

Caregivers in the sample included wives, husbands, adult daughters and sons, and a niece and nephew. Although caregivers were not asked to disclose their age, some did express how old they were. The approximate range of ages for caregivers was 28 to 84. There were 3 male caregivers and 9 females.

Seniors who were interviewed could be included if they were 50 or older. In our sample they ranged in age from 67 to 81. There were 3 males and 7 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 physicians, community health care workers, traditional healers and specialists. Focus group participants were nurses and personal support workers.

## DATA ANALYSIS

Interviews were digitally recorded and transcribed verbatim, and were coded and entered into the qualitative data software package QSR NVivo8. This software was used to manage the data (store, code, organize, query) but not to analyze 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

No one in long term (nursing home) care was interviewed. These individuals were not purposely excluded, but our exclusion criteria stated that participants could not have severe/advanced dementia which likely decreased the chances of nursing home residents participating.

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

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.

## FINDINGS

*Healthy aging well...it's like, it's like when you are well and you do things yourself, when you help yourself, when you cook. And if you take care of yourself, and if you don't have much of any illnesses.*  
(KP Senior 02)

### LOCAL PERCEPTIONS OF HEALTHY AGING

Understanding how older people 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. These characteristics include good overall

health, taking positive measures to promote and maintain health, an active social life including contact with friends and family, participation in spiritual and cultural life, a positive attitude and sense of purpose, keeping busy and maintaining appropriate autonomy. Although within these discussions most seniors also accept that they face physical limitations that restrict their participation in community. Seniors present the ideal of autonomy "helping yourself", "taking care of yourself", "having purpose and independence" "thinking of yourself" while at the same time participants talk about the importance of community supporting Elders and the importance of family in care and or support. We interpret the discussion of autonomy in the Aboriginal context as a positive reflection on self and not statements that indicate support is not available or would not be accepted. We believe these comments are suggesting that these individuals feel that at this stage of their life their focus should be on their body and health and that they are responsible for taking care of it. The advisory group suggested that we speak of "appropriate autonomy" to reflect culturally appropriate meanings of autonomy as well as autonomy appropriate to individual circumstances and health. When thinking about appropriate autonomy then the data suggests we respect that autonomy is important to maintaining good health for Aboriginal seniors but that understandings of what is meant by autonomy and how to facilitate this should be negotiated between the individual, their family and health care providers.

The questions concerning healthy aging also contain a discourse on the role of traditional teachings in the process. Acceptance of aging for some is tied to the Seven Grandfather Teachings and giving gifts of thanks. Some participants suggested that the idea of balance is central to healthy aging and that not accepting aging creates imbalance (and illness).

Maintaining balance is necessary for healthy aging and that the role of the seniors or their place in the medicine wheel needs to be respected and honoured by those in the community. Participation in ceremonies is viewed as important to healthy aging and traditional healing such as sweats can be used to restore balance.

Older participants shared the perspective that a person should work to stay active and engaged in life by continuing to participate in activities they enjoyed when they were younger, but recognized that it may be necessary for individuals to alter certain activities or shift roles to accommodate the changes that occur as they age. Health, self-sufficiency, and having a sense of purpose are important to First Nations older adults.

Factors that participants believed to contribute to the maintenance of good health in old age included making positive lifestyle choices including eating well, exercising, and avoiding alcohol, smoking and substance abuse as well as making efforts to stay actively engaged in life and keep busy. Adequate cognitive and social stimulation were also believed to be important. Reading, puzzles, and word games were believed to be helpful, as was participation in tasks that require memory or learning, such as cooking or attending workshops. Being social was seen to lift spirits and keep a person's mind off negatives in their lives. Sharing company with other people was believed to be especially useful in warding off loneliness and isolation.

## PREVENTING DEMENTIA

Many participants in this study perceived dementia to be a new or worsening problem in their community, and linked the emergence of dementia with changes in their overall lifestyle, such as a shift away from traditional extended family structures, changes in food procurement practices and diet, a more sedentary lifestyle, and changes in the roles of older people in their communities. These individuals noted that older people did not get dementia in the past because they had more social support and important roles in their families such as being responsible for keeping the fire or caring for grandchildren.

The importance of traditional practices and spirituality to healthy aging and dementia care were expressed by most participants. There were some people who felt that traditional ceremonies can help memory loss and that participation in ceremony can help keep the mind healthy, for example the need to memorize 'the old words' that aren't used anymore for the ceremony and having to know the procedures for ceremonies are akin to brain exercises. Listening to the teachings and storytelling were seen as beneficial as well as listening and feeling the drumming being good for the heart, smudging for clarity. There was just one senior who mentioned a specific medicine used for memory loss - this is a medicine for the heart and blood and it works by thinning the blood. It was noted that language use is linked to a healthy

mind. In more general terms participants mentioned that the medicine wheel can help with acceptance and sweats and vision quests can be used to heal and balance. Healing from residential school experiences was viewed as necessary to achieve healing. One participant noted that she/he draws strength from the Christian faith. Culture was also noted in relation to the value that families take care of each other, humour, and the value of traditional foods.

Participants' beliefs about healthy aging and the prevention of memory loss also include minimizing exposure to environmental contaminants, prescription medications, and head injury. Working to maintain one's overall health was also believed to reduce the risk factors for developing dementia, especially those associated with cardiovascular disease.

## LOCAL PERCEPTIONS AND UNDERSTANDINGS OF DEMENTIA/FORGETFULNESS/MEMORY LOSS

### DEMENTIA SYMPTOMS

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

When caregivers and seniors were asked to describe dementia symptoms they most commonly mentioned forgetfulness, repetition of stories, inability to recognize people, altered sense of time, getting lost or disoriented in familiar locations, forgetting life events such as the passing of a spouse, neglecting hygiene and appearance, driving dangerously, leaving the stove on, or being unable to complete familiar tasks or hobbies. Individuals who knew a person with dementia or had previously been involved in the care and support of a person with dementia in their personal lives or through prior employment experiences had better defined understandings of what dementia was and the type of symptoms that might be exhibited.

Most people with dementia expressed that forgetfulness was the main symptom that they were experiencing. This included forgetting people's names, losing things, having difficulty finding the right words, and forgetting to turn off the stove. One person with dementia expressed that she sometimes heard noises that she believed to be in her head, and another questioned whether she might start to wander since her father had wandered when he had dementia.

Some of these symptoms, especially forgetfulness, were understood to be a normal and natural part of the aging process. However, many people, especially individuals or families who had

experience caring for a person with dementia, recognized that there was a difference between normal, age-related forgetfulness and more serious, problematic cognitive decline. Perceptions of normal versus problematic memory loss were usually related to the severity of symptoms. People recognized that memory loss was no longer normal when symptoms escalated to a point that they were a safety risk, involved marked changes to a person's behaviours or personality, or significantly interrupted activities of daily living.

## LOCAL EXPERIENCES OF DEMENTIA

### EMERGENCE OF A NEW DISEASE

Our data suggest that there is conflicting evidence around the presence and prevalence of dementia in past generations. Generally, most people perceive that Alzheimer's and dementia is a fairly new phenomenon. However, some individuals recalled older people with memory problems living in their communities when they were children.

Informants speculated that if dementia did occur in the past there was either less of it or the symptoms were less pronounced. Many people explained the emergence of dementia as being linked to older people being less engaged in the communities due to changing social roles. It was expressed that in the past they kept busy and had more defined roles – including transmission of knowledge, which may have helped to prevent memory loss and other symptoms of cognitive decline.

One of our traditional participants feels that dementia has always been around, but that that today people are getting it at younger ages. We also heard that dementia may have been around but it wasn't thought of as a disease; for example, a participant mentioned that in the past people talked about forgetfulness in terms of normal aging, but that now people use the word Alzheimer's. Her remark highlights that perhaps people talk about dementia now because there

*Well, no there was no one before with dementia. I didn't know of anyone who was like this. Like, what I am saying about these, my grandparents, they raised us, these people. They always visited each other, these old people long ago...For sure it was always full, my home where I was raised, the old people, the old ladies came to visit, they would come to eat. My grandmother always was cooking, if someone came in, "oh, come and eat," ah, they were happy eating, visiting, smoking pipe, they were feeling really good, there was no one there with dementia, to say it truthfully. There was no one there who was like that, everything was talked about, the future, the past, they knew their thoughts, their thoughts were good, their mind, that is how much I know what I would say for that one. (KP Senior 02)*

is a word for the symptoms or because it has a medical meaning and diagnosis.

Finally, another traditional Elder expressed certainty that dementia existed in past generations because she could identify an old Ojibwe word that describes the symptoms.

It is difficult to tell from medical data whether the prevalence of dementia has changed over time because it has not been consistently diagnosed. However, participants comments suggest that historically people with similar symptoms to dementia are known and there is some evidence to suggest it did occur. The comments also support the notion that there is more dementia now than can be remembered in the past.

*"...we don't bother worrying about it, what's going to happen in going to happen. Worrying is like trying to get somewhere in a rocking chair...you can go as fast as you want, but you're actually going nowhere fast, eh?" (JP Caregiver 01)*

#### NATURAL/ACCEPTANCE

Age-related dementias were most often described as a natural part of the circle of life and memory loss was perceived to be a normal part of the aging process. The cultural framework of the medicine wheel and the circle form the basis for this understanding. Because of this perception, many people were very accepting of memory loss and dementia symptoms. The acceptance of the illness is clearly tied to cultural understandings of aging

and the place of older Aboriginal people on the medicine wheel. This view was most often expressed by the seniors and traditional key informants we interviewed but also in some cases people with dementia and their caregivers. For those who held the view that dementia is natural they would refer to people with dementia using endearing terms such as "special people" and "childlike". Some participants emphasized they are "coming full circle" and "there isn't anything wrong with them". The discussion around dementia being natural and accepted were often accompanying by teachings on the medicine wheel or the seven grandfather teachings. In one case it was expressed by one participant that there are seven life cycles of seven years 0-7, 7-14, 14-21, 21-28, 28-35, 35-42, 42-49 and after 49 we travel backwards to infancy.

The perceptions of dementia as a second childhood is widespread and many people spoke not only of people requiring care that a young child would need, but also suggested that people with

*Well, for me it is a natural process. I think that if you, you know, like again, back to being a child as you get older as we get older to the point of as, so as, like a child. We have to, a child has to learn how to walk so how to, you know, it's a, you forget how to, like, going back to being a child, like an infant so it's and, ah, like I said, we finished our circle of life, you know? (KP Senior 01)*

*Yeah, I mean...there's some older people out there who can remember things that happened back when they were kids and, 'course, some of them are going to forget. I mean, I think it's just natural. (JP Person with Dementia 03)*

dementia can take on the traits of their younger selves, such as giggling like a teenager or becoming possessive of their belongings. Through this mechanism, it is considered normal when older adults begin to lose the capacity to carry out some adult tasks and need to be cared for the way a child needs to be cared for or lose skills such as memory or the ability to feed themselves. That they may also need assistance with basic daily tasks such as dressing and toileting is also considered to be normal.

Care workers and physicians were especially likely to comment on how much their clients accepted memory loss as natural which lead to an acceptance of the illness – a point which we will return to later in the report.

#### WORRY

Although there is such a strong tendency towards the acceptance of dementia as natural by Aboriginal people on Manitoulin Island, we also detected an undertone of fear or worry. People who have some experience with the disease (personal, family member or friend) were more likely to describe dementia as worrisome and frightening. Senior's concerns ranged from worrying about who would care of them if they developed dementia and not wanting to be a burden, to specific symptoms such as wandering.

Some individuals with dementia also expressed worry and were afraid of what might happen to them as their disease progressed. One person with dementia was concerned that the disease would impact her ability to know who she was, another PWD expressed that she felt fear when her dad had it because he used to wander and she worries that this will happen to her. This fear related to the thought that no one would look out for her to make sure she was safe. Another person with dementia also expressed that she worried about what would happen to her when her mind goes. She perceived that people with memory loss were often treated poorly, and worried that she would be "shoved around".

Family caregivers expressed the most worry about dementia. These people had the most direct experience with the effects of dementia and had a strong desire to keep their loved one safe. In that respect caregivers' concerns focused on the overall health of the person with dementia, whether the person would hurt themselves, and a fear of the unknown. Fear of the unknown was closely related to a lack of knowledge of the disease process. That is, people did not know how quickly current symptoms would progress, what new symptoms might emerge and how

they would manage to provide the care that was required. Ensuring that families have more access to knowledge about dementia and available supports to assist them in their care-giving has the potential to alleviate some of this fear and concern.

Health care workers also exhibited worry in relation to dementia. Their worry was more closely tied to their observation that the prevalent view of memory loss as normal was stopping people from accessing health care to seek diagnosis or treatment. Health care providers worried that this response, especially on the part of families, was a barrier to people seeking care for symptoms even if the situation, in their opinion, was becoming unsafe.

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#### 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 our 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.

*Like, it's not saying like uh, in other words you could say, oh, she's crazy. But that's not the word, not crazy, it's just that they're older and they're just not there anymore, you know? They don't have it anymore, in more ways than one. (JP Senior 03)*

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#### ENGLISH WORDS FOR DEMENTIA

When participants described memory loss in English, they used terms such as forgetfulness, being forgetful, memory problems, memory loss, having a bad memory, or not being able to remember anything. Few individuals used the words Alzheimer's disease or dementia. However, health care providers mentioned that these terms were occasionally used by some families who automatically associated memory loss with Alzheimer's disease. This suggests that people may not recognize or understand other mechanisms through which symptoms of memory loss can be triggered. Words for memory loss were often related to old age including getting old, having a senior's moment or "Oldtimer's" disease.

Although many of the terms mentioned above are quite neutral, some words used to reference memory loss had negative connotations including senile, confusion, losing it, not all there, or going crazy. This terminology may indicate that there is some underlying shame or stigma associated with dementia.

## OJIBWE WORDS FOR DEMENTIA

*Yeah, it's disrespect, you'd be disrespectful if you say that you know so and so is losing their mind, we just say that's a part of aging, and then, and then when they eventually pass away you don't, you don't describe how, it's just that they had lived a full life. (JP Care Giver 02)*

We were advised that there is no single word for “dementia” in the Anishinaabe language. Alzheimer’s disease is most often translated as “forgetting”. We were told that there are words in the language for “confused”; “forgot completely” and “not knowing anything anymore”. Some Ojibwe descriptions of dementia, memory loss and confusion and dementia are nuanced and demonstrate that

dementia can be conceptualized in several different ways. For example, one older man used the word *NEN DUM-GEWNENDAAMAAWSAA* to refer to memory loss. He elaborated by explaining that *GEEWNGOSHKAAGWAN WE EKENDANG* could also be used, which suggests that the knowledge a person had “*is buried within, his knowledge of what he knows, it got buried inside, like to bury someone, buried.*” (KP Senior 04).

Another perspective came from a female senior who equated a person with dementia to a developmentally delayed child, saying that they need help to do everything and they forget easily and don’t retain information.

Our results do not allow us to determine the most appropriate Ojibwe words to use for dementia on Manitoulin Island but the research did result in enough of a vocabulary that what was shared can be used as a starting point to work with a local language group to refine these findings into a set of terms describing various types or stages of cognitive decline.

Descriptions of memory loss in Ojibwe were similar to those in English in that generally the terminology was quite neutral. However, there was also some commentary that demonstrates some of the more negative aspects of dementia. Two individuals with dementia described their symptoms as

*It would be GAAGEWTAAWAAJIMAA, telling stories in circles. ‘Cause that’s what that is, it’s, ah, you are talking about one thing and then another. ‘Cause my dad would sit there sometimes and he’d catch himself, “oh boy, I am telling stories in circles, aren’t I?” (laughter) I’d say, “yah, you were just hunting and then all of a sudden you were sliding.” (laughter) (KP Senior 04)*

frustrating. One described what was happening to his memory as “miserable.” Two individuals used the phrase “brain full of blood in frustration” to explain what was happening to them. Other English words employ humour to talk about dementia for example “Old Timer’s Disease”

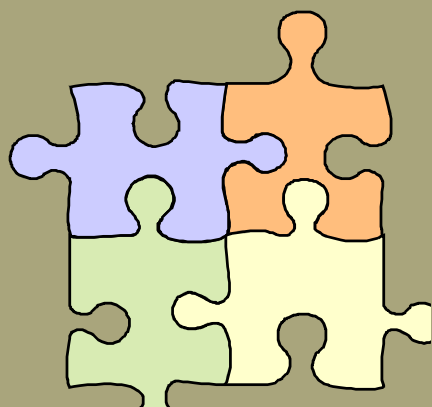
and having a “seniors moment” these appear to be used for milder forms of dementia or memory loss.

Although many people told us about Ojibwe words for dementia, a few informants suggested to us that it was disrespectful to discuss dementia or that it was not something people talked about. One informant made it clear that it is disrespectful to label someone with any word that referred to their memory loss.

The way that people expressed their understanding of dementia in Ojibwe demonstrates several perspectives of what dementia is or what it is like to experience it. These descriptions demonstrate both acceptance and respect, but also frustration at the experience of living with the symptoms as well as possibly negative perceptions of people with dementia including stupidity, insanity and losing it.

## PERCEIVED CAUSES OF DEMENTIA

- Age
- Environment and food contamination
- Eating habits and food preparation
- Lack of cognitive and social stimulation
- Lack of physical activity
- Trauma, stress and grief
- Spiritual causes
- Head injuries
- Other illnesses
- Western medicines
- Alcohol, smoking, 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. The most common understanding of memory loss was that it was a natural movement around the medicine wheel and caused by old age. 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 – environmental toxins, concurrent illnesses, trauma, and stress.

*I think it's more to do with aging, like, from what I see around here and how people understand it, eh? Like when you go to be a certain age, you know? Well, I've always heard that, eh? The way they say that 'cause you're old your memory or whatever, it's expected of that you, eh? Sometimes I wonder about myself, so, am I going to be like that, too, when I grow older? (JP Focus Group 01)*

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

### PHYSIOLOGICAL

Changes to a person's memory are primarily perceived to be **natural** and part of the aging process. Forgetfulness is believed to be a natural part of growing older and is not usually considered to be something to worry about. Many older people referred to changes in their ability to remember as they grew older, especially misplacing objects or forgetting to turn off appliances.

**Family history** was also recognized as a potential cause for dementia. Individuals who had witnessed severe cognitive decline in several members of their family were more likely to talk about the potential for it to be hereditary.

Other **health issues** (i.e. cancer, diabetes) and their treatments were seen as a potential contributor to cognitive decline. Vascular problems including stroke, mini-strokes, heart disease, blood clots and heart attacks were all perceived to contribute to forgetfulness. Improper brain functioning including chemical imbalances and blockages in the arteries of the brain were also believed to cause memory loss.

**Prescription medications** (pain medicine, antibiotics, anesthetics, chemotherapy drugs) are believed to have the ability to cause both short and long-term disorientation and memory loss. Participants believe that medicines are over-prescribed and that individuals take more medicines than their bodies are able to process, which can lead to cognitive decline. This understanding came from people with dementia themselves but most often was expressed by a family caregiver and often in relation to medications prescribed in relation to diabetes amputations.

*My grandmother she had that too, eh, and my mother she, she had the same symptoms. My dad he is dead from something else. (KP Person With Dementia 04)*

*Sometimes it's uh, I know I think my brother got it from uh, heart disease because, uh, um, he started having these little mini strokes and then uh, and then he started this wandering business. (JP Senior 02)*

*So, that's when I noticed anyway, after all that trauma, that severe pain from her, like from her first foot and then all the medications after that and for a while there I could fill the palm of my hand, I was just, you know, every pill that she got there was another one to cancel out the side effects from that previous one, and so on and so on, eh? So we had to get back to the doctor's after because she wasn't, you know, in her right mind most of the time there, just too many meds. So, kind of gradually got her weaned off and she's fairly normal now as far as memory and knowing what's going on around her. (JP Care Giver 01)*

**Head injuries** emerged as a significant cause of memory loss in our sample. Three individuals directly described head trauma as the cause of their symptoms. Others referenced people they had known who had lost their memory after an accident involving a head injury. Participants described cases where memory symptoms immediately followed a head trauma as well as delayed effects on memory linked to childhood head injuries.

## PSYCHOSOCIAL

**Emotional, physical, and spiritual traumas** were all discussed as having a potential impact on a person's cognitive health. Although some participants referred specifically to imbalance in the medicine wheel, others mentioned grief, depression, stress, worry and other forms of emotional distress as causes of cognitive decline. The effects of historical trauma were also perceived to have the potential to cause memory problems. One participant spoke about the process of reliving residential school trauma during the settlement process as the cause of onset of their parent's dementia. Taking the time to solve emotional problems, heal, and work to regain balance in the areas of the medicine wheel were considered to be ways that a person might prevent memory loss.

**Alcohol** was perceived to have the potential to impact memory. Alcohol use in particular was linked to both short and long-term memory loss. This either involved temporary forgetfulness while drinking or experiencing deterioration in cognitive function after prolonged heavy drinking. Although smoking was not directly linked to memory loss by individuals who were interviewed, they recognized links between smoking, poor overall health and the potential for memory loss.

*Yeah, well, as I mentioned, eh, there's this old man that used to live next door. His was because of an injury, eh. And I knew him intimately, personally for quite a few years and he was just as sharp as a whip before that young man threw him off of the eight foot stairway, eh? He rolled all the way down and he hit the back of his head (slaps hands together) like that, eh? (slaps hands) Like that. (JP Care Giver 01)*

*Well, we lost our son real suddenly uh, before it was, it was four years and uh, or three years in November and I noticed him going downhill after that. 'Cause it was too sudden. (JP Care Giver 06)*

*Alcoholism. (pause) Alcoholism is one of the things that uh, I have seen that people uh, uh, lose their memory at a younger age than the aged. (JP Traditional Knowledge Keeper 02)*

## INDIGENOUS

**Disruptions in the traditional way of life** are seen to be major contributors to the emergence of dementia.

Older adults specified that changing family structure and a shift away from traditional roles and activities were leading to loneliness and isolation and reducing peoples' ability to get adequate cognitive and social stimulation. A shift to store-bought foods also impacts the quality of people's diet because food procurement and preparation practices including gardening, harvesting, cooking and preserving are no longer a source of physical exercise and mental stimulation which are beneficial to brain health. People felt that the chemicals and preservatives in store-bought food may also be linked to dementia. There was also a concern that traditional food procurement practices were no longer as healthy as they once were because of the contamination of water sources and wild foods by environmental pollutants.

*Foods...I...it does in a way, because uh, they're not preparing the stuff that used to be prepared by the people way back, eh? Now they just, they buy it so there's no brain stimulation in uh, knowing how to prepare these foods. And in those days they didn't use recipes, they just had to think and process the foods to uh, preserve them. (JP Traditional Knowledge Keeper 02)*

**Bear walking** was perceived by one individual to lead to poor health, including memory loss. No other participants mentioned bear walking as a potential cause of memory loss. Other participants were more likely to perceive the cause of memory loss as part of the process of coming around the medicine wheel to complete the full circle of life.

Other Indigenous explanations of the causes that were mentioned less frequently included elders who had "**not lived a good life** in how they treated others" and elders who were "**living backwards**" and they relive past traumas.

## DIAGNOSIS AND TREATMENT

### DIAGNOSIS

There was a shared perception among care workers that dementia is under-diagnosed in their communities and that there were likely many more people experiencing memory loss than they were aware of. Interviews with people with dementia and caregivers revealed that few people were aware of diagnostic procedures, whether testing had taken place, or what the results of the test had been. Physicians reported that because dementia is often secondary to other diseases, especially diabetes, that diagnosis and monitoring of the dementia symptoms is not a priority.

In the sample of Aboriginal people with dementia on Manitoulin Island (n=10) we identified only one person with dementia we interviewed who reported that they had no other health issues beyond their memory problems. Six people self-reported that they have been diagnosed with diabetes; the same six people reported multiple diagnoses (combinations of high blood

*Yah, and then he asked me the last one he asked me (laughter) something start with the letter "F". He said to me say, give me 10 words, I couldn't even come up with one word (laughter), but you know what come into my head right away "F" off, "F" word. I said no, I don't know anything, no, there's lots of things, you know, fun, farm and all of that. I couldn't even come up with one word that begin with an "F". (KP Person with Dementia 03)*

pressure, high cholesterol, heart disease, diabetes, amputations, kidney failure); 2 other people reported being treated for cancer (and had no other significant diagnoses).

Many families take on the care of a person with symptoms of cognitive decline without first seeking medical advice because of the perceptions that memory loss is natural or because they feel that they can cope with the early symptoms. The key reasons that families seek diagnosis or treatment are: concern for the safety of the person with dementia, changing or inappropriate behaviours that interfere with regular routines and activities of daily living, and inability to cope with increasing care needs. In some cases, where medical care is already being received by the person with dementia for other health issues, it is one of their health care providers who makes note of changes to

cognition and recommends further investigation into the symptoms.

Because many of the participants in our sample did not have a diagnosis or were not undergoing formal treatment for dementia, it can be difficult to get a clear picture of peoples' experiences with dementia health care. Although few caregivers or people with dementia had much to say about the tests two people with dementia indicated that certain questions about the Canadian prime minister or listing words that began with the letter F had little meaning to them.

*I don't even know who the Prime Minister of Canada [is] (laughter). I don't bother with that (laughter). (KP Person with Dementia 01)*

Formal care providers, including physicians we interviewed, also expressed some concerns about the nature and content of cognitive screening tools and felt that they were not always the most appropriate assessment of cognitive decline for First Nations clients they work with.

One physician key informant suggested that diagnosis and monitoring of Aboriginal patients with dementia is best achieved through continuity of care their family physician and a good long-term relationship between the family and patient with their physician. It was also suggested that physician home visits provide ideal dementia assessment opportunities.

Three family caregivers in Wikwemikong had a better sense of the diagnostic process than other caregivers in our sample. These individuals were knowledgeable about the testing procedure and the results of the tests. They also spoke about experiences they had with follow-up appointments related to the diagnosis. Understandings of the diagnostic process seemed to be less clear among caregivers and people with dementia living

*They're usually quite irrelevant. They don't work. In fact, when we first went up there we realized that the traditional screening tools were useless. And we, um, we tried to use tools that were transcultural and were not very successful, so for the most part we're relying on the staff of the nursing home to interpret the behaviours and inform us about the uh, the, uh cognitive deficit. (WW Specialist 01)*

in UCCM communities. In this context, few people were aware of the assessment process or the results. One issue that was occasionally discussed by our caregivers and people with dementia was a lack of communication or follow-up related to the results of cognitive assessments.

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## TREATMENT

Two main treatment approaches for dementia were discussed in our interviews: western medicine and traditional medicine. As with diagnosis, few people discussed the details of the course of treatment for dementia. A few participants referenced Western medicines including Ativan, Seroquel, Haldol, and Aricept indicating that the participants were being treated for various psychological illnesses which may or may not have been related to what we refer to as 'age related dementia' (neurodegenerative). We noticed during early community consultations with seniors and through the interviews that there is a reluctance to take prescription medications in general but also specifically in relation to cognitive function. Their main concerns about these drugs were side effects including hallucinations and a shuffling gait. Although clearly some participants were also very distrustful of pharmaceuticals stemming from distrust of the western medical community in general. One participant expressed that he had opted not to take Aricept when it was offered because of his concerns about the possible side effects. Other participants felt that they were already taking too much prescription medication and were not interested in having to take even more. Concerns about dosage,

effectiveness, cost, side effects, and possible interactions with traditional medicines were the biggest issues.

The physicians who were interviewed also believed that there were several problems with the dementia specific drugs that are currently available. One physician believed that these medicines were not effective and another believed them to be problematic because they are supposed to be prescribed in relation to a person's performance during cognitive screening and these tools are not consistently used and are not always culturally appropriate. One of the main benefits of the drug was seen by one physician to be the delaying of nursing home admission.

*Well, in nursing homes I rarely prescribe the Alzheimer's drugs. Maybe I'm a bit atypical there. Well, my argument is this: these drugs are not incredibly effective. They are modestly effective at best. Sometimes you see a good, positive response, but mostly not very much, quite honestly. So, if I have somebody who's living at home where a slight improvement in their cognition might be the difference between them having to move into a retirement home in 2 weeks or perhaps being able to manage at home for another 6 months, I think that's a good investment of our resources into a drug that may help. If they're already institutionalized where the marginal benefit of those drugs is relatively tiny, I can't bring myself to prescribe it. Similarly, if they've been on drugs before I will generally stop them when they move into a nursing home. Now, I'm definitely in conflict with some of my colleagues over that, other of my colleagues agree with that approach. With regard to the drugs that affect behaviour, however, then I'm going to prescribe those the same way in an institution as I would in the community. (WW Specialist 01)*

Interview data suggests that the majority of people caring for a person with dementia are not using traditional healing or medicines to cope with memory loss. Many stated that they were not aware of traditional approaches to dementia treatment or that the person with dementia had ceased using traditional medicines as the disease progressed because they forgot how to prepare them or no longer had the ability to seek out the appropriate plants and materials. Family caregivers expressed little knowledge of traditional medicines used specifically to treat memory loss. Instead, traditional healing was used more holistically to help with other health issues or general well-being.

Formal caregivers also had some perspectives on the use of traditional healing in dementia care. Again, there was little knowledge about dementia-specific traditional treatments. Many health care providers who were interviewed were non-Aboriginal and they felt that people likely were not sharing their experiences with traditional healing with them, or they made a conscious effort not to get involved with their clients' choices about traditional healing since they felt it was not their place to get involved. The fact that many care providers are non-Aboriginal may mean that traditional individuals are reluctant to share their traditional beliefs and practices because they feel care providers will not understand or accept them. This suggests that there is a need for access to cross-cultural care training for the non-Aboriginal providers.

Healing circles, sweat lodge ceremonies and liquid cedar were discussed, but again, these were used in the context of overall health and well-being and less specifically in the context of dementia.

The importance of a holistic approach that focused on healing trauma, including counseling or using tobacco and prayer to call upon spirit helpers was discussed by our two traditional healers. They also recommended that it was important for the person experiencing memory loss to put in effort to take care of themselves, including getting cognitive and spiritual stimulation.

### OVERVIEW

People living with dementia on Manitoulin Island experience several different types of care. Family care is overwhelmingly the preferred mode of support when the person with dementia has family nearby who are willing and able to provide care and support. However, some people with dementia do not have family who live nearby or are able to be involved in a care-giving role. Although family care is preferred, it is recognized that familial support often needs to be supplemented by homecare and other services, such as respite, to ensure the continued safety and well-being of both the person with dementia and the caregiver. Support for a community-dwelling person with dementia who does not have family care may also be provided by homecare services including nursing, personal support workers and homemakers. Nurses, physicians, specialists, and community services for older people may also be a part of the care and support team for a person with dementia.

Many seniors' perceptions about how to best care for a person with dementia seemed to be motivated by thoughts of how they would like to be treated if they were to experience cognitive decline. These participants spoke about the importance of social stimulation, visiting and communication. They also talked about how important it was for a person with dementia to still feel that they had a purpose and were part of society. Seniors believed that it was important for other people around a person with dementia to create an environment that supported their ability to stay engaged in life. This sentiment strongly echoes the feelings that seniors had about their own aging experience and the desire to maintain meaning and purpose in their lives. Older people also spoke about the belief that people experiencing memory loss should be treated calmly and with respect. This perception included the idea that a person's remaining abilities should be accepted and that they should be supported in what they are still able to do. It was strongly believed that family members should be involved in providing care and support to a person with dementia. Almost all of the people with dementia in our sample also expressed the importance of family as a source of support.

Despite the belief that family care is optimal, some participants recognized that nursing home care may become necessary for families coping with dementia. However, individuals who were interviewed perceived that individuals in nursing homes do not get as much personal attention or respect as people cared for by family because care workers in nursing homes may lack time or patience.

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### WHO PROVIDES CARE?

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Most often, caregivers in our sample were family members, usually spouses or adult children. Siblings, nieces and nephews also occasionally play a role in providing care and support. We did not interview any non-related informal caregivers, but it sometimes occurs that a friend or neighbor supports a person with dementia. Although one family member usually acts as the primary care provider, many families work together to share care-giving responsibilities.

Both men and women provide care, but it is difficult to get a clear picture of the differences between male and female caregivers because only two male caregivers were interviewed in the sample. Male and female caregivers expressed similar reasons for providing care, concerns about the person with dementia's safety and well-being and resistance to the idea of enrolling the person with dementia in a nursing home unless it was a last resort. One area where men and women may differ in their care practices is that men may be less comfortable taking on tasks related to personal care and hygiene. Female caregivers appeared to participate more directly in doctor's appointments for the person with dementia. However, it is very difficult to accurately identify differences between men and women in care-giving in a sample this small.

*Um, well, she took care of me for 29 years and I figure it's about time to give back. Um, and just seeing like, how much she had been suffering prior to her surgeries and stuff it was – it's hard, especially when it's your family member, it's your mother. (JP Care Giver 03)*

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### WHY DO FAMILIES PROVIDE CARE?

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Family members expressed that they took on the care-giving role because of their relationship to the person with dementia and that they felt they needed to support them in their time of need. Some informants elaborated on their reasons for providing care and specifically mentioned a feeling of filial responsibility or reciprocity. Adult children caring for a parent often expressed that their parents had raised them and they felt that she should give back and provide for her in their time of need. Spousal caregivers mentioned that they had been in a relationship with the care recipient for many years and they always supported each other.

*There was, if there was a female that could, almost like a live-in, you know she needs the female touch in her personal care and that, but then that's just wishful thinking but that would solve lot of the problems. (JP Care Giver 01)*

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## WHEN DO FAMILIES BEGIN TO PROVIDE CARE?

Family plays a major role in the support of people experiencing memory loss and can also act as important advocates for the safety, personhood and quality of life of older people experiencing ADRD. Family members often provide support to older relatives even if they do not have dementia. Many of the caregivers we spoke with expressed that they were already assisting the person with dementia before symptoms began to appear. More involved care usually begins when there is a concern about the safety of the person with dementia, when their behaviours or personalities change drastically, or if they are unable to cope with the basic activities of daily living.

Because it is common for families to already be in regular contact and supportive roles with older relatives they are in a unique position to notice changes to a person's memory and behaviour which could be early indicators of ADRD. Several people with dementia that we interviewed mentioned that it was a family member who had first alerted them to changes in their memory. Family members are an important place to direct educational materials about warning signs for dementia, since early detection can increase treatment options.

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## WHERE IS CARE PROVIDED?

Care is most often provided in either the caregiver or the care recipient's home. Some caregivers live with the care recipient on a full-time basis; others live in the care recipient's home on a part-time basis, rotating with other members of a family care team. Some live nearby and provided care on an as-needed basis by visiting the person with dementia or taking them out to run errands. Often, caregivers bring the person with dementia into their home when their care needs increase. Institutionalized care is seen as a last resort,

but some families do turn to nursing homes when care needs become too demanding for them to handle. Often families will continue to provide care and support to a person with dementia even after they have been enrolled in a nursing home if the nursing home is close to where they live and easy to visit.

*Well I am his wife we've been there together all of these years I told him I'd be there for him as long as I can you know till such time I can't do it anymore for some reason or other (KP Care Giver 04)*

## WHAT DOES DEMENTIA CARE ENTAIL?

**Care-giving tasks** that were expressed by family caregivers who were interviewed include, but are not limited to, preparing meals, transferring the care recipient from a wheel chair to a chair or bed, bathing, changing diapers if the person is incontinent, dressing, assisting with personal hygiene, organizing medications, providing activities to keep the person entertained, accompanying the person on outings, and providing encouragement and social support.

One of the biggest challenges of caring for a person with dementia reported by caregivers in this research is the constant nature of their care needs. Although the intensity of care required may vary from person to person and at different stages in the disease, most caregivers expressed that one of the most notable aspects of dementia care was the need to provide near-constant supervision. Supervision was needed to prevent safety issues such as wandering, falling, or burning things on the stove as well as to keep the person comfortable and assure that they were not hungry, thirsty or in need of assistance for personal hygiene.

The needs of a person with dementia occur throughout the day and night, and caregivers are often unable to get a full, high quality sleep during the night. The twenty-four hour a day care needs also means that caregivers often have to sacrifice their free time, and even activities that they enjoy or carry out to maintain their own health and well-being. In addition to all of these tasks, many caregivers also have full or part-time jobs, attend school, are raising their own families, are involved in their communities, or have their own health issues to manage.

Because knowledge of dementia and the underlying medical mechanisms of the disease are low, First Nations caregivers may face additional challenges because they do not know what to anticipate as far as the disease progression. Further, many caregivers did not know that there were services and supports available to help them or how to access them. Although many people and families are able to cope quite well in the early stages of the condition, few have much preparation for the types of challenges and behaviours that may occur as the person with dementia's condition deteriorates.

*I spend majority of my time here, I go home for, you know, a quick lunch and then I'm off at my other client's house for three hours, um, and then I get home, you know, and have to take care of my kids and supper and things like that. (JP Care Giver 03)*

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## STRENGTHS AND BENEFITS OF CAREGIVING

Although there are many challenges associated with providing care for a person with dementia, we also observed that a family care model had many strengths and that there were benefits to this approach to care for both the person with dementia and their family members. Benefits that relate to family care include that people with dementia have more access to emotional support and cognitive stimulation and benefit from being cared for by people who know their interests and history. Benefits may also include more culturally appropriate care that reflects the language and beliefs of the care recipient, helps maintain continuity in families, and provides the opportunity for older adults to have a meaningful role that respects traditional values of teaching and passing on knowledge, which can benefit both older people and younger generations. The preference for family care over nursing home care is another strength.

Caregivers also expressed positive gains that they experienced as a result of providing care. They spoke warmly of how good it made them feel to be able to make life safer and easier for their family member who was experiencing memory loss. Many caregivers learned to celebrate the small successes, when then their family member had a good day or was able to complete a task. This attitude, the willing acceptance of the care-giving role, and care-practices centered around respect, acceptance and supporting the person with dementia physically, mentally, emotionally and spiritually were significant strengths. In light of these benefits and strengths, family care should continue to be supported and encouraged.

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## HOW DO FAMILIES PROVIDE DEMENTIA CARE?

Family caregivers have little formal knowledge or training related to dementia and dementia care. Despite this, many family members are able to intuitively meet the needs of the person with dementia, especially in the earlier stages of the condition. Some of the strategies that family caregivers mentioned included speaking calmly, helping to orient the person with dementia if they were confused, redirecting the conversation or activity if it was causing the stress or anxiety, and engaging the person with dementia in activities they enjoyed. Many family caregivers also acted as the power of attorney for the person with dementia.

Many individuals expressed that they had no knowledge of traditional treatments for Alzheimer's disease or dementia, and some outright expressed that they did not believe in traditional healing. However, some traditional practices did come to light that demonstrate a specific First Nations approach to dementia care. These include the use of ceremonies and traditional medicines for the overall maintenance of good health, storytelling as a therapeutic activity, the use of prayer and spirituality to help both caregivers and person with dementia find the strength to cope, and the pride and engagement that came with participation in cultural

activities such as powwows.

Friends and neighbors in the Manitoulin Island First Nations are also a source of support for people and families coping with dementia, and often play an important role in assisting a person with dementia to complete their activities of daily living and to provide social stimulation and emotional support. Many individuals also mentioned the importance of their church as a source of strength and as a key factor in helping them to continue to feel connected to their community.

Although many caregivers are able to devise effective care strategies, there is a great need for training and support to assist them in coping with more difficult care tasks. This training might also provide them with knowledge of how to provide a care environment that not only supports the physical needs of the person with dementia but also provides them with meaningful and fulfilling activities that support their mental, emotional and spiritual well-being.

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#### TRAINING AND KNOWLEDGE NEEDS - COMMUNITY MEMBERS/PEOPLE AND FAMILIES WITH DEMENTIA

Families and community members also require training related to dementia. Basic information about what can cause dementia and how to prevent it would be a good starting point. Education about the symptoms of dementia would also be useful, especially if there was a focus on when symptoms of memory loss should be a concern. Although there are benefits to local understandings of dementia through which memory loss is accepted and considered to be a natural part of aging, there is also the risk that this understanding will keep people from seeking care. This is a concern because some kinds of memory loss are reversible, and if people are able to identify when memory loss is a problem they will be better able to seek help, and in some cases this may lead to effective treatment. Community members should be trained to recognize that in some cases memory loss becomes a safety risk. This could be supplemented by the creation of community planning for senior's safety. Alongside of education about how to recognize dementia, there should be resources easily available that instruct people when, where, and how to seek assistance along with highlighting the potential benefits of accessing health care resources around memory loss.

One issue that many people coping with dementia expressed was that they did not know if there was help available for memory loss or where to access it. Although many people and families are able to cope quite well in the early stages of the condition, few have much preparation for the types of challenges and behaviours that may occur as the person with dementia's condition progresses. Resources and training need to be made available to families who are providing care to a person with dementia that teach them strategies for managing

behaviours and changes to a person with dementia's needs, coping strategies for dealing with the round-the-clock demands of dementia care-giving and avoiding burnout, what services are available nearby as far as home care, respite, activities for the person with dementia, support groups, etc. Caregivers who have knowledge about the types of changes AD/DRD can cause for the person with dementia, and how dementia progresses would be better equipped to deal with the care needs of the person with dementia as well as the stresses brought on by care-giving and would be in a better position to act as an advocate when navigating the health care system.

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## COMMUNITY HEALTH SERVICES

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### SERVICES

Supports for older people with dementia vary between different communities on Manitoulin. Most communities have a health centre, a home and community care program including nursing, homemaking and PSW services, meals on wheels, and an Elder's program that organizes activities for older adults. Many communities also offer some kind of housing for seniors. Wikwemikong is the only community with a nursing home within its boundaries. If a nursing home is required, families in other communities (and Wikwemikong if no beds are available locally) must rely on nursing homes in Little Current, Gore Bay or off the island.

The support that people with dementias and their families received from local home care services was perceived to be particularly beneficial. The ability to access home care services provided by caregivers with knowledge of local language and culture was perceived to be especially beneficial. On the whole, people with dementia and family caregivers spoke very positively of home care services that they received from nurses and PSWs. These care workers were perceived to exhibit a lot of compassion. Despite having limited resources, nurses and PSWs seemed genuinely concerned about the safety and well-being of clients with dementia and expressed interest in learning more about how to best provide care to individuals experiencing cognitive decline. They also seemed very interested in finding strategies to involve family members in the care and support process so that optimal care could be provided. One care worker noted that a strength of the Aboriginal health community was the ability to organize meetings with family and care partners of clients with

*[The PSW is] quite helpful when she's here. And she talks, she talks the language too, so it's really nice to hear that too, when anybody comes in and talks the language she's [the Person with Dementia] right in her peak then. (JP Care Giver 01)*

dementia so that the complete picture of the needs of that person and the supports they had available could be discussed.

Although there is a representative for the Alzheimer's Society who services Manitoulin Island there are few other services designed specifically for dementia care. The availability of Elder's centers in each community was perceived as beneficial. Although programming for Elders is not currently organized to meet the needs of people with dementia, the programs that exist for older people have the potential to be modified to offer physical, cognitive and social stimulation for people with dementia, especially those in the early stages of the condition.

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## SERVICE NEEDS

Despite the available services on Manitoulin Island and their strengths, there are many unmet needs for families coping with dementia and the availability of and access to appropriate services is a challenge. In particular, interviews revealed that there was a significant need for respite care, increased hours of home support and dementia-specific programming such as an adult day centre. Respite care and increased hours of home care services were among the most frequently mentioned.

Both health care staff and family caregivers repeatedly mentioned the challenges that occurred because of a lack of respite care and evening and weekend home care services. The lack of availability of weekend and overnight care was especially a concern for clients who did not have reliable family care to support them. Overnight care hours was also perceived as desirable by family caregivers, who expressed that one of their biggest challenges was not being able to get enough sleep because of the need to constantly supervise the person with dementia. This was especially true for caregivers of people with moderate to late stage dementia. Although some respite care is available on Manitoulin, the hours are very limited. The hour or two of respite available to most family caregivers was often inadequate and didn't allow them enough of a break. Caregivers living in more remote communities experienced the biggest challenge with these limited hours because of the long distances they needed to drive in order to run errands or buy groceries which often consumed the majority of their allotted respite time.

In addition to a lack of in-home respite services, there is little in the way of relevant programming for people with dementia. No dementia-specific programming or adult day services are available on the island. Although many of the communities have Elders' centers and some have very active programming for seniors, these activities are often unsuitable for individuals with dementia and are not equipped to provide them the support or expertise they need in order to engage in activities. Programming was especially lacking for older men, and it was noted that many of the activities that are offered for older people cater specifically to

women, such as quilting or crafting groups. If programs and services for people with dementia were devised, they would need to be well advertised and communicated to families coping with dementia and transportation would need to be made available. Some older adults who were interviewed also mentioned that friendly visiting volunteers would be beneficial for people with dementia. A friendly visiting program would combat the isolation and loneliness that is often experienced by people with dementia, especially those living alone. Again, transportation would be a key factor if such a program were devised.

A further need that was mentioned by some caregivers was the need for support groups in their community with other First Nations people, with a facilitator who speaks the language. At the time the research was conducted, a support group was offered on the island through the Alzheimer's Society. However, there was only one representative for the Alzheimer's Society for the whole of Manitoulin Island and the support group that was offered met at a central location in Little Current or Manitowaning which prevented some families from easily accessing this service. In addition to culturally relevant support groups, participants voiced the need for educational materials in the language that represent First Nations people experiencing ADRD. An advisory group member suggested that one reason mainstream family support groups are not always appropriate for First Nations is the age difference in the caregivers. First Nations people diagnosed with dementia tend to be younger as are their caregivers.

Access issues were also frequently mentioned by participants as a significant barrier to diagnosis and treatment. These issues included the high cost of transportation and medications and long-distance travel required to access the services of specialists. Specialist services such as geriatrics or diagnostic imaging often require travel to a larger city on the mainland. Access to services is the most difficult for the more remote communities (Zhiibaahaasing and Sheshegwaning) and transportation was an especially big problem for individuals who did not drive or did not have a car. A final need that was discussed is housing. There are very few options for supportive housing for older adults on Manitoulin Island. Older people either live alone, with their families or in a nursing home, but there are few options that bridge the gap between home care and nursing home care.

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#### HOME CARE WORKERS

Formal caregivers are most often nurses and personal support workers (PSWs). These individuals provide care in the person with dementia's home during hours allotted to that client on weekdays between 8am and 4pm. Nurses provide physical care required to address a client's health needs (including foot care, wound care, etc.). PSWs assist their clients with activities of daily living such as personal hygiene, nutritional needs, assistance with mobility or

medications, and addressing basic health needs. These services also provide an opportunity for the person with dementia to receive some social stimulation.

Formal care providers who participated in our focus groups discussed their experiences with providing care for people experiencing memory loss and expressed some of the challenges they face when providing dementia care. Nurses and PSWs expressed that they were very concerned about the number of hours of care that some of their clients received and that they worried about clients who did not have family support, especially during evenings and weekends when no formal care is available. The biggest worry of formal caregivers was the safety of the client, and the idea that a client who had little social support and inadequate hours of care was left unsupervised for many hours which might be a safety risk, especially for clients with dementia who may have a tendency to wander, leave the stove on, or improperly manage their health and medications.

While many formal caregivers were well trained and were knowledgeable about dementia and dementia care, some PSWs lacked specific knowledge of the condition and strategies for how to cope with the symptoms. For these individuals, clients with dementia posed a special challenge and added extra stress and sometimes fear to their jobs. One example that stands out is a PSW that did not know how to cope with a client who became aggressive when it was time to prepare her for her bath. This care worker often felt that she had no option but to leave the client's house when this occurred because she worried about her own safety. Better dementia-specific training, including strategies for how to engage a person with dementia in ways that make them feel comfortable and how to manage challenging behaviours would greatly improve this type of situation and would lead to better outcomes for all involved. A need for PSW education and training emerged as a more significant problem in Wikwemikong than the other communities. This need was in the process of being addressed during the later stages of the research.

PSWs also expressed the concern that they were often unaware if their clients had a diagnosis of dementia, which made it difficult to assess exactly how to care for them. These same PSWs expressed that they felt that they had little power to influence the diagnosis of dementia or to communicate issues they observed to other medical personnel, such as doctors or nurses. This also emerged as more of a concern from PSWs in Wikwemikong. The Mnaamadzowin and Noojmowin Teg nurses and PSWs worked more closely as a team and appeared to share their knowledge to a greater degree. This may be important because PSWs have regular contact with their clients, often long-term, and may be among the first to notice changes to their memory or behaviour. The development of a system whereby PSWs had an opportunity to communicate with other health care workers about their concerns about changes to their cognitive status of their clients and receive advice about how to cope with challenging dementia behaviours would

have the potential to improve the ability for health centres to identify clients who may need dementia screening and to improve the quality of care that people with dementia receive.

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#### TRAINING NEEDS

Service providers at various levels need different kinds of training related to dementia and dementia care on Manitoulin Island. At the highest level, physicians and specialist require training about cultural perceptions of dementia and how to provide care that respects the culture, language and beliefs of their Aboriginal clients.

This training should address appropriate screening processes for Aboriginal people with dementia, so that clinicians can ensure that they do not rely too heavily on assessment tools that may be inappropriate for use in an Aboriginal setting.

One care worker pointed out that nurses need more training relating to long-term care placement applications for the CCAC and assessing the capacity of a person with dementia as far as their needs for a substitute decision maker or power of attorney. Training related to exactly what dementia is and how to recognize it is also needed, especially for PSWs. Along with education about how to recognize warning signs for dementia; PSWs need to have a protocol for communicating their concerns about a client's cognitive state to other health care personnel so that assistance can be provided where needed.

Another training need for workers who provide care to people with dementia is strategies for coping with behaviours and improving the care experience for people with dementia. There are many care practices that can improve a person with dementia's quality of life and can reduce agitation and negative behaviours. Training in this area would have the potential to improve the quality of care interactions for both the PSW and the person with dementia.

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#### NURSING HOME

The majority of participants expressed that institutional care is not a desirable option for the care of a person with dementia. Families much preferred to care for a person with dementia in their own homes. However, because of the nature of ADRD, nursing homes often become the only option as the person with dementia's needs and abilities change. Although most of the individuals who we interviewed were resistant to the idea of nursing homes, many recognized that they may need to enroll their family member in this type of care if their needs became too difficult to handle or if the caregiver was under duress and unable to continue to provide care for the person with ADRD.

Families who had decided to use a nursing home for the care of their family member expressed that they made the decision because the person with dementia was becoming too difficult to handle, got easily agitated, or was causing harm to themselves or others. Nursing home placement also occurred if the caregiver was unable to handle physical care needs such as lifting and bathing. Caregivers who had enrolled a family member in a nursing home expressed that it had been a difficult decision, but that it had become the only option since they were burning out and unable to cope any longer. The belief that institutionalized care may be detrimental to the person with dementia is not unfounded. Institutionalization has been shown to negatively impact health status and can double the mortality rates for a person with dementia (McClendon, et al. 2006).

Some families experienced challenges after enrolling the person with dementia in a nursing home such as having to travel long distances to visit them, being dissatisfied with the quality of care that their family member was receiving, or observing that their family member was not happy in the nursing home environment. Some families who enrolled a person with dementia in a nursing home pulled them out of the nursing home again after a short time even if it was a crisis situation that led them to put them in the nursing home or if it had taken significant effort from health care staff to secure their family member a bed.

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#### CARE-GIVING SUMMARY

Knowledge shared with us in this study demonstrates that care experiences for people with dementia are diverse and are often comprised of multiple sources of support including informal family and community care as well as more formal services including home care support, physicians, specialists and nursing homes. Although all of these factors may be necessary at different stages of the disease, it is clear from our data that a family and community care model is both preferred and the most beneficial to Aboriginal people experiencing dementia.

Family care practices are closely linked to traditional cultural values. Traditionally, an extended family structure was the norm and older people were cared for in their home or a family member's home by their adult children or other family members. In addition to support, older people traditionally had more defined roles in the family which allowed them to maintain a sense of purpose and to stay engaged physically, cognitively, and emotionally. Research participants referenced family structure and the roles of older people as elements that prevented the onset of cognitive decline for older adults in the past, and recognized that a shift away from these practices has left some older people with a lack of purpose and too little physical, social, and cognitive stimulation. Although there have been changes in older peoples'

roles and in family structures, family care remains the preferred mode of support for a person experiencing dementia. The focus of this type of care is to support the person with dementia physically, emotionally, mentally and spiritually and is often centered around respect, acceptance of the changes that the person with dementia is experiencing, and a focus on supporting their strengths and abilities. A traditional approach to care may involve traditional healing or other cultural activities and spirituality may be used as a source of strength.

In light of these benefits and in the strengths exhibited by Aboriginal caregivers, family care should continue to be supported and encouraged. Family members might be more inclined to take on the care-giving role if they had more knowledge and support related to dementia care-giving. This might include more knowledge about the disease and its progression, better access to education about providing a positive care environment and coping with behaviours, and adequate access to respite and adult day services they could lean on to help fit care-giving in with the other responsibilities in their lives.

#### CULTURALLY SAFE DEMENTIA CARE

In addition to the references to culturally appropriate care throughout the report we have identified key themes related to the provision of culturally safe dementia care for Aboriginal people on Manitoulin Island. While the themes are clearly inter-related we have categorized this discussion around: Access to Care, Supportive Environment, Relationship with Care Provider, and Structural Inequalities.

Many of the components of cultural safety have already been discussed in this report. For example, **Access to Care** has several dimensions such as receiving a formal diagnosis, culturally appropriate screening tools, timely appointments, and transportation. As noted previously in this report, few people are receiving a formal diagnosis of dementia. Moreover, there is some concern as to whether the tools used to screen for dementia are culturally appropriate. Also related to access to care is the availability of timely appointments. Care providers described the difficulties of fitting dementia screening sessions into the short booking times available. One physician commented that a proper screening would take 4 – 30 minute sessions, posing a huge challenge as there simply are not enough appointments available to have an individual come back again and again for screening and follow-up.

*So those little elderly people will have to come back again. We have no ability to see an elderly person 4 times in 8 weeks here or in Wiky, even more so in Wiky. The ability to follow a chronic illness in Wiky, because we just don't have enough appointments in Wiky to have people coming back at the frequency of having them come back to get all the work up done and then to follow them up. (Local Physician)*

Concern was also raised about access to transportation to get to appointments. For example, one care worker stated;

*Travel is always a problem. The travel budgets in the communities are always exhausted usually by the summer time, so they're always looking for more funding through Health Canada and sometimes it comes and sometimes it doesn't. So that's just an additional burden, you know, on the communities. (JP Care Worker 06)*

Culturally safe dementia care must also strive to achieve a **supportive environment** that respects the cultural norms and expectations around dementia care and care of the elderly.

*[W]hen you get old you just pass on those teachings and you've done your work in the community so it's a time for the community. It's a reciprocal process so the community starts to take care of the elderly eh? It's not designated just that family, you also have that community to monitor that elder, take care of them too, eh? So that's the role of the elderly, but for the elder because of their physical inactivity, you know, there isn't- it's less that you can do physical things, so the, what you contribute to the community is those teachings, eh? (JP Traditional Knowledge Keeper 01)*

Overwhelmingly, there was agreement that family members would try very hard to keep individuals with dementia out of nursing homes. Many care givers were adamant that they would rearrange their living arrangements and work schedule in order to care for a family member. Despite a lack of supportive living opportunities, many indicated flexibility in the home environment that would prevent family members from being admitted to a nursing home. People most often related this to the cultural expectation of family caring for family, reciprocity and respect and a tension between this expectation and modern pressures.

*[W]e've always been told to take care of each other and when I was younger we had a lot of extended family life, like cousins, um, that would actually come and – come live with you, till you know, in their old age, take care of them, that's what we used to do. Now they have nursing homes. So, I don't know. Like, with me, my kids are just ready to take me in they, they're just waiting to jump on it and I'm here and I tried to explain to them, I said, you know, I like being independent, I want to do things for myself. I said, when I do get sick, I said, I'll come to you. (KP Senior 02)*

One physician observed the positive outcome of the model of care suggesting that Aboriginal patients appear less isolated as a result.

*... it is much more common to have two or three or four generations in the house or if not in the house right close by you know it's a very common situation to have the ah two generations in the same plot of land with maybe different housing or same housing so I think ah and there's more likely to be family members in the community still...it's the reason why um maybe First nation people are less likely to suffer from the same degree of isolation and loneliness as the Non Native clients. (Local Physician).*

As community members shared their views on culturally safe or appropriate care, they also spoke about the structural barriers and facilitators to achieving this. For example, a major concern for care-givers and care-workers is access to respite care and social supports. Many care givers described burnout resulting from lack of access to respite care. Others pointed out that PSW services and physician home visits were important elements of good, accessible and appropriate care for Aboriginal people with dementia.

Another key theme of culturally safe care for Aboriginal people with dementia on Manitoulin Island is a person's **relationship with their care provider**. Overall, people with dementia and their caregivers we interviewed reported that they are receiving good care from their physicians and other health care providers. Participants did, however, have some suggestions to improve the appropriateness of care by focusing in on some key elements of the patient-health care worker relationship. Basic to this relationship is that the care provider should have an awareness of cultural norms and beliefs. In particular, cultural attitudes toward medication and perceptions of forgetfulness as a natural part of the aging process were repeated throughout the interviews, as discussed previously in the report. Other key considerations in the relationship with the care provider included: flexibility in approach, adequate time, home visits/house calls, interactions in Aboriginal languages, trust, respect for traditional medicines, and appropriate knowledge sharing.

A gentle, unrushed, flexible approach was viewed as appropriate care:

*It's all about approach, and how gentle you approach them, and if you're not rushing and you're not threatening them, you're not going to hurt them, some, you know, you can treat it as a visit instead, and if you get resistance say, "You know what? Let's just visit while I do this", you know? It's always about how you approach it. (JP Care Worker 04)*

Flexibility in appointment type and scheduling was found to be key in providing care in a manner that was not rushed. For example, one physician suggested that house calls with elderly patients were far more effective than typical clinic visits:

*I found that when I changed over to a house call system for seeing the elderly people its vastly, vastly improved method of seeing people for so many reasons: one is the flexibility of time and the fact that you can take more time and the other is you are seeing the person in the context of how they function. (Local Physician)*

Communication was also a key attribute in the relationship with the care provider. This includes opportunity for the person with dementia to be able to speak and interact in care-giving encounters in their Aboriginal language:

*And she talks, she talks the language too, so it's really nice to hear that too. When anybody comes in and talks the language she's right in her peak then. (JP Care Giver 01)*

Language use was also important to building trust, especially with elders. Trust was described as something that takes time to establish as patients are concerned about breaches to confidentiality in the small, close-knit communities on Manitoulin Island. Also related to trust was the need for a relationship that allowed patient's to discuss traditional medicines and approaches to their care. Patients reported difficulties communicating with health care providers about traditional medicines and approaches to care:

*...so I know I've tried talking to different nurses and ask questions and to doctors too, and you know, what do you think about fasting for health periodically, stuff like that eh, and what do you think about this or that and I've heard this about some of this food, you know, or this alternative, uh, health system. And they don't want to hear that at all. (JP Care Giver 01)*

Finally, one aspect of the relationship with the care provider is that information is accessible and conveyed in a meaningful way.

**Structural inequalities** have the potential to undermine efforts to provide culturally safe care. The main structural inequality that was discussed by participants was financial hardship. In particular, participants described the stress of not being able to afford healthy foods as well as difficulties paying increased hydro bills during winter months. Related to this is not being able

to afford or having access to transportation for medical appointments, events and visiting.

Jurisdictional issues related to the integration of services is another structural inequality identified in this study. This issue is fairly complex but it was clear in our interviews that there could be differential access to care based on what program or system one was receiving care from (federal /provincial). Specific specialist physicians were often only accessible if the patient accessed services through a specific system or community (e.g. provincial nursing home care or family physician referrals). And most people were required to travel to see traditional healers and to travel to Sudbury for specialist care.

Overall, the data informs the beginning of a culturally safe model of care for Aboriginal people with dementia on Manitoulin Island. Key elements of culturally safe care for participating First Nations include: ensuring access to care, policy and program support for a family care model, honouring the importance of Elder's roles, addressing structural inequalities such as poverty and jurisdictional issues affecting access to care, enhanced patient-provider clinical interactions through cultural training.

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