Community Care Providers' Perceptions of Dementia in Aboriginal Seniors:
A Qualitative Study

By

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Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Little research has explored dementia within Aboriginal communities in northwestern Ontario; as a result, we know little about the experiences of health service providers in caring for these populations. This research study focused on community care providers' perceptions of dementia in Aboriginal seniors that reside in rural communities in northwestern Ontario. The study used qualitative research methodology. Eight community care providers were contacted through purposeful and snowball sampling and were interviewed using open-ended semi-structured interviews to generate study data. Eight prevalent themes emerged from the data analysis which was conducted through using the constant comparative method. The emerging themes include 'Views of Dementia: A Normal Part of Aging', 'The Inaccessible Population', 'Crisis and Caregiver Issues', 'Dwindling Services and Supports', 'Housing', 'Continuity of Care', 'Cultural Sensitivity' and 'Bright Future'. The study outlines the experiences of community care providers when caring for Aboriginal seniors with Alzheimer's disease and related dementia and what the care provider's need to deliver these services. The study is focused on care providers who have lived and worked in small rural and/or northern communities for an extended period of time to best reflect the realities of caring for Aboriginal seniors living with dementia in a small community. This study offers a foundation of dementia research in northwestern Ontario with hopes to guide further research as well as current and future supports and services for Aboriginal seniors living with dementia in these communities.

The findings indicate the need for the increase of both formal and informal supports and services in rural and remote communities for Aboriginal seniors with dementia. The research also exposes the need for educational initiatives surrounding dementia and cultural competency among community care and health care providers in rural northern communities along with the need for awareness and education in the Aboriginal community surrounding Alzheimer's disease and related dementia. This study suggests that community care providers and organizations need to work together to provide the most effective person-centered, culturally sensitive care for Aboriginal seniors and to deliver these required supports and services to seniors in a culturally respectful way.

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Chapter One: Introduction

Canada is at the forefront of the multifaceted issues that affect public health and health care delivery and practice in rural and remote settings. When focusing on Aboriginal people, their health care, and related research initiatives in the health care field, these issues are even more pronounced and complex. An aging population also provides an additional layer of complexity. Few researchers have studied issues of aging and dementia in Aboriginal populations, and as such, our knowledge of this area is limited in Canada.

This paper outlines research focused on Aboriginal peoples of Canada and their overall health, dealing particularly with Alzheimer's disease and related dementias. First, I cover the topic of aging and dementia starting from an international scale down to a Canadian perspective, and end with discussing the rural and remote context. Next, I embrace the topic of Aboriginal people and their health in Canada as well as health care delivery. Subsequently, I cover Alzheimer's disease and related dementias in Aboriginal Canadians and highlight recent research studies on the population before covering the research findings of this study.

The purpose of this research was to explore the experiences of community care providers working with Aboriginal seniors diagnosed with dementia who live in rural, northern off-reserve communities in northwestern Ontario. The research questions guiding the study were:

1. What types of services and interactions do community care providers in rural northern Ontario provide to persons with dementia and their family members?
2. What are the experiences of community care providers who work with Aboriginal seniors with dementia?

3. What are the needs of community care providers who work with Aboriginal seniors with dementia in rural northwestern Ontario?
4. What are the challenges faced by community care providers working with Aboriginal seniors with dementias in rural northwestern Ontario?
5. What types of services and/or supports are needed for community care workers to better care for Aboriginal people with dementia in rural northwestern Ontario?
6. What are the perceptions of community care providers of the needs and issues surrounding dementia in Aboriginal communities in rural northwestern Ontario?

Finally, I discuss culturally sensitivity and the medicalization of dementia and outline implications for future research initiatives.

Chapter Two: Literature Review

2.1 Aging and Dementia

2.1.1 The Aging Population

The world's population, especially in developed nations such as Canada and the United States, is rapidly aging due to the 'baby boom' (Camicioli et al., 2000). The aging population in Canada will continue to sharply increase as the first of the "baby boomers" reached 65+ starting in 2011 (Alzheimer Society of Canada [ASC], 2010). The World Alzheimer Report (Alzheimer Disease International [ADI], 2009) found that this demographic aging or the "greying" of the population is occurring much more rapidly than previously anticipated across the world. In addition, people are living longer due to improvements in housing, sanitation, medical care and public health initiatives. The result is the proportion of elderly people will peak during our generation. As life expectancy increases and overall mortality levels fall, the world is experiencing a period of rapid aging. Population growth is slowing or reaching a stasis point as fertility rates fall. As the population ages, more people are reaching the later stages of life than in any other point in history and many are living with chronic diseases which can last over many years (Kelley, 2007). According to the World Alzheimer Report (ADI, 2009), between 1990 and 2020 the oldest cohort of the population will have increased by 200% in low and middle income countries and increased by 68% in the developed world. By 2020, 66% of the world's population over 60 will be living in developing countries (ADI, 2009).

According to Nightingale (2003), increased longevity in the population can lead to increases in "morbidities including physical limitations, chronic conditions, acute illnesses, and dementia" (p.380). With the help of modern technology in health care, the aging population has the ability to live for years with chronic conditions. This lengthening of the human lifespan increases the incidence of Alzheimer's disease and related dementias since age itself is the largest risk factor for having the disease (Nightingale, 2003).

2.1.2 Dementia

The World Alzheimer Report 2009 defines dementia as a "syndrome due to disease of the brain, usually chronic, characterised by a progressive, global deterioration in intellect including memory, learning, orientation, language, comprehension and judgement" (ADI, 2009, p.6). According to the World Health Organization [WHO], (2010), dementia is a syndrome due to disease of the brain "in which there is a disturbance of multiple cortical functions, calculation, learning capacity, language and judgement" (p.2). Dementia should not be viewed as a "variant of old age" or a part of "normal life" but rather as a chronic disease (Jacques & Jackson, 2000). Dementia does not discriminate and affects people of all racial types, social class, occupation and life-style (Jacques & Jackson, 2000). However, more women are typically affected than men but it is not known why this occurs (ASC, 2010).

Dementia syndrome includes Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia as some of the most common forms of the syndrome (ADI, 2009). The two main illnesses, dementia of Alzheimer Type (DAT) and vascular dementia (VAD), remain the major causes for the decline and disability of dementia (Jacques & Jackson, 2000). Alzheimer's disease is the most common type of dementia and in Canada, Alzheimer's disease accounts for 64% of all dementia cases (ADI, 2010). Alzheimer's disease, as stated in the Rising Tide study (ASC, 2010), is defined as a "progressive, degenerative, and fatal brain disease" (p.3) that results from the loss of cell to cell connections in the brain, where these cells eventually die. Vascular dementia is the second most common form of dementia which results from an inaccurate blood supply to the brain (ASC, 2010). People can suffer from more than one type of dementia such as having both Alzheimer's disease and vascular dementia concurrently (ASC, 2010). Statistics provided by Forbes et al. (2006) suggest that eight per cent of Canadians 65 years of age and older and 35 per cent of those over the age of 85 have dementia. "Alzheimer's disease (AD) is the most common form of dementia, affecting 5 per cent of those over the age of 65 and up to 26 per cent of those 85 years and over. Half of those with dementia live in the community with family members or friends" (Morgan et al., 2009, p. 321).

A definite diagnosis of dementia according to the WHO cannot be given until at least 6 months have passed since the impairments have presented themselves (Jacques & Jackson, 2000). Dementia diagnosis usually occurs when a person's cognitive decline begins to increasingly affect his or her ability to perform necessary routine activities (ADI, 2009). Health professionals in Canada currently receive inadequate and/or limited training to be able to effectively and efficiently prevent, identify, diagnose and care for persons with dementia while following "best practices" throughout the course of the disease (ASC, 2010). According to the World Alzheimer Report (ADI, 2009), only 31% of primary care doctors feel that they have received adequate training to diagnose and manage dementia. Early differential diagnosis of dementia is key as people with dementia can benefit from treatments such pharmaceutical interventions which can treat symptoms and slow the progression of the disease as well as manage behaviour, which in turn benefits not only the individual but also the family and/or caregivers (Cammer, 2006). Current research suggests that many people either ignore symptoms of dementia or fail to acknowledge them and tend to seek support and services at a later stage when treatment may be less effective, and thus their quality of life is reduced, and undue stress may have been put on family and/or caregivers (Cammer, 2006).

Dementia can progress relatively fast, relatively slow or anywhere in-between; however, this decline is always progressive (Jacques & Jackson, 2000). Although the person may exhibit temporary improvements or static periods, the disease will eventually continue its progressive decline (Jacques & Jackson, 2000). Resulting challenges of dementia include memory impairment, disorientation, apathy, repetitiveness, uncontrolled behaviour, and incontinence, yet this list is far from exhaustive (Jacques & Jackson, 2000). Dementia is a leading cause of disability among older people, and is second only to blindness (ADI, 2009). At the present time, there are no treatments available that cure or alter the progression of dementia (ADI, 2009).

Alzheimer's disease and related dementias reduce a person's projected lifespan. In developed western countries, one can expect to live 5 to 7 years after disease onset and diagnosis (ADI, 2009). Nightingale (2003) suggested that "individuals diagnosed with AD may live for years with ever diminishing capabilities and eventually require 24-hour custodial care" (p.380). People residing in Canada who have dementia now live an average of 9 years and require either care in the home or in a long-term care setting (Smale & Dupuis, 2004). Dementia may result in a long-term disability for the person and may also cause stress for informal caregivers and family members (ASC, 2010). The levels of dementia are classified in three stages; however these stages are given as a guide only and a person can progress through them either faster or slower (ADI, 2009):

1 Early stage – first year or two
2 Middle stage – second to fourth or fifth years
3 Late stage – fifth year and after

The main risk factor for developing dementia is aging (Smale & Dupuis, 2004) and the prevalence of dementia roughly doubles every five years after the age of 65. At 85, the odds of developing the disease increase to 50% (ADI, 2009). The other risk factors for dementia include lifestyle, the environment and genetic factors (ASC, 2010). High cholesterol, high blood pressure, and diabetes have all been linked to potentially aiding in the onset of dementia (ASC, 2010). The available scientific evidence for a causal link between cardiovascular risk factors and cardiovascular disease, in relation to Alzheimer's disease and related dementias, is quite high (ADI, 2009). Such risk factors as atherosclerosis, hypertension, diabetes, high cholesterol and smoking have a higher risk of incidence of dementia (ADI, 2009). Onset of dementia earlier than the age of 65, called early on-set dementia, is less common and suggests a strong genetic cause (ADI, 2009). Developing dementia after age 65, also called late-onset dementia, is thought to be caused by combined genetic and environmental risk factors (ADI, 2009).

Prioritization in healthcare funding and contributions is more focused on chronic diseases that cause mortality compared to diseases such as dementia that contribute to long-term disability (ADI, 2009). For example, most health care spending, research and investment is substantially higher for cancer and heart disease than for dementia and stroke (ADI, 2009). For example, "chronic diseases that contribute most to mortality have the largest number of research papers focussed on them, but the chronic diseases that contribute most to disability are the subjects of the fewest research papers" (ADI, 2009, p.9).

2.1.3 Alzheimer's Disease and Related Dementias Worldwide

The incidence and cost, both economic and social, of dementia on an international scale is unequivocally rising (Camicioli et al., 2000). The World Alzheimer Report underscores that Alzheimer's disease and other dementias "are the single most significant health and social crisis of the 21st century" (CTV News, 2010, p.1). Numbers released from the World Alzheimer Report (ADI, 2009) state that approximately 35.6 million people are affected by dementia world-wide. According to Alzheimer's Disease International, as the world's population starts to live longer, the incidence of dementia will double every 20 years from 66 million in 2030 to 115 million in 2050 (ADI, 2009). The cost of dementia worldwide today is US$604 billion and this cost will increase substantially as the rate of people with dementia triples by 2050 from current numbers (ADI, 2010). The World Alzheimer Report (ADI, 2010) stated that if dementia care were a company it would have the world's largest revenue exceeding both Walmart (US$414 billion) and Exxon Mobil (US$311 billion). This enormous socio-economic impact results in costing approximately 1% of the world's gross domestic product (ADI, 2010). The greatest culprits for cost in high-income countries such as Canada rest on the expense of long-term care facilities, while in low-income countries this cost falls onto the families and informal caregivers when facilities are not available (CTV News, 2010).

The cost per person with dementia is highest in North America at US$48,605 and lowest in South Asia (US$903) and Western Sub Saharan Africa (US$969) (ADI, 2010), indicating that the cost per person with dementia is over 50 times higher in the richest countries than in the poorest (ADI, 2010). In high income countries, studies show that the economic costs of dementia to society already exceed those of other chronic conditions such as cancer, heart disease or stroke

(ADI, 2010). The high level of costs to care for persons with dementia is driven mainly by long-term disability, dependence and social care costs (ADI, 2010). The World Alzheimer Report also states that currently societal and caregiving costs are largely met by unpaid family caregivers (ADI, 2010). Governments may regard care provided by families as free; however, the costs are both financial and social.

Alzheimer Disease International, in the World Alzheimer Report 2010, is calling on governments to extend the following recommendations, among others, regarding dementia on a global scale: 1) to make dementia a health priority and to develop a national dementia strategy; 2) that investment into chronic care should always include dementia; 3) to invest into research regarding dementia and prevention; and 4) to develop long-term care plans to address both societal and demographic needs as well as protecting vulnerable people with dementia. "World governments are woefully unprepared for the social and economic disruptions this disease will cause" (CTV News, 2010, p.1). The World Alzheimer Report stated that global awareness of the disease is needed as there are many misconceptions about dementia (ADI, 2010). Some of the most common misconceptions of dementia include: it is not a common problem; it is a normal occurrence of aging; there is no treatment for the disease; and that families are responsible for care, therefore relieving governments and health care systems of the problem (ADI, 2010). The report stated that awareness of dementia is inadequate worldwide due mainly to decreased education, stigmatization of the disease, being viewed as a normal part of aging or viewed as a disease where nothing can be done (ADI, 2009). The following six principles should be adopted to make Alzheimer's disease and other dementias a global priority, according to the ADI (2009, p.68): Promote awareness and understanding of the disease; respect the human rights of people with dementia; recognize the key role of families and carers; provide access to health and social care; stress the importance of optimal treatment after diagnosis; and take action to prevent the disease through improvements in public health.

The National Institute of Health in the United States alone spend 14 times more on cancer research and 5 times more on cardiovascular disease research than is spent on dementia research (ADI, 2010). Worldwide, between 2000 and 2010, there were 16 times as many research publications on cancer, and 11 times as many publications on heart disease compared to publications on Alzheimer's disease and related dementia (ADI, 2010). Research expenditures in 2008 in the United States included $5.6 billion on cancer, $2.0 billion on cardiovascular disease, $0.3 billion on stroke, and $0.4 billion on dementia (ADI, 2010). Currently in Canada, for every $100 spent on cancer research, only $15 is spent on researching dementia (The Globe and Mail, 2010).

2.1.4 Alzheimer's Disease and Related Dementias in Canada

The Rising Tide report (ASC, 2010) stated that 500,000 people in Canada have dementia and it is the leading cause of disability over the age of 65. By 2038, this number will have risen to 1,125,200, or 2.8% of the total Canadian population, and cost over $872 billion (ASC, 2010). In turn, the demand for long-term care will have increased tenfold in the next 30 years (ASC, 2010). Canada is expected to follow the world-wide two-fold increase in dementia rates over the next 20 years (ASC, 2010). In relation to incidence, in 2008, there were 103,700 new cases of dementia or 1 new case every 5 minutes, whereas by 2038, it is projected that there will be 257, 800 cases or one new case every 2 minutes (ASC, 2010). According to the World Alzheimer Report (ADI, 2010) the annual cost per person with dementia in Canada is US$30,812. Dementia in Ontario is expected to rise by 40% in the next ten years and cost the province more than $770 million per year in medical costs and lost productivity (ADI, 2010).

New findings from the 10/66 Dementia Research Group outline that dementia is the leading chronic disease contributor when it comes to disability and care needs (ADI, 2010). The demand for long-term care beds will rise dramatically from approximately 280,000 beds in 2008 to 690,000 beds in 2038, leaving a shortfall of a projected 157,000 beds across Canada (ASC, 2010). The Rising Tide report (ASC, 2010) stated that over the next 30 years, the demand for long-term care in Canada will expand tenfold from 2008 values, thereby overwhelming the country's health care system.

Canada presently is unprepared for the impending crisis of the increasing aging population and rising levels of dementia. On the heels of the report "*Rising Tide: The impact of dementia on Canadian Society*" released in 2010 comes the "*World Alzheimer Report 2010*" released in September 2010. Debbie Benczkowski, CEO of the Alzheimer Society of Canada, states that "This report is the second wake-up call for Canada" (Terrace Bay-Schreiber News, 2010, p.6). If something is not done, then the surge of new dementia cases will overwhelm Canada's health care system and strain already stretched health care budgets across the country, unless Canada acts now (ASC, 2010). There is a need for political will to invest in research and care options and to develop a comprehensive National Dementia Strategy (ADI, 2010). In 2004, Australia was the first country to make dementia a national health priority (ADI, 2009). Canada should be following the leads of countries such as France, Australia and England who have already made dementia a top priority and developed a national plan to handle the social, economic and health consequences (ADI, 2010).

2.2 Rural Aging and Dementia in Canada

2.2.1 Rurality

It was boldly stated by Kirby (2002) in *The Health of Canadians – The Federal Role*, that if there is a two-tiered medical system in Canada, it is not rich versus poor, it is urban versus rural (Cammer, 2006). It is well researched that, in regards to health care and the social determinants of health, those residing in rural and remote areas are disadvantaged compared to those who reside in urban areas (Cammer, 2006).

Rural, as used in the Canadian Community Health Surveys (CCHS), is defined as "the population living outside of continuously built-up areas having a population concentration of 1,000 people or more and a population density of 400 or more people per km^2 based on the previous census" (Forbes, Morgan & Janzen, 2006, p.322). Rural Canada is defined as all of the territory outside of urban centres and comprises over 95% of the country's total land mass (Ministerial Advisory Council on Rural Health, 2002). "Depending on which definition of rural is used, between 21 and 30 % of the Canadian population lived in rural communities in 2001 (Ministerial Advisory Council on Rural Health, 2002, p.1).

> *Rural* usually is defined as dichotomous to urban or metropolitan areas. These dichotomies focus only on the quantitative dimensions of population density and spatial distribution and fail to capture the qualitative variability between and within groups. More recently, *rurality* has been described as a continuum with small town or remote areas at one end and large cities or metropolitan areas at the other end. Additional factors, such as economics, occupation, and distances to emergency services, have been considered. (Rosswurm, 2001, p.232)

More than half of Canada's 1.4 million Aboriginal people live in rural, remote and northern areas in Canada (Morgan et al., 2009). "The rural, remote, northern and Aboriginal communities, which make up rural Canada, have diverse social, geographic and economic characteristics" (Ministerial Advisory Council on Rural Health, 2002, p.1). In 2000, over 66% of residents that resided in rural and remote regions of Canada lived more than 100 kilometres away from a physician (Ministerial Advisory Council on Rural Health, 2002). Although approximately 30% of Canadians live in rural and northern areas, only 17% of family physicians, 4% of specialists, and 18% of registered nurses practice in rural, remote and northern communities (Ministerial Advisory Council on Rural Health, 2002).

2.2.2 Rural Population Health Statistics

According to Forbes et al. (2006), individuals who reside in rural and remote areas can be at an increased risk of suffering from poorer health in relation to those who reside in urban areas. Data compiled from the Canadian Community Health Survey (CCHS) *How Healthy are Rural Canadians? An Assessment of Their Health Status and Social Determinants* found many health concerns in relation to rurality and health care. Rural areas in Canada have a higher proportion of older adults (age 60 and older), have a lower proportion of immigrants and a higher proportion of Aboriginal people (Health Canada, 2010; Ministerial Advisory Council on Rural Health, 2002). Generally, the risk of many chronic diseases is higher in rural regions of Canada and residents, on average, have a lower life expectancy and higher overall mortality rates (Health Canada, 2010; Ministerial Advisory Council on Rural Health, 2002; Rosswurm, 2001). Compared to urban populations, rural populations have lower incomes, less education, decreased access to transportation, fewer formal services and health care services which are located at a greater distance from their community (Forbes et al., 2006; Ministerial Advisory Council on Rural Health, 2002; Rosswurm, 2001).

2.2.3 *Availability of Health Care and Dementia Care in a Rural Setting*

The provision and access of healthcare supports and services in the north is complex and multi-faceted (Ministerial Advisory Council on Rural Health, 2002). Health care and long-term care needs are intensified as the population ages and requires more services and assistance with daily living. Rural and remote areas often have a low population density and are often far away from urban centres and centralized health care services (Kortes-Miller, Habjan, Kelley & Fortier, 2007). According to Kortes-Miller et al. (2007), over 30% of the Canadian population live in rural and/or remote communities, and of this, a growing number of residents are aging.

Health services and programs in these rural areas are often suffering from lack of resources which include a need for more health care facilities, services, quality of care and health care providers (Kortes-Miller et al., 2007). Health care and community support services that are available in urban centres such as respite care, home care, rehabilitation, and transport services may not be available in rural environments (Bédard et al., 2004). Many rural and remote communities experience a limited availability of alternative community-based services, inadequate health services and supportive services such as senior centers, respite care, and meals-on wheels which may often be "unavailable, unaffordable, or inaccessible to families" (Rosswurm, 2001, p.232). "Family caregivers of dependent elders provide the bulk of home care, often without any training in basic home nursing skills" (Rosswurm, 2001, p.232).

With the increasing population in Canada, along with increases in rural and remote areas, it is estimated that the prevalence of dementia will drastically increase (Smale & Dupuis, 2004). Rosswurm (2001) explained that in many rural communities in the United States, seniors comprise over 25% of the population, compared to their urban counterparts who average only

12%. According to Morgan et al. (2009), existing studies of rural dementia care in Canada show that there is currently a lack of formal supports and health care services, along with transportation issues regarding distance to health care.

As expressed by Romanow (2002), the overall health of a community seems to be inversely related to the rurality of its location and ability to access health care services (Forbes et al., 2006). Rosswurm (2001) noted that providing health care to rural seniors should be a top priority especially with the increasing aging of the population. Rural residents should have the right to health care services that are reasonably accessible, appropriate, affordable, and culturally sensitive. "The availability, accessibility and acceptability of services are critical factors in rural health service delivery. In Canada, the aging population and the consequent increase in prevalence of dementia challenge the ability of many rural communities to provide specialized dementia care" (Morgan et al., 2009, p.17). The *Romanow Report's* (2002) health care recommendations exclude the rural population in relation to supports and services necessary for people with dementia and their caregivers. Without a restructuring of health care services and supports needed by these populations, a larger number of people with dementia, and their voluntary caregivers, will continue to lack required health care to meet their needs and be forced to resort to institutionalization which is more costly (Forbes et al., 2006).

Rosswurm (2001) stated that the NINR Priority Expert Panel on Community - Based Health Care described primary health care as a "community-based, culturally sensitive approach to care that focuses on health promotion and disease prevention across the continuum" (p.232). Health, economic, and social types of programs need to be integrated to be most effective; however, community based programs in rural and remote areas usually fail to meet these criteria

(Rosswurm, 2001). Rosswurm (2001) highlighted that many of these programs used in rural settings are poorly adapted urban programs which do not address the often fragmented delivery of health care in rural areas, nor do they fill the gaps in the continuum of care.

Cammer (2006) listed many of the barriers to accessing formal health care services by rural residents and these barriers are magnified when dealing with elderly and Aboriginal populations. A large challenge is travel, which not only includes the time and distance of travel in the north and the expense and stress associated with travelling, but also includes the physical challenges of seniors having to travel. Moreover, caregivers in rural areas report a greater number of barriers when caring for a relative with dementia than their urban counterparts (Morgan et al., 2009). Health care for rural and remote elders and their families should be community-based and culturally sensitive to increase the use of these resources and services by residents (Rosswurm, 2001). Rural health care providers need to form a base of trust built on a "sense of relationship and reciprocity within the community" (Rosswurm, 2001, p.233). A main goal for health providers requires the involvement of seniors and their family members and/or caregivers in health care planning and decision making processes (Rosswurm, 2001).

2.2.4 Dementia Diagnosis and Treatment in a Rural Setting

The limited access that rural residents have to specialists, such as geriatricians, means that early diagnosis and treatment of persons with dementia is required by primary care physicians (Morgan et al., 2009). According to a study in the United States, both rural and urban primary care physicians make few new diagnoses of Alzheimer's disease or related dementias, rarely use published diagnostic criteria or procedures or recommended approved drug therapies for dementia (Brown, Mutran, Sloane, & Long, 1998). Impediments to diagnosis and treatment options for dementia that were voiced by rural primary care physicians included limited access to specialist consultants and limited community support and education resources (Morgan et al., 2009). A study of rural physicians in Australia found that only 39% used formal instruments for screening for dementia (Brodaty, Howarth, Mant & Kurrle, 1994). A study of rural U.S. physicians in Illinois resulted in an even lower number using formal screening instruments at only 10% (Glasser, 1993). Rural physicians instead used passive diagnosis by relying on and responding to patient, family and/or caregiver complaints (Camicioli et al., 2000). Some barriers to using current standardized screening instruments include lack of knowledge of their availability, time constraints, and a perception that testing their cognitive ability might offend older people (Camicioli et al., 2000). In one Scottish study, it was found that physicians may feel that there is not enough to be gained from making an early diagnosis of dementia (Wolff, Woods & Reid, 1995). Bédard et al. (2004) found that seniors who reside in rural or remote regions may be institutionalized prematurely when compared to seniors living in more urban centres.

Therefore, the above challenges of receiving a diagnosis of dementia in a rural or remote community means that people may miss receiving medications and services during that critical window of time. Physicians working in rural and remote locations need to have the training and awareness of dementia signs and symptoms to diagnosis the disease early in its progression or refer patients to a specialist.

2.2.5 Current Dementia Research in a Rural Context

Current research in the development of memory clinics by the New Emerging Team initiative in conjunction with the Canadian Institute of Health Research (CIHR) include objectives to "increase the availability and accessibility of dementia care in rural and remote areas, to determine the acceptability of a one-stop clinic and of Telehealth vs. regular follow-up, and to develop culturally appropriate assessment protocols for assessment of dementia in aboriginal older adults" (Morgan et al., 2009, p.19). The memory clinic program is widely supported by rural and remote health care providers as they voiced an increase in the prevalence of dementia in their Saskatchewan practices (Morgan et al., 2009). The program acknowledged that there is also an ever growing need for information, education and resources to diagnose dementia and help the person with dementia manage as well as the need to help support caregivers in the north (Morgan et al., 2009). At the memory clinic, patients are assessed by multiple health care professionals at one time and the family is involved in the process (Morgan et al., 2009). The clinic also makes extensive use of Telehealth videoconferences for both pre- and post-clinic assessment of the patient (Morgan et al., 2009). Both health service delivery strategies for providing services to persons with dementia and their caregivers have been deemed feasible and acceptable methods of care in rural and remote settings (Morgan et al., 2009).

There is currently a paucity of ongoing research and current literature on Aboriginal people and dementia in Canada. The rural and remote memory clinics can provide models for other provinces, both for rural and remote communities (Morgan et al., 2009).

2.3 Aboriginal Health and Health Care in Canada

2.3.1 Background and Statistics

Aboriginal people of Canada include First Nation, Métis and Inuit Peoples as referenced in the Canadian Constitution (Castellano, 2004). According to the 2006 Canadian Census, there are 1,172,790 Aboriginal people in Canada, which equates to 3.8% of the country's total population (Statistics Canada, 2006). Of the total population of Aboriginal people in Canada, 50,485 are Inuit, 389,785 are Métis and 698,025 are First Nations people (Statistics Canada, 2006). The Aboriginal population grew by 45% from 1996 to 2006, nearly six times greater than the 8% growth rate in the non-Aboriginal population in Canada (Statistics Canada, 2006). In general, Aboriginal persons are younger due to the increased birth rate compared to the province as a whole, with 46% of all Aboriginals under the age of 25 (Ontario Health Quality Council, 2007).

According to the 2006 Census, Ontario has the largest Aboriginal population at 242,495 out of 12,028,895 residents with a far second being British Columbia at 196,075 (Statistics Canada, 2006). The statistics of the aging population in Ontario are drastically illuminated by the difference seen in the numbers between the 2001 and 2006 Census. From 2001 to 2006 the change in non-Aboriginal Ontario residents age 65 and over in Ontario rose by 12.5% compared to a 46.6% increase for Aboriginals in the same age category. During this 5 year span, the increase in non-Aboriginal Ontario residents from 55-64 rose by 27.5% compared to the increase in the Aboriginal population in this age range by 62.0% (Statistics Canada, 2006).

The growing Canadian population along with the rising senior Aboriginal population is outlined in Tables 1 and 2 focusing on the Thunder Bay area and the three study communities.

Table 1. Changing population demographics in northwestern Ontario (Statistics Canada, 2001, 2006)

Location	Total population 2001	Total population 2006	Total Aboriginal population 2001	Total Aboriginal population 2006	Total Aboriginal population over 55 2001	Total Aboriginal population Over 55 2006
Canada	30,007,094	31,612,897	976,305	1,172,785	92,505	137,550
Ontario	11,410,046	12,160,282	188,315	242,490	20,565	31,955
Thunder Bay	109,016	109,140	7,245	8,845	590	920
Community 1	5,662	4,906	860	975	100	115
Community 2	1,964	1,752	370	405	30	110
Community 3	8,198	8,195	570	780	80	75

Table 2. Percentage increase from 2001 to the 2006 Census of Aboriginal seniors over 55 years of age (Statistics Canada, 2001, 2006)

Location	% increase of Aboriginal seniors over 55 years of age between 2001 and 2006
Canada	32.75
Ontario	35.64
Thunder Bay	35.86
Community 1	13.04
Community 2	72.72
Community 3	-6.67

In the report, *Rural Health in Rural Hands,* the Ministerial Advisory Council on Rural Health (2002) outlined that:

> Rural health research is necessary to under-stand, forecast and positively influence the health of people living in rural, remote, northern and Aboriginal communities. Through research, health challenges can be examined and monitored, appropriate rural health policies can be developed, and the effectiveness of health programs and services can be evaluated. To improve the health and well-being of all Aboriginal people, it is important to invest in and build on the strengths and capacities of First Nations, Inuit and Métis communities, in collaboration with provincial and territorial governments and Aboriginal partners. There is also a need to promote the rejuvenation of cultural and community life. Culturally sensitive and relevant programs and health services are prerequisites for improving the health and well-being of First Nations, Inuit and Métis people. (p.4)

Aboriginal people's health in Canada continues to be significantly lower than the non-Aboriginal population despite considerable efforts to change this statistic (Garvey, Towney, McPhee, Little & Kerridge, 2004). The health and well-being of Aboriginal Canadians is comparable to citizens of many developing nations (Estey, Kmetic & Reading, 2007; Reading & Nowgesic, 2002). Aboriginal people are more likely to be obese, smoke, suffer from high blood pressure, have mental health problems and to have increased rates of depression, substance abuse and suicide (OHQC, 2007; Shan, Gunraj & Hux, 2003). Aboriginal people are also three to five times more likely to develop Type 2 diabetes compared to the general population (OHQC, 2007).

Many aboriginal people have difficulty accessing basic care due to the location of their homes within rural areas, the discrepancies regarding the social determinants of health, along with jurisdictional issues of providing care. "More than half of Canada's 1.4 million" Aboriginal Canadians live in rural, remote or northern regions of the county (Morgan et al., 2009, p.17). The above factors result in four out of ten Aboriginals that live in rural or remote areas having a lack of, or limited amount, of primary care (OHQC, 2007). For example, those living within remote communities with diabetes are three times more likely to suffer serious complications from this illness than those in larger urban communities (OHQC, 2007).

2.3.2 Brief History of Aboriginal People and Their Health

Health is a basic human right (Mann, 1995). The Alma-Ata Declaration declares that "health is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal" (Parker, Gould & Fleming, 2007, p.7). Aboriginal people have suffered through multiple infringements on their health, their well-being and their basic human rights over the course of Canada's tainted history (Castellano, 2004). Aboriginal people in Canada continue to suffer from the long-term scars left by the effects of colonization and residential schools. Such injustices included removal of Aboriginal children from their homes, forced relocation and removal of communities from their land, removal from their traditional lifestyle and loss of their language and cultural traditions (Garvey et al., 2004). The forced relocation and removal from their land has led to a loss of cultural practices and a loss of a 'sense of self', resulting from paternalistic influences and state interference in a liberalist view. Although colonization occurred many years ago, its effects are still seen today. In a recent survey, six out of ten First Nations people stated that the effects of colonization and residential schools continue to lead their people to poor health (Health Canada, 2007). Failure of the general population and the health care system in acknowledging and dealing with historic issues, such as the devastation caused by residential schools, is a leading factor to poor health and a disconnect between Aboriginal people and non-Aboriginal people (OHQC, 2007).

Adelson (2005) outlined the many reasons for distrust by the Aboriginal population in Canada.

> A history of colonialist and paternalistic wardship, including the creation of the reserve system; forced relocation of communities to new and unfamiliar lands; the forced removal and subsequent placement of children into institutions or far away from their families and communities; inadequate services to those living on reserves; inherently racist attitudes towards Aboriginal peoples; and a continued lack of vision in terms of the effects of these tortured relations - all of these factors underlie so many of the ills faced by Aboriginal peoples today. (p.S46)

There is a disconnect between the Aboriginal people of Canada and the rest of the country's population. There are five underlying reasons for this disconnect proposed by Romanow (2002) which include: competing constitutional assumptions, fragmented funding for health services, inadequate access to health care services, poorer health outcomes, and different cultural and political influences. There is also a disconnect regarding the constitutional responsibilities for Aboriginal health care and the Canadian government, which results in a mix of programs and services being run by the federal, provincial and territorial governments. The Canadian government funds programs and services to First Nations and Inuit people who reside on reserves. However, there is no constitutional treaty that states that the federal government has to offer health services or programs directly to Aboriginal peoples which results in an unequal treatment of citizens (National Aboriginal Health Organization, 2004).

The Aboriginal population in Canada are impacted by many of the social determinants of health and suffer from health disparities similar to those in Third World countries, including infrastructure, housing, employment, income, environment, and education (Adelson, 2005). Adelson (2005) defined health disparities as "those indicators of a relative disproportionate burden of disease on a particular population" (p.S45) and that these health disparities are "related to economic, political and social disparities - not to any inherent Aboriginal trait - and because of the limited autonomy Aboriginal peoples have in determining and addressing their health needs" (p.S45-46).

Adelson (2005) remarked,

> Health inequities point to the underlying causes of the disparities, many if not most of which sit largely outside of the typically constituted domain of "health". The literature reviewed for this synthesis document indicates that time and again health disparities are directly and indirectly associated with social, economic, cultural and political inequities; the end result of which is a disproportionate burden of ill health and social suffering upon the Aboriginal populations of Canada. (p.S45)

Adelson continued to suggest that

> Cultural differences in how we come to understand what health means, economic conditions, living and social conditions, and one's level of formal education are all elements that must be addressed in concert with public health priorities and initiatives if we are to understand and effectively take on the formidable task in reducing health disparities and promoting equity in Aboriginal Canadian populations. (2005, p.S46)

Until current health disparities are acknowledged by all levels of government and action is taken, Aboriginal people will continue to suffer from a disproportionate amount of health problems compared to the general Canadian population. Aboriginal people, both on and off-reserve, require proper access to, and availability of, required social determinants of health such as adequate housing, access to quality food and drinking water and proper sanitation.

2.3.3 Aboriginal Health Care in Canada

Medicine and contemporary bioethics reflect Western and liberal values which are founded on corresponding conflicting ethical beliefs, principles and values which have a negative impact on the Aboriginal population (Garvey et al., 2004). Health care system logistics have followed Western philosophy and reflect the "primacy given to liberalism, autonomy and rationalism" (Garvey et al., 2004 p. 573). These ethics, values and beliefs are not necessarily held by Aboriginal populations yet they have been used as a framework for the delivery of health care services to Aboriginal people, thereby at times contradicting their traditions and their personal identity (Garvey et al., 2004). The traditional western biomedical model of care that requires a "passive and compliant patient" is not in line with traditional Aboriginal views and culture (Adelson, 2005, p.S46). The biomedical model tends to overlook the physical, emotional, mental and spiritual aspects of individual and family connections, which are taken into account in the Aboriginal wellness model. The concepts of the Aboriginal wellness model are not usually incorporated or translated across into standard biomedical health care centres, regardless of their location (Adelson, 2005).

Garvey et al. (2004) stated that non-Aboriginal people have "frequently developed stereotypes about a homogenous Aboriginal culture along with generalizations about Aboriginal values and spiritual beliefs" (p. 572). For example, the risk factor of 'Aboriginality' in research studies has little meaning as a social construct in regards to Aboriginal people who are diverse in cultural, historical, socioeconomic and political composition (Smylie, 2005). There is a definite lack of Aboriginal-led research to identify specific Aboriginal priorities and goals. Without this type of information it is nearly impossible to develop programs to provide culturally sensitive and specific care to meet Aboriginals' health requirements, thereby improving First Nation health, including dementia focused strategies and programs (Minore & Boone, 2002).

2.3.4 Improving the Delivery of Aboriginal Health Care and Services

When the Aboriginal population is given control over health services through self-empowerment and training, studies have shown that these measures result in an improvement of health and to the access of services due to a supportive, culturally-appropriate environment (Lemchuck & Jock, 2004). Health services need to base care on Aboriginal moral values which can include the balancing of the spiritual, emotional, physical and intellectual aspects of the medicine wheel teachings which correspond with the child, youth, adult or elders within the community setting (Bell et al., 2007). Aboriginal health care must not be blinded by the treatment phase. One must look at the surrounding cultural, social, economic and political environments that paint the picture of a population experiencing a disproportionate measure of illness, mortality, injury, addiction, and family violence (Lemchuck & Jock, 2004). The Aboriginal population also suffers from the lack of basic human rights which includes overcrowded conditions, inadequate housing and community structure along with decreased levels of employment, overall income, and education, particularly in northern communities (Lemchuck & Jock, 2004). Lemchuck and Jock (2004) stated that "Aboriginal peoples rate significantly lower on virtually every measure of health and well-being when compared to the general Canadian population" (p.31), which is a result of compounding barriers.

Barriers that result in lack of health care services for Aboriginals include language differences, cultural appropriateness, the lack of Aboriginal health providers, and the inaccessibility of services due to distance and jurisdictional divisions (Lemchuck & Jock, 2004). As an example, for 35% of the Aboriginal population in Canada, a physician is over 90 km away and three out of every five of these communities do not have road access and rely on flights to bring in health professionals or to access specialty services and emergency care (Lemchuck & Jock, 2004). This lack of the ability to maintain continuity of care between health care professionals and Aboriginal people is seen as a large problem and adds to the unequal access to health care for the Aboriginal population. Many of these barriers result in an unequal treatment of Aboriginal people compared to non-Aboriginal people in the health care system. Lemchuck and Jock (2004) stated that the lack of knowledge by health care providers of the language and cultures of Aboriginal people result in communication errors in treatment along with a mistrust between provider and patient, which adds to the list of things that need to be improved in health care delivery to Aboriginal people.

A method of improving the health of Aboriginal populations and aiding in community development and empowerment is through the use of Aboriginal health centres. These centres share a moral philosophy where care is delivered in a culturally appropriate manner directed at improving and balancing the physical, mental, spiritual, and emotional well-being of the client, which also includes the use of traditional healers as part of the health care team (Lemchuck & Jock, 2004). These centres take into account Aboriginal values which are deeply-held beliefs about good and evil and a worldview that human actions must, in most situations, include both a spiritual context as well as a physical context (Castellano, 2004). There is no quick solution to fix the health problems of the Aboriginal community and yet Aboriginal people have the right to self-determination as well as to access culturally appropriate and comprehensive health care (Bell et al., 2007).

> Indigenous peoples have the right of self-determination by virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development. Just as colonial policies have denied Aboriginal Peoples access to their traditional lands, so also colonial definitions of truth and value have denied Aboriginal Peoples the tools to assert and implement their knowledge. (Castellano, 2004, p. 102)

Health care for Aboriginal people can be improved by allowing communities to have ownership and control over health services, which has been shown to improve access and attendance of Aboriginals to these services (Bell et al., 2007). It should also be ensured that the population has equal access to primary health care services and that the care is provided in a culturally appropriate, sensitive and inclusive way, while catering to the social and cultural needs of the Aboriginal community (Bell et al., 2007). There is also a need to prevent hidden and obvious racism from non-Aboriginal staff working in Aboriginal health and to prevent unethical behaviour and presumptions about 'lifeways' and illnesses by the health care field (Bell et al., 2007). The delivery of culturally appropriate health care services in a sensitive way requires that health care staff needs to acquire the knowledge, tools and skills, through cultural sensitivity training, to understand Aboriginal views of health, culture and history (Bell et al., 2007). McKay-McNabb (2006) stated that cultural and traditional programs and resources for Aboriginal people need to be available to meet the population's health care and research needs. These programs and culturally specific initiatives can be used in the diagnosis and management of dementia in Aboriginal populations. Therefore, by respecting Aboriginal culture and lifeways, by removing barriers to health care and services for Aboriginal people and by providing culturally sensitive and appropriate care in which Aboriginal people have ownership in, improvement in the delivery of health services to Aboriginals can be attained.

2.4 Dementia and Aboriginal Populations

2.4.1 Background

Aboriginal Canadians still bear a disproportionate burden of illness according to Cammer (2006). Even at present, we see a marginalization of health and social care to minority ethnic groups which includes the Aboriginal population (Nightingale, 2003). There is currently little known about Aboriginal people, dementia and their experiences in accessing health services relative to Alzheimer's disease and related dementias (Morgan et al., 2009). Although the health care community is aware of the challenges of healthcare delivery in rural and northern settings, the awareness of culturally centred services and care for northern populations and dementia has been overlooked. Pollitt's (1997) review of dementia in Australian Aborigines and Torres Strait Islander communities found that dementia in this society had no equivalence or meaning and that these populations had more urgent health and societal problems such as inadequate housing, education, primary health care, and a lack of clean water (Pollitt, 1997). It was also found that in some Aboriginal cultures, dementia was not always an acceptable diagnosis (Pollitt, 1997).

Alzheimer's disease and related dementias are classified as chronic diseases (Alzheimer Society of Ontario, 2007). There are extreme limitations to the available research related to Alzheimer's disease and related dementias in rural northern communities, and even less is known about the effects of these diseases on the Aboriginal population (Pollitt, 1997). In general there is a lack of statistical information related to Aboriginal people and ADRD in Canada. The 2001 Aboriginal Peoples Survey did not calculate the number of Aboriginal seniors with Alzheimer's disease and dementia when they looked at chronic conditions; however, the percentage is speculated to be approximately the same as the rest of the Canadian population. Performing a literature search on the topic of Aboriginal people and dementia yields very little specific information or statistics. The only study data on Alzheimer's disease prevalence rates in Canadian Aboriginals found a 4.2% prevalence rate in Cree populations residing in Manitoba which is lower than the 8% Canadian population average in people over 65 years of age (Canadian Mental Health Association, 2003; Lombera, Butler, Beattie & Illes, 2007).

A roundtable held in Sudbury, ON in 2010 found that issues concerned with Aboriginal seniors and dementia were not well understood by health care workers (Jacklin, 2010). There is a need for services to provide access to education and training in dementia awareness regarding Aboriginal seniors which would include cultural sensitivity training for staff (Alzheimer's

Australia, 2006). Ontario has the largest number of Aboriginal seniors in Canada at 8,623 in 2006 (Statistics Canada, 2006). The population in this country is aging, and it is expected that the Aboriginal senior population will double by 2017 (Statistics Canada, 2006). Aboriginal people also have a higher prevalence of diabetes and cardiovascular disease which are risk factors for dementia (Alzheimer Society of Ontario, 2007). Aboriginal people in Ontario are three times more likely to have diabetes than the non-Aboriginal population (Alzheimer Society of Ontario, 2007). The second risk factor identified by the Alzheimer Society of Ontario (2007) is the ever increasing life expectancy of Aboriginal people. With advanced age comes the increased risk of developing Alzheimer's disease and related dementias (Alzheimer Society of Ontario, 2007).

2.4.2 Utilization of Dementia Services

There is an apparent under-utilization of health and social services by ethnic minorities. Daker-White, Beattie, Gillard & Means (2002) state some of the reasons that are prominent in the literature, including:

> differences in prevalence rates between groups; cultural deficiencies in the instruments used to assess cognitive function; differing cultural perceptions of the signs and symptoms of dementia; different age structures found in minority populations in some countries; the stigma attached to mental illnesses; a lack of knowledge about services; and, a general reticence to use health and social services which some members of ethnic minorities may view (or have experienced) as culturally inappropriate, or even racist. Language, particularly in the case of first generation migrants, was highlighted as a particular issue in dementia diagnosis and service delivery. (p.102)

In Nightingale's (2003) review, she stated that delivery of health care services will be most effective when they can develop a high level of trust and credibility with the communities that they are working with. Health care providers should receive cultural awareness and sensitivity training, thereby increasing their ability to be able to work effectively with, and have the capability of caring for people with diverse cultural backgrounds (Nightingale, 2003).

Nightingale (2003) also posits that health care providers assessing people with dementia would benefit from having access to interpreters that are trained in the assessment of language and cognition and that diagnostic tools that are culturally appropriate would be beneficial. It has been shown that there is an importance in dementia assessments being undertaken by staff with the specific language skills and/or cultural awareness necessary to achieve an accurate diagnosis for the person with dementia (Daker-White et al., 2002).

In Nightingale's (2003) study it was found that religious beliefs and/or spirituality can aid in the caregiving process for people with dementia and that coping strategies used can vary, depending on ethnicity.

> In order to provide adequate health interventions to assist diverse caregivers and care recipients, we must understand their particular beliefs and cultural values. By acknowledging these belief systems, medical professionals may be better able to help the caregiver provide the best care possible for the impaired elder. For outreach efforts to succeed, we must understand the underlying beliefs of the people who are going to be served so that they can be incorporated into the planning of service delivery. (Nightingale, 2003, p.389)

Cultural competency would involve being sensitive to cultural beliefs, practices, expectations and to the background of Aboriginal people and the overall community (Helman, 2007). Cultural awareness aids in improving access to, and quality of, health care for this minority group and also plays a part by reducing organizational barriers, such as structural policies and procedures in the health care system (Helman, 2007). Training in these areas would address health care providers' own cultural perspectives and beliefs, or reflexivity, in regards to Aboriginals and the health care system.

2.4.3 Tailoring Health Care and Dementia Services to Aboriginal People

In the study, *Negotiating culturally incongruent healthcare systems: The process of accessing dementia care in Northern Saskatchewan*, the aim was to "explore the systemic and personal characteristics that influence the access to and experience of formal dementia care for Northern Saskatchewan residents with a particular focus on Aboriginal Older Adults" (Cammer, 2006, p.4). Interviews with community members and health care providers were conducted to identify the "specific barriers and challenges to accessing diagnosis and care for dementia by those living in Northern Saskatchewan" (Cammer, 2006, p.4).

According to a study done by Kramer (1996), the fact that there is little to no data on the prevalence of Alzheimer's disease and related dementias in Aboriginal people, could paint a picture of the possible barriers to getting a diagnosis and to the limitations of current screening and diagnostic tools. "Canadian Aboriginal culture is diverse, with many different tribal affiliations and language bases, as well as different geographic locations and urban versus rural versus reserve occupancy" (Cammer, 2006, p.15). Cammer (2006) posits that there may be a cultural bias in currently used assessment tools and protocols which could lead to misdiagnoses of Aboriginal seniors with dementia. Dementia health care, services and research are already severely limited when compared to other chronic diseases (Means, Beattie, Daker-White & Gillard, 2003) and "ethnic minority groups are even more vulnerable as a subset of the already marginalized situation of dementia care" (Cammer, 2006, p.16).

Cammer (2006) argued that, in Northern Saskatchewan, Aboriginal health care and dementia is both judicious and focused with the growing aging and Aboriginal populations in Canada along with the parallel need for culturally sensitive and appropriate health care services for the "diverse ethnic minority groups" within the country (p.16). Bédard et al. (2004) raised the point that past and current research initiatives on dementia and the provision of dementia care services in rural and remote areas have not included the Aboriginal population.

Cammer (2006) voiced,

> Without understanding the cultural beliefs that shape understandings of dementia among Aboriginal people living in northern Saskatchewan, it is difficult to examine the experience of accessing care for dementia. That is, culture is a very important aspect of the experience of any disease. Cultural values, norms, and beliefs are a framework that guides individuals' interpretation of their sense of wellbeing and direction in life. (p.14)

During the study in northern Saskatchewan the research team identified many factors for the underutilization of health care services by Aboriginal seniors in the north. These factors included cost, lack of public transportation, difficulties travelling long distances, language barriers, cultural barriers, and varying attitudes towards dementia (Cammer, 2006). This study also revealed that health providers from northern Saskatchewan felt that dementia in northern Aboriginal populations is under-recognized and under-addressed (Cammer, 2006).

Northern Saskatchewan Aboriginal communities' participants voiced that language was a barrier to accessing formal health care services since most services are delivered in English (Cammer, 2006). Many aging Aboriginal residents in Saskatchewan were not fluent in the English language and many of the direct translation of words regarding dementia and dementia care into Aboriginal language were voiced as problematic (Cammer, 2006). Cammer (2006) stated that the evident language barrier provoked the non-use of health services by the Aboriginal population. In northern Saskatchewan, there was not enough resources and personnel to provide adequate health services for people with dementia and their caregivers (Cammer, 2006). It was found that limited personnel and financial resources were directed to other necessary health concerns rather than to dementia and dementia care (Cammer, 2006). Another barrier to accessing formal care by Aboriginal families and their caregivers was the fear that they would have to be removed from their home community and forced to move into a hospital or long-term care facility and become passive recipients of care (Cammer, 2006). By having no other options for care the thought of having to submit to the healthcare system which may lead to culturally insensitive or oppressive situations were voiced as large barriers to accessing formal care (Cammer, 2006).

Cammer's 2006 article included a quote from the 2004 Gerontological Society of America publication, *Closing the Gap: Improving the Health of Minority Elders in the New Millenium*, which states that,

> Culture is linked to Alzheimer's Disease through interpretation and perception of the illness; the meanings that are assigned to it; the history within the family; local customs surrounding how people have addressed the disease; community views of the disease; and local healing/medical systems that diagnose and treat disease, as well as care for affected individuals. It can be hypothesized that cultural behaviours may influence biological risk through differences in exposures to different lifestyle factors such as diet. (Allery et al., 2004, p.83-84 cited by Cammer, 2006, p.15)

Health service providers need to be culturally competent in respect to delivering culturally appropriate health services and have the willingness to address issues of culture ethnicity and racism (Cammer, 2006; Innes, 2001). Health service providers should be aware of, and be sensitive to differences in cultures "but also systems and procedures in place that contribute to dissatisfaction among service users" (Innes, 2001, p. 28 cited by Cammer, 2006 p.16).

In the 2007 study by Lombera et al., northern Aboriginal communities voiced a need for long-term care facilities close to home. Residents were sent over 700 km away to a facility (Lombera et al., 2007). When asked what the needs of residents were when dealing with dementia, responses included the need for support groups, community forums and workshops which would help to educate the community about Alzheimer's disease and related dementias (Lombera et al., 2007). There was a desire for further education about dementia symptom recognition and management on a community level since, in the Aboriginal community, the entire community comes together when caring for someone with dementia (Lombera et al., 2007). Also, when deciding whether or not to send a person to a long-term care centre, the primary caregiver, along with input from health care providers, makes the decision (Lombera et al., 2007). If the senior does not have any family, an elder is consulted in the decision making process (Lombera et al., 2007).

Lombera et al. (2007) quoted that "some North American Aboriginal groups use 'white man's medicine' for 'white man's diseases' (e.g., diabetes, hypertension) and traditional medicine for other conditions, including behavioural and emotional problems" (p.1). These Aboriginal groups utilize their culture and community to shape their views on coping mechanisms and thoughts about the utilization of healthcare services (Lombera et al., 2007).

In some studies done on North American Aboriginal groups, a view was expressed that dementia is a part of old age or that the cognitive decline related to dementia is a necessary transition to death (Lombera et al., 2007). Lombera et al. (2007) identified the three belief systems used for understanding the disease among First Nations groups: 1) a combination of biomedical and lay models; 2) the belief that dementia is part of normal aging; and 3) the belief that behaviours are a means of communication during transition to the next world" (p.1).

Caregivers who were interviewed in the Lomera et al. (2007) study reported they experienced fear and anxiety when placed in a situation where the senior may have to be transferred outside of the band's territory into a long-term care facility. This fear was outlined by the disorientation caused by the move on the senior and that the sense of the duty of care for the senior by the local community seemed disregarded (Lombera et al., 2007). Letters were distributed to the community by caregivers to notify the community about seniors who had a tendency to wander (Lombera et al., 2007). The research enlightened the need for better local resources for education, for the development of effective outreach programs and for the requirement and promotion of informed health policies when caring for Aboriginal seniors with dementia (Lombera et al., 2007).

2.4.4 First Nations First Link Program

The First Nations First Link program is an adaption of the ASC First Link program specifically geared towards aboriginal people. The program was developed to help First Nations people and their families living with dementia as there is currently a gap in community support for the disease (The Canadian Press, 2010). The targeted First Nations First Link program was developed through collaboration between the Alzheimer Society London and Middlesex and Oneida Nation of the Thames. The program includes individual and family support, crisis intervention and long-term care preparations (The Canadian Press, 2010). This First Link program is tailored to the First Nation community and takes a holistic approach to dementia by including culture, traditions and spirituality into the care model as well as the use of adapted screening tools (The Canadian Press, 2010), which are modified from the Montreal Cognitive Assessment (MoCA). Some of the changes include adapting the lion, rhinoceros and camel on the standard MoCA to a bear, wolf or turtle, each of which represent a clan in Aboriginal culture (The Canadian Press, 2010). Another change includes swapping the regular 3-D cube for the medicine wheel (The Canadian Press, 2010). Assessment, counselling and support are offered in the home as well as to the extended family (The Canadian Press, 2010). Bereavement support is available privately, or in a group setting, and can include traditional drummers and elders (The Canadian Press, 2010). This support is also unique as it continues for three months and if the family requires longer support, they can continue indefinitely (The Canadian Press, 2010). This circular model of care follows Aboriginal beliefs of life being a 'full circle'. Their program's 'full circle' and 'open-door' policy allows the Alzheimer Society to bridge the gap in the education and prevention of dementia and decrease the disconnect between communities (The Canadian Press, 2010).

The program utilizes the basic principles of truth, respect and dignity when working with clients and helps them to understand that dementia is a disease and that there are ways to cope (Alzheimer Society of Ontario, [ASO], 2010). When the Society staff is on the reserve, they educate community members about the increased risk of dementia when one has diabetes and vascular illnesses and how important these risk factors are, considering the Aboriginal community has a higher incidence rate of these conditions compared with non-Aboriginal Canadian citizens (ASO, 2010). The Aboriginal First Link Program understands and sympathizes with Aboriginal people who are living with dementia and must either attend Western-based support programs or nothing at all (ASO, 2010).

There is also a need for culturally specific tools and support for health care providers (Pollitt, 1997). The Roundtable, held in 2007, stated that "there is little awareness or visibility for Aboriginals with ADRD, that service providers lack the understanding of history and cultural differences and that there is a lack of understanding by local political and community leaders"(ASO, p.7). By determining the specific challenges and needs of health care providers in rural communities, specific supports and tools can be implemented to increase the quality of care for Aboriginal seniors living with ADRD (Pollitt, 1997). Best practice care models need to be implemented and adapted to local and regional needs that deal with rural, northwestern-specific requirements.

According to an excerpt of the study *The Death Knoll for the MMSE: Has It Outlived Its Purpose?* Nieuwenhuis-Mark (2010) remarked,

> Accurate detection of early stage dementia is crucial as treatments begin to evolve. Currently, only those able to slow down progressive disease are available. A cognitive screen that is used as a first step in dementia diagnosis clearly needs to perform well in those with early dementia. This ability to differentially diagnose, especially in the early stages of dementia, is one of the major difficulties of the MMSE and calls into question its usefulness as a diagnostic tool. Age and education are not the only variables which can affect test scores: race, socioeconomic status and (some researchers find gender) can also affect scores making translated MMSEs difficult to interpret in heterogeneous, culturally diverse populations. (p.155)

By tailoring dementia services and supports to the Aboriginal community, such as the First Nation First Link program, as well as specifically designed cognitive assessment tools for assessing cognitive impairment in the Aboriginal population, Canada will be heading in the right direction to provide equal care to its Aboriginal residents.

Through covering rural aging and dementia in Canada, along with an overview of Aboriginal health and health care in Canada, the links between dementia and Aboriginal populations have been brought to light. Although little specific research has been conducted on dementia and First Nations communities, the challenges of rural and northern care provision for seniors as well as cultural differences in First Nations communities are evidenced in the research that has been reviewed here.

Chapter Three: Research Design and Methodology

3.1 Statement of Intent and Rationale

This research study was an extension of the research being conducted by Dr. Elaine Wiersma that was funded through the Alzheimer Society of Canada (ASC) Research Grants Program, which focused on Alzheimer's disease and related dementia (ADRD) in rural northern communities. My research, however, specifically examined dementia in rural, northern communities by addressing issues of dementia related to Aboriginal populations. Specifically, the research examined issues from the perspectives of community care providers about Alzheimer's disease and related dementias in Aboriginal people who live in rural northern communities in northwestern Ontario. Community care providers from three northern communities were invited to participate in this research. This study will help to illuminate the issues related to providing dementia care and support to Aboriginal populations, and will also help to better understand how community care providers can provide effective care and support to Aboriginal communities and populations affected by, and living with, dementia. This study aimed to be one of the first of its kind looking at Alzheimer's disease and related dementia concerning Aboriginal seniors in northwestern Ontario. A search of available literature presented little, if any, relevant information on the aim of this study, therefore strengthening the need for implementing this research project.

There is a need for culturally specific tools and support for health care providers (Pollitt, 1997). The Roundtable, held in 2007, stated that "there is little awareness or visibility for Aboriginals with ADRD, that service providers lack the understanding of history and cultural differences and that there is a lack of understanding by local political and community leaders"(p.7). This research planned to build on the recommendations posed at the 2007 Roundtable and highlighted the experiences of community care providers in rural, northern communities caring for Aboriginal seniors living with ADRD.

The *World Alzheimer Report 2010* warned that

> There is an urgent need to develop cost-effective packages of medical and social care that meet the needs of people with dementia and their caregivers across the course of the illness, and evidence-based prevention strategies. Only by investing now in research and cost-effective approaches to care can future societal costs be anticipated and managed. Governments and health and social care systems need to be adequately prepared for the future, and must seek ways now to improve the lives of people with dementia and their caregivers. (p.6)

3.2 Purpose and Research Questions

The purpose of this research was to explore the experiences of community care providers working with Aboriginal seniors diagnosed with dementia who live in rural, northern off-reserve communities in northwestern Ontario. First, off-reserve communities were targeted for this research since an array of both Aboriginal and non-Aboriginal community care organizations provide services to this population off-reserve. Second, feasibility and vast distances needed to be travelled to collect data steered the study to focus only on off-reserve communities. The research questions guiding the study were:

1.What types of services and interactions do community care providers in rural northern Ontario provide to persons with dementia and their family members?

2.What are the experiences of community care providers who work with Aboriginal seniors with dementia?

3.What are the needs of community care providers who work with Aboriginal seniors with dementia in rural northwestern Ontario?

4.What are the challenges faced by community care providers working with Aboriginal seniors with dementias in rural northwestern Ontario?

5.What types of services and/or supports are needed for community care workers to better care for Aboriginal people with dementia in rural northwestern Ontario?

6.What are the perceptions of community care providers of the needs and issues surrounding dementia in Aboriginal communities in rural northwestern Ontario?

3.3 Methodology

This research was best addressed using qualitative inquiry methodology. Qualitative research is

> A situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world viable. These practices transform the world. They turn the world into a series of representations, including fieldnotes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. (Denzin & Lincoln, 2005, p.3 cited in Creswell, 2007, p.36)

Following the epistemological assumption, research data was collected in the field with face-to-face interviews with all participants. This research was informed by a worldview focusing on constructivism. Constructivism as stated by Schwandt (2001) means

> That human beings do not find or discover knowledge so much as construct or make it. We invent concepts, models, and schemes to make sense of experience, and we continually test and modify these constructions in the light of new experience.

> Furthermore, there is an inevitable historical and sociocultural dimension to this construction. We do not construct our interpretations in isolation but against a backdrop of shared understandings, practices, language, and so forth. This ordinary sense of constructivism holds that all knowledge claims and their evaluation take place within a conceptual framework through which the world is described and explained. (p.30-31)

3.3.1 Data Collection Methods

This research used open-ended, semi-structured interviews. Creswell (2007) stated that constructivism is a world-view where "individuals seek understanding of the world in which they live and work" (p.20). Research conducted using social constructivism relies on the study participants' views of the subject and through social interactions (Creswell). Data was gathered specifically through individual, open-ended, semi-structured audio-taped interviews, which lasted an average of one hour, with eight community care providers. Interviews were conducted at a place that was most convenient for the interviewee which was either located at her home or place of employment. Interview questions for the research were kept broad and open-ended (See Appendix D) so that study participants could construct their own meanings of the subject. Questions focused on the community care provider's experiences, challenges and needs regarding Alzheimer's disease and related dementia in Aboriginal seniors and the types of supports and services needed by Aboriginal people living in rural northern communities. Interviews were conducted at a time and place requested by the interviewees. Interviews were audiotaped with participants' consent, and then transcribed. Field notes were also taken during the interviews to record pertinent points, questions for follow-up, and other details of the interviews that will not be recorded, such as emotions, facial expressions, and interactions with the interviewer.

3.3.2 The Communities

Community 1 was a community that had a population of approximately 2,500 people and had a large Aboriginal and Francophone population. The district had a population of approximately 5,000 of which 975 were self-identified Aboriginal people. Between 2001 and 2006, there has been a 13.04% increase of Aboriginal people over the age of 55 years in the district. The community served as the hub for health care services, education, retailers and restaurants in the area. The Health Centre was immediately adjacent to the District Hospital. The community had a Mental Health Illness Support Network, a Community Care Access Centre branch, a senior's centre, transportation services and two seniors' residences. Through the Family Health Team, residents had access to a health educator and a social worker. The district was designated as a Family Health Team and was serviced by the hospital along with a thriving hospital auxiliary.

Community 2 was a small town of approximately 1,700 people of which 405 were self-identified Aboriginal people. Between 2001 and 2006, there had been a 72.72% increase of Aboriginal people over the age of 55 years in the community. The District Hospital was a hospital which served 4,200 people in the community and the surrounding area. The hospital provided acute care, chronic care, extended care and respite care beds for the community. The community was serviced by the Community Care Access Centre (CCAC), Wesway and a Meals on Wheels program.

Community 3 was a larger town that had a population of approximately 8,000, of which 780 were self-identified Aboriginal people. Between 2001-2006, there had been a 6.67%

decrease of Aboriginal people over the age of 55 years in the community. Due to the town's geographical placement and increased traffic flow, it had established strong commercial and development opportunities including over 500 businesses. The community had mental health and addictions services, a Community Care Access Centre, a Northwestern Health Unit, chronic disease prevention programs, Telehealth and a Family Health Network.

3.3.3 The Participants

Participants were selected through purposeful and snowball sampling. Some participants were recruited through contacts already made during the ongoing study "*Understanding Dementia in Rural Northern Communities*" (E. Wiersma, PI), through the Alzheimer Society of Thunder Bay and the North West Community Care Access Centre (CCAC) as well as through referrals and internet searches.

The following criteria were established in order for participants to be eligible to participate in the research:

a) Be working for a community organization such as a Community Care Access Centre or other home care organization;
b) Have lived and worked in a northern community for a minimum of 5 years;
c) Be working with or have worked with seniors living with dementia in the last two years; and
d) Be working with or have worked with Aboriginal people living with dementia in the last two years

Eligible participants were required to have lived and worked in a rural northern community for at least five years to help ensure that participants had the depth of experience and knowledge regarding providing supports and services to seniors in rural communities, and that they understood the dynamics of northern populations and health care in small communities. The amount of time that a participant lived and worked in the community was a key issue when selecting participants. Many of the participants had lived in their home community all of their lives resulting in a comprehensive knowledge and understanding of northern culture. Recent work with seniors with dementia and Aboriginal seniors in the north was also a critical part of the recruitment regulations because the participants would have the capacity to be able to reflect on the current state of the community care sector in the north.

3.3.4 Participant Profiles

Gloria was an executive director of a community care organization in a small, rural northern community. She had spent her entire life, except for the first two years, living in her home community. Her entire work experience was with clients who lived in rural communities. She enjoyed living in the north and has stayed there to be close to her family and to raise her children. In her role as executive director, she did a lot of networking and collaboration in the region with other service providers to bring services and supports to people who were in crisis. She has worked with many senior clients during her career and at the time of data collection had many Aboriginal senior clients that came for counselling. Gloria stated that the population of Aboriginal people in her community ranged between 30-40%.

Mona was a community care coordinator for a community organization and was responsible for delivering home care services and supports to seniors and caregivers across the region. Her services also extended to the long-term care facilities in the region. Another role that she had was to travel to nearby reserves to coordinate and provide services to Aboriginal seniors and their caregivers. She provided supports to fly-in reserve communities as well through teleconferencing.

Avila was a self-identified Aboriginal woman who worked as a support worker for an Aboriginal community organization in a rural northern community. She worked with Aboriginal people right across the continuum of the lifecycle from infants to seniors. Her programs promoted healing and wellness as well as healthy lifestyles for Aboriginal people in the community. She worked closely with many of the traditional healers in the surrounding area to provide supports and services to her clients. She has lived and worked in her community for many years and also grew up in the north.

Traci was a self-identified Aboriginal woman who worked for a life-long care program for people who were elderly and/or disabled. She cared for clients whose needs ranged from short-term to long-term care requirements. She also provided extended care to Aboriginal seniors, acting as a health liaison to help them navigate through the health system and access the care they required. She also worked in a day program for seniors which was open to patients and members of the community.

Charlene was a manager for a health organization which provided services to the district. The organization that she worked for provides supports and services across the north to seniors and people with disabilities in their home. Charlene's previous and current work experiences have dealt with the senior population and she stated that many of the seniors that she has worked with have Alzheimer's disease or a related dementia. She has specifically worked with many Aboriginal families to provide them with alternative respite services in the north.

Randi worked in health promotion in which she focused on delivering Alzheimer's disease and related dementia supports to seniors and caregivers in the community. She also organized and facilitated community education sessions to seniors, caregivers and community members in her community. She has lived and worked in a rural northern community for most of her life. She was a mother and also had a relative who has dementia.

Roxanne was a community counsellor that worked for an agency which delivered services to many small communities in the north. She mainly worked with senior clients and also worked directly with community service volunteers which provide services to seniors in their homes. Her organization also funded and organized local education sessions for the community.

Joy was a self-identified Aboriginal woman who was a geriatric consultant. She provided education, consultation, and support to point of care staff, informal and formal care providers, and to seniors with Alzheimer's disease and related dementia. She also worked within the long-term care sector and with community support services. She has provided supports and consultation to many Aboriginal families both on and off reserve.

3.3.5 Data Analysis

Field notes and interview transcriptions were transcribed into a word document. All interview transcriptions were transcribed by hand to provide myself with a familiarity of the study data. Transcripts were read to remove any identifying information and were then downloaded into QSR NVivo8. The transcripts were analyzed and coded using the NVivo8 program. Interview transcripts were read over multiple times to familiarize myself with the information. The constant comparative approach was used to attempt to provide saturation in each category (Creswell, 2007). The process of writing theoretical memos occurred during all steps of the coding process to keep track of the categories formed and continued until the end of the project (Corbin and Strauss, 1990). First, in the open coding phase, the interview Word document files and field notes were read thoroughly and examined for prominent "categories of information supported by the text" using line by line analysis (Creswell, p.160). These key points each formed a single concept of the extracted data. Next, axial coding, also performed in NVivo, was used to take the concepts found in the open coding and organize them into similar concepts thereby making connections between them and grouping them into categories (Creswell).

> Not all concepts become categories. Categories are higher in level and more abstract than the concepts they represent. They are generated through the same analytic process of making comparisons to highlight similarities and differences that is used to produce lower level concepts. Categories are the "cornerstones" of a developing theory (Corbin & Strauss, p.7)

Finally, selective coding was used, which takes the information from the coding phase and organizes it into a figure where a theoretical model can be built and theories are constructed or generated (Creswell, 2007). "Selective coding is the process by which *all* categories are unified around a "core" category, and categories that need further explication are filled-in with descriptive detail" (Corbin & Strauss, 1990, p. 9). Participant anonymity is a large concern when researching in small communities and all identifying information was removed. Pseudonyms were used or a generic label 'community care provider' was attached to quotes and other experiences outlined in the research.

3.3.6 Consent and Ethics Review

This research study was granted approval by the Lakehead University Ethics Committee. An information letter was provided to all participants containing an overview of the study and contact information (Appendix B). Written informed consent was obtained from all study participants before the interview in accordance with ethics guidelines (Appendix C).

Chapter Four: Research Findings

Research data was collected from each audiotaped, one-on-one interview with community care providers who worked and resided in a rural and/or remote community in northern Ontario. Eight prominent themes resulted from the meticulous data analysis and will be discussed at length below. First, however, I will give an overview of the context of rural, northern and Aboriginal communities and cover some of the characteristics of small communities that were voiced by participants throughout the interview process. Next, I will briefly cover Aboriginal health and, finally, end with dementia in rural communities before engaging into the themes that evolved from the study data.

4.1 Illuminating a Complex Context

4.1.1 The Demographic Context of Rural, Northern and Aboriginal Communities

Participants voiced that rural northern communities in Ontario have their own "dynamics" and can face many different problems compared to more urban or southern communities and cities in the province. This "dynamic" of rural northern communities needs to be conceptualized to be able to understand the unique needs of the residents that live and work in these communities. Some of the characteristics of small rural communities voiced by participants included the large number of aboriginal residents, an aging population and an increasing out-migration of young people.

4.1.1.1 Percentage of Aboriginals in Northern Communities

All of the communities in the study had a high Aboriginal population both living in the community as well as residing on surrounding reserves.

> Those four [reserves] included in our population of Stonewall I think they probably make up, I'd say a good 30 to 40%. (Gloria)
>
> I provide home care in the community and we have a lot of Aboriginals there also that live in community and off reserves. (Mona)

Care providers stated that they are seeing an influx of Aboriginal seniors into larger communities from the reserves, since the amount of services and supports they need are not available on reserves to allow them to reside in their home. Some of the factors that may lead to this influx, as stated by some participants, included the need for medical services as well as home care options and other formal supports. Participants outlined the difficulties Aboriginal seniors experience when learning to cope with the new environment of a rural community if they come from a nearby reserve or from a fly-in reserve.

> ...but I think there's a large, because I find a lot of the elders that live either up north or even Eagleland because the services are so sporadic and they're not coping, that they're tending, I find that I'm noticing them moving into Trenton. And I just remembered them just by their names and from being up in the north about 8 – 10 years ago that you were seeing them move into the community now. Yeah. (Mona)
>
> Especially the ones from the north because they'll fly in because they just can't cope in that isolated reserve anymore so then they'll come in to Trenton and get an apartment here, kind of try to exist now in the community in which they're not familiar with or, so that's pretty tough. (Mona)

Due to the high Aboriginal and Aboriginal senior populations in rural northern communities, participants felt that there was an increased need to help support these populations and that it should be a large focus both in the present and in the future, as the Aboriginal senior population steadily grows.

> Yes… I think that there's, there needs to be a focus certainly on Aboriginal culture because I think I read somewhere very recently that within our LHIN over 20% of the people identify as being Aboriginal or Métis so that's very significant in terms of population. And then I think just, you know, patient voices are supposed to be driving health care more and more, we're supposed to be patient-centered, and patient centric and I think we're only going to get that way through teaching our, you know, building our workforce and teaching people to be sensitive to diversity for all cultures and being sensitive to that. (Joy)

Despite a younger Aboriginal population in Ontario compared to non-Aboriginals, smaller northern towns were found to also have a higher percentage of Aboriginal seniors. Randi stated that she observed more Aboriginal seniors coming into towns from fly-in reserves and surrounding reserves to be closer to available supports and services not offered or accessible on the reserve.

> Yes, there's quite a few [Aboriginal seniors] now. I haven't really noticed them before. But as time went on, like in Traci's program, she had quite a few up there. And a lot of them too are dying off so we've lost a lot of elders already. (Avila)

Therefore, as the population of older Aboriginal residents steadily increases, small rural and remote communities in northern Ontario may start to experience a greater need for services and supports for Aboriginal seniors in their communities and surrounding areas.

4.1.1.2 The Aging Population

The increasing aging population, especially in rural and remote communities in northwestern Ontario, was a large concern for all of the participants that were interviewed. Some participants acknowledged that the Rising Tide Study, along with the aging of the baby boomers, had created awareness in the local communities, in the health care sector, and at the governmental level, that extra measures need to be put into place to accommodate this generation.

> ...of course as we all know, the Rising Tide study and the population increase and those baby boomers turning 65 this year and older so it's a real problem. (Gloria)

All of the people interviewed talked about the higher senior population in rural and remote communities when compared to the larger urban centres. One of the reasons for the predominately senior population was the outflux of the younger generation leaving for school or to find employment, as many of the larger local employers, including the forestry and mining sectors, have closed or will be closing in the near future. One community was fortunate in having their local industry start up and was seeing a slow influx of the younger generation back into the community, along with increased housing prices and sales.

> Our communities do seem to have a high senior population. A lot of the middle aged people are gone for work and in some of the communities now, mines are re-opening and industry is starting up again. There is kind of a higher middle aged group that is starting to move back in. But I would think it's predominantly senior. (Roxanne)

4.1.1.3 Out-Migration of Young People

There is significant concern across the region about the out-migration of the community's youth as they go away for school or have to leave to find employment. One participant stated that many youth and middle-aged workers have headed out to Alberta and Saskatchewan to find employment. Community care providers talked about the strain on the communities because of this out-migration since aging parents and extended family usually remain in the community with limited support if their family has moved.

> ... because the younger population is all leaving for jobs and leaving their parents behind, their elderly parents behind. Like I'm talking about in Trenton, and so who's going to take care of those people, right? (Gloria)

> I think it makes sense with the aging population. All the young people are leaving. You know, there's no one to care for the seniors because all of their kids are gone off to Alberta or wherever to work... (Randi)
>
> ...but from the inside looking out, a lot of people are leaving, a lot of families are separated because men are going to Bristol or to wherever they need to go to work so, yeah I think it's a problem. (Gloria)

One of the community care providers described an increased need for services from the organization that she worked under due to the out-migration of family and the younger generation in her community. Seniors whose families had moved away may have to find alternate supports either informally, such as friends or neighbours, or by seeking formal services and supports from organizations such as Community Care Access Centres (CCAC).

> Yes, it's actually creating a need for the services because without family and friends to stop in and visit some of the clients, they just don't have that social interaction. You know, their kids, their grandkids have moved away to a city or just another location to find employment. So they're kind of relying on their neighbours to help them out. So that's just how the program got started. (Roxanne)

4.1.2 The Historical Context of Aboriginal Rural Communities

To understand the current health status and culture of Aboriginal people today, Canadians must familiarize themselves and understand the trials and tribulations Aboriginal people have experienced in the past in this country. Distrust of the health care system and related services controlled by the government and other organizations can stem from such experiences as residential schools, the 60's scoop of adopting or fostering out Aboriginal children in Canada, and cultural assimilation.

Many participants talked about the residential school experience of Aboriginal seniors as well as the historical issues between the Aboriginal and non-Aboriginal population as being a determinant in affecting the social, psychological and physical health of Aboriginal seniors that are living in the communities today.

> Certainly we are a volunteer driven agency – so we have... volunteers that respond to calls and then there's myself and a worker who deals a lot with the Aboriginal population in regards to the residential school survivors and the historical sexual abuse that went on there. (Gloria)

Some community care providers also saw a distrust of asking and/or receiving services by the Aboriginal population from the health care community due to experiences such as residential school and marginalization of the culture. Some participants noted that it is important to understand and be respectful of the history as well as Aboriginal culture and traditions and that this understanding is of utmost importance in rural communities as they tend to have a high population of Aboriginal people.

> Well, I think, I think there's psychological distress. I think there's historically that distrust you know between people who have been marginalized and set apart from the main stream culture by being, you know, designated on reserves and so I think there's, by virtue of that, I think there's just a distrust for the white community and I think there is, you know, and even the whole residential school experience, where we had to have a truth commission and trying to address some of the trauma that has been inflicted on these folks historically. I think it emerges in problems present today. So I think you have people that have not had... they've had their culture interrupted, they haven't had values passed along. They've been isolated from their families and not allowed to express their culture and so now I think that translates to people who have been exposed to the residential school experience and have trauma left from that. And also, not being able to care and nurture for their own families properly. They have a whole legacy of litany... children that were removed from families and adopted. I mean this culture is in disarray. It's going to take a long time to try and build a network of trust and have these people accept services that we have to offer. (Joy)

4.1.3 The Health and Social Context of Aboriginal Communities

4.1.3.1 Aboriginal Health in Small Communities

Participants voiced that the overall health and well-being of the Aboriginal and Aboriginal senior population in small rural communities was not adequate. Poor health was caused by a variety of factors including the social determinants of health, such as access to adequate housing and potable water. These factors were expressed as casual determinants leading to an unhealthy community.

> But I think just some of the things like the social determinants of health like just having clean water, suitable and adequate housing, employment, all of those things that go into maintaining and sustaining healthy communities, they don't have that- and infrastructure... (Joy)

Aboriginal seniors had many of the more common health concerns seen in the Aboriginal population, such as high blood pressure and diabetes.

> ...and I know that they have an aging population and so the incidents of dementia... and certainly they have a lot of cardiovascular risk factors and diabetes so there's, like I said, there's a lot of work to be done. (Tracy)

4.1.3.2 Abuse and Suicide

Substance abuse problems and suicide were also a big concern in all of the communities.

> We're looking at building partnerships right now with a lot of the Aboriginal communities because their population is having a lot of issues around teen suicide so in particular that's something that we've been dealing with recently. (Joy)

Elder abuse was prominent in all of the communities. Care providers found that elder abuse, intertwined with people who had dementia, was especially concerning. There was much trepidation about children and grandchildren taking money and/or prescription medications from their parents and grandparents and then denying any wrong-doing.

> It's [elder abuse] right across the board. (Gloria)
>
> And we've seen cases in my new job where it's elder abuse, you know, people are getting dementia and the grandkids are ripping them off, they're taking their pills, they're taking their wallets, you know and then they're saying well "I didn't do it, you know grandma's crazy or whatever", so it's really, it's a double edged sword for them. (Tracy)

A concern for Aboriginal seniors that are experiencing elder abuse in the form of stealing medication is that the seniors are left without necessary medications until they can get another prescription or get the prescription refilled again. Participants described situations where children or grandchildren were taking medications of the elders. Participants spoke of the hardship and pain that seniors have to endure because of this, in addition to explaining to health care providers the reasons for requesting a new prescription. Participants found that it was common for the elderly parents or grandparents to conceal the issues to protect their children or grandchildren.

> So young people come along and they steal it off them and that and a lot of times, they'll find that the relatives are hanging around because of their pills and they steal them. And then the doctors give them heck, "Now where is your pills, we gave you pills and we can't give you anymore". You've had your, you know, but all the while, the elders a lot of the times are not going to say anything against their little relative, their little grandchild, great grandchild has taken their pills. They're not going to say that one took it because they don't want to get them in trouble you see. (Avila)
>
> Medication is number one. So, that's for my clients I try and make sure they have them in those pill packs, which is easier to hide and they're not, they're all labelled but they're not labelled as they would be in little blue bottles where a lot of people can recognize, oh this bottle has say...like say some of them – some of their cash patients may be on OxyContin or Percocets and its labelled. (Tracy)

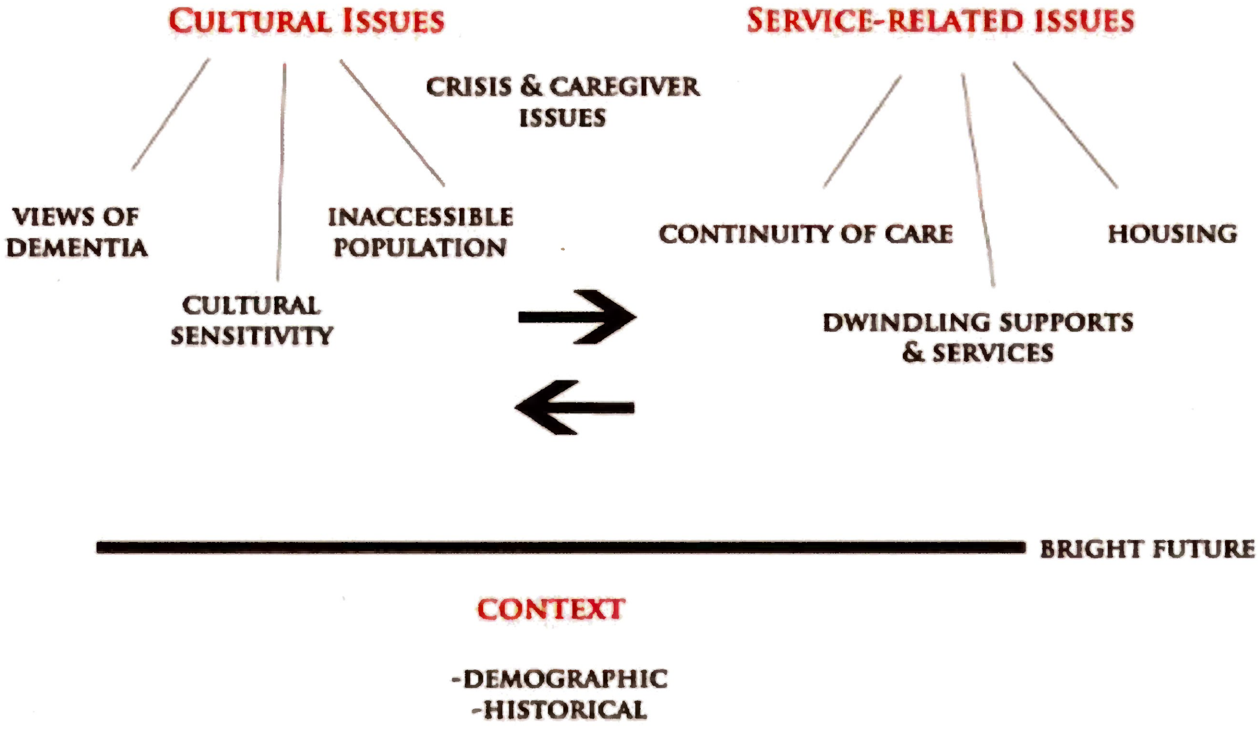
In summary, the unique dynamics of living in a small community, along with the historical aspect of Aboriginal life and current health status of the Aboriginal population, was illuminated as a concern for community health care providers when working in a rural northern community.

4.2 Illuminating the Complex Context of Dementia

Taking into account the dynamics of rural communities, the uniqueness and cultural differences of Aboriginal people, as well as the complexity of living with dementia in a rural community, I move on to the main themes that developed through analysis of the participant interviews. I looked specifically at community care providers who provided supports and services to Aboriginal seniors with dementia that lived within rural northern communities in Ontario.

Eight prominent themes clearly emerged from the data after careful analysis. Due to the richness of the interview data, as well as the lack of current studies on dementia and Aboriginal seniors, I felt that it was necessary to include each of the themes. The emerging themes include 'Views of Dementia: A Normal Part of Aging', 'The Inaccessible Population', 'Crisis and Caregiver Issues', 'Dwindling Services and Supports', 'Housing', 'Continuity of Care', 'Cultural Sensitivity' and 'Bright Future'. Each theme is supported using direct quotes from the community care provider's audio-taped interview. Each care provider resides or works in a rural community and works directly with Aboriginal seniors that have dementia or cognitive impairment. Figure 1 outlines the prominent emerging themes from the study data. The demographical and historical context of the Aboriginal population and supports for Aboriginal seniors with dementia can be broken down into cultural issues and service-related issues when looking at dementia supports and services. Each of the subthemes listed under the two main headings affect each other and this is represented by the two-way arrows in the diagram. Crisis and caregiver issues at situated in the middle as they sit on the balancing point between the two main issues. This balancing point represents the large importance caregivers have in the care and support for Aboriginal seniors who have dementia in rural communities. The bold black line represents that once all of the factors from the eight themes are addressed and summed together, a bright future for people with dementia, along with their caregivers, can be achieved.

Figure 1: Prominent Emerging Themes



CULTURAL ISSUES

4.2.1 Views of Dementia: A "Normal" Part of Aging

Many of the community care providers stated that they are noticing a large population of seniors that have memory problems, Alzheimer's disease or related dementia in the general population that reside in rural communities.

> We also work with seniors and that's a big piece of what we do is working with seniors. And a large number of the seniors that we serve, have Alzheimer's disease or related dementia. (Charlene)

4.2.2 A Normal Part of Aging

A very large issue that was voiced by all of the participants was the fact that a large proportion of the Aboriginal population believe that Alzheimer's disease and related dementias are a normal part of the aging process. Since dementia is viewed as part of the normal aging process, people are not seeking medical attention or getting a diagnosis and, therefore, are seeking medical attention in the later stages of the disease.

> Certainly I've come to be made aware that it is a big problem that's not being acknowledged...yes, I think it's late stages because it goes unnoticed or just chalked up to a regular, normal part of aging in that you forget things and that you act strange usually or that, you know, you put the, I don't know, something where it doesn't belong – a jar of pickles in the dryer that that's part of aging, and they don't seem to get that that's not a normal part of aging. And I don't know if it's stigma, I think it's really a lack of education. (Gloria)
>
> But people don't identify it as such – they'll tell you that they have poor memory or problems with safety. So, for instance, this son was identifying that, you know, he can't trust his parents to leave a pot boiling on the stove because they may forget to turn it off, those types if things- or the wandering. So it's more the behaviours that are brought up and then when you start to look at the whole set of circumstances you understand that these people are experiencing, you know, some form of dementia but it's not getting identified as such. (Joy)

Participants stated that more education about the signs and symptoms of dementia needs to be available to the Aboriginal population so that people will be able to recognize these signs sooner and not see it as a normal part of the lifecycle.

> ...so I think there needs to be a lot more education in the Aboriginal communities about dementia and Alzheimer's because a lot of them might just put it to they're getting old and that's just part of what's going to happen to them. A lot of them, if they need a diagnosis, they need that Alzheimer's support. (Mona)
>
> You know and we have to watch and a lot of people they just don't think – because like I have, I have dementia in the family and it may pass on and you watch for the signs and it's easy to pick up. And a lot of people here just think, oh, seniors moment. And there's no senior's moment. There are definite signs for it. (Tracy)

One of the Aboriginal participants expressed how the older population encompassed dementia as part of the lifecycle, whereas some of the younger generation that have been educated about Alzheimer's disease and related dementias know the signs, and know that medications and other alternatives can be used to help slow the progression of the disease in the early stages.

> In some parts yes and no, because in some areas they will say it as it's part of the circle – it's just like how I was given this, this is what I have to deal with and we move on. And some of the younger ones that have been educated or they say, "Oh I recognize that, maybe we can get some extra help for them to..." like in their early medications and things like that to help prolong it as much. Just to give them that little edge. (Tracy)

4.2.3 Fearing a Dementia Diagnosis

Participants stated that Aboriginal seniors were not typically getting a diagnosis of dementia due to many barriers such as accessing health care services as well as cultural beliefs and lifeways. Aboriginal seniors not attending specialist appointments to be assessed for dementia, was also described. As Tracy commented, "No, they don't normally run and go and get a diagnosis."

> Well it's getting basically getting a diagnosis, they don't want to leave home, they don't want to go to Millbrook and be tested. (Gloria)
>
> I think that they, it depends if they'll go for an assessment or not right. I mean they'll give you likely a diagnosis of dementia without the test if they need to – in my experience. But I think they try to refer to Dr. Bell whenever possible. But certainly a lot of them won't go. (Gloria)

One community care provider stated that she did not see a difference between Aboriginal and non-Aboriginal seniors obtaining a diagnosis of dementia in rural communities.

> ...but, even if they're living in this area, then like main stream lives, whatever you want to call it, as opposed to out in the bush, they have, I don't find too much difference between natives and non-natives trying to figure out if they're going to go for an assessment or not. (Tracy)

Participants stated that Aboriginal seniors may not be rushing out to get a diagnosis of dementia due to the fear and anxiety that diagnosis can cause for the senior and for their family and friends. Fear of the lack of support, the stigma surrounding dementia, the possibility of having to leave their community and the lack of available infrastructure in the north were all voiced as possible reasons seniors were not following through with getting a diagnosis.

> ...yeah people are really scared – it's like a death sentence when they hear that and it's not as main stream accepted because there is no, you know there is no Alzheimer Society you can go to and be a part of a group of people that are experiencing the same thing. (Gloria)
>
> Because I find that even if families are in denial, because I find even if they think it, that's one thing – if they say it out loud, then they know it's true, so that means then something bad is going to happen. And they're not going to remember me, like little things like that. (Tracy)

Therefore, if Aboriginal seniors are not seeking a diagnosis of dementia, rates of dementia in Aboriginal seniors could be disproportionately low in northern Ontario. If a decreased rate of dementia or other cognitive impairments were found, then the country may see this result as a decreased need to provide supports and services directly targeting the Aboriginal population in rural and remote areas.

4.2.4 Differing Views of Medicine and Treatment

One participant noted that there was a difference between Aboriginal and non-Aboriginal caregivers and seniors when it came to getting a diagnosis of dementia and seeking the possible medications that could help to slow down the progression of dementia. Different views of medicine, such as a more traditional approach encompassing the medicine wheel and not the westernized biomedical model that many western societies tend to follow, was positioned by some participants as a reason that seniors did not want to pursue a diagnosis.

> They have health centres they I don't know, I think they're doing what they can. They seem more kind of more, I don't know if complacent is the right word, but they seem okay just staying at home and living it out, you know. Whereas, when my Grandma started to act strangely I was like, "Oh my Gosh, we got to get her some help, maybe we can get her on some Aricept so it will at least slow it down". Like right away, I wanted to get her in to see someone. She didn't so much, so we respected that, but I mean, I don't see, I don't see them jumping all over medicine like we do in our western kind of way. So I mean, I really respect what they do and how they do it and I think that that's a positive but it also has some negatives to it. (Gloria)

However, another participant stated that Aboriginal seniors are coming in for help during the later stages of the disease when medication would no longer be very beneficial, in most cases.

> Yeah, because you can give them medications in their early stages to help prolong it. Most of them don't catch it until the 3rd or 4th stage. By then it's too late in a lot of places because then it goes quickly. It can go very fast. (Tracy)

Many participants voiced the fact that health care and community care providers have to respect the choice of seniors and family members and realize that medication isn't always the only option. Both Aboriginal and non-Aboriginal community care providers firmly accepted the use of alternative medicines and practices in their organizations. Another participant said that alternative options always have a place in the medical field if the practitioner is providing person-centered care and following best practices. She stated that the use of traditional healers and alternative medicines can be very beneficial and care should be provided on a personal level.

> Yes, big time, yeah. I think it's very unfortunate that a lot of the professionals because they're so, you know, you need to do this and this and this and if you don't follow their little box you know that they're not trying, they're not trying to do, or they're not you know listening to my directions and so, you know, what more can I do? You know what, look at your little box, look at their box and see how you put them together because a lot of them, they don't believe in the medicine, you know, the pills that they push and stuff so maybe see what their beliefs are, because they tend to go to those medicine people on the reserves. I don't know what they're called...you know a lot of... kind of come together and be together so there's such pain and stuff that they're going to feel and stuff, you know, get away from the pain pills, support them with that kind of medicine and see what you can do and what else they need besides that. You know, you have to try to work with them, it's like anything with us and herbal medication or chiropractors, or you know, if the doctors are so set in their way that they, you need to kind of combine them all. (Mona)
>
> What's wrong with seeing the herbal guy or a traditional healer or chiropractor if it's going to stop the pack of pills you're going to take. Why not? What does it do, you know. (Mona)

A few of the Aboriginal community care providers talked about the views of their culture when an elder in the community has dementia or memory problems and how their tradition is to follow the medicine wheel. One participant stated how elders with dementia are treated with the same respect and courtesy as an elder who does not have dementia.

> Well, with the culture, we follow the medicine wheel so they all know the stages of life. Because it goes continuous from new born right up to when you pass away so when they're in the passing away stage, they're elders, so whether you have dementia or not, you are still considered an elder and you still receive the respect. If you happen to have

> dementia or any kind of health issue, they still get that same honour and they still- the younger generation will look after them and so that's how they do it and they get the same if they pass away they have the same burials, techniques, and everything. It's no different than if it was just somebody who hadn't had dementia and they are still respected the same way. (Tracy)

Participants all felt that Aboriginal views and cultural beliefs about dementia should be respected. Community care providers should work together with Aboriginal seniors, their families and/or their caregivers to develop a plan that is respectful and culturally sensitive to the Aboriginal culture.

4.3 The 'Inaccessible Population'

4.3.1 Accessing the Aboriginal Population

An encompassing concern from all of the community care providers was the issue that they, and the health care organizations they represented, were facing in reaching out to access the Aboriginal population, especially the Aboriginal senior population, to deliver their services. All of the organizations that were interviewed found that subset of the Aboriginal population difficult to connect with to provide services for them. One participant said that the problem of not being able to connect with Aboriginal seniors to deliver services that were available was a problem that was not being acknowledged in her community.

> No, we never were able to attract that particular part of the population. What I know I know from working with the service providers and health care providers that go on the reserve and home care people and such, different agencies like Dearhurst and it is a huge problem. It's a huge problem that's not being acknowledged and it's difficult to provide service because they're on a First Nation territory and so you have to ask permission to go onto the reserve. (Gloria)

> We have very few [Aboriginal clients]. Our services are available to any of the First Nations communities in that catchment area, so again from Whistler to Branford and up to Stonewall. We haven't had much of a response really at all. I would say, maybe right

> now we have one Aboriginal involved in the program that I'm aware of. With that being said, our volunteers do go out and visit sometimes, people in hospitals or long-term care, things like that so they interact with a number of people so I don't necessarily know all of them. Yeah, but there's really a low number of Aboriginals. (Roxanne)
>
> [Sigh]... I'm not sure, I'm not sure if there's services specifically for them [Aboriginal seniors] that they have available in their own communities that they're accessing or if the services don't appeal to them for some reason... I'm not sure what the reason is for the lack of response...It might be a good point to bring up – something that we should advertise more too. (Roxanne)

In one of the communities, a problem that was mentioned was that Aboriginal organizations in the community had a plethora of services available but the seniors and the caregivers were not accessing those services and supports and the community care providers did not know why this was.

> I think it's hard to reach them [Aboriginal seniors] because it seems to me that if they wanted a service there's a lot of really phenomenal Aboriginal agencies waiting to help. I mean, they'll put on workshops and nobody will show up so it's there, I mean, the programs are there, the money's there, the agencies are there, it's how do you connect that to the people? There's a missing link, there's a gap out there and I don't know what it is. I don't know if it's a matter of just well we'll just bury our head in the sand and we don't have this in our community or this isn't part of our family or it's not part of our culture. I don't know what it is, but there's a missing piece there for sure. (Gloria)

The participants said that the communities need to research and find ways to reach out to the Aboriginal community and find out what supports and services they need and how they should go about engaging the population. One of the ways mentioned was to start to build a relationship with these communities through trust and respect.

> Yeah – finding ways to reach out to them. We often do things like place flyers in post office boxes and things like that. We sort of target the communities where we know there is a need and so in the next round maybe we should consider the First Nations communities. It's something to think about. (Roxanne)
>
> I think they are very isolated… I think they are a very isolated community from the mainstream and I think that for all the reasons that we mentioned I think there is a

> distrust. I think that health care providers have to build relationships to that culture and kind of be immersed in it and do things from the standpoint of how the community wants them done. I think that we need to be sensitive that that may differ from one community to another but I think that, right now there's, I think that they're very aloof and I'm not sure how to engage them at this point. (Joy)

One participant spoke of the fact that her organization's services were overstretched in the community since there was a large need in the community to access the services provided. However, they did not have very many Aboriginal clients. She voiced that if there was a large need in the non-Aboriginal population then it raised the question of whether this need was also as great in the Aboriginal population, as they were not sure.

> And see what the need is. Yeah, for sure. Because I'm sure if there's a need for those [health] services in the other communities, there is in their communities as well. There shouldn't be much difference you would think. (Roxanne)

One possible reason for the lack of response from the Aboriginal population to services was that Aboriginal people may not want services and supports from outside agencies. Participants noted that families and seniors may often have difficulty asking for the help as they feel they should be able to handle the situation by themselves.

> They [Aboriginal people], for the most part, don't want services from outside agencies so it's difficult- it's really difficult... Certainly I've come to be made aware that it is a big problem that's not being acknowledged. Certainly not for a lack of trying to help but because there's different barriers there that don't exist in our culture. (Gloria)

4.3.2 Communication Challenges

Participants spoke of their experiences with Aboriginal seniors who had dementia and how trying to prevent loneliness and isolation can play a key role in keeping seniors happy, healthy and a part of their community. Cultural differences, language, literacy, as well as different traditions and backgrounds, were listed as some of the reasons why seniors may feel isolated or lonely in a rural northern community. Participants spoke of the need to address communication challenges and barriers to enhance supportive and care concerns for persons with dementia. Participants noted that Friendly Visiting Programs were available in the communities for seniors to access.

4.3.2.1 Language and Literacy

One of the most prominent barriers that led to loneliness and isolation, as well as the seniors availability to access community care services, was communication. Participants mentioned that language was an even larger barrier for seniors who moved into communities from fly-in reserves or more isolated regions as it was very likely that they could not speak any English.

> There's language barriers, just the way they communicate is very different as well, like they're story tellers right they don't... so I mean I'm open and honest and forward and they're story tellers and so it's very different way of communicating and I think they're more passive and more accepting and a lot of them just want to stay at home... (Gloria)

Language was also a barrier for them in seeking help and actually getting a diagnosis of dementia and understanding that they had dementia. A few of the communities were noted as having good access to translators so that seniors who had limited English, or who could not speak English at all, were able to understand community care providers and health care providers. "I'm not sure how many of them actually get help, like how many of them really know that they have dementia because of the language barrier". (Mona)

> And, in saying that, I think the closest that I've come to working with them is doing translation for them in terms of anything to do with medical that they don't understand. I

> escort them, I'll go with them to their appointments as a translator because they don't speak English some of them. (Avila)

One issue was the vast array of Aboriginal dialects in the north. Languages spoken range from Ojibway, Oji-Cree and Cree, and the availability of translators to help bridge the language barrier was limited. Some of the translators were not able to understand the clients, and vice versa, due to the complexity and differences in many of the dialects in the northern communities.

> And then, the problem around that too is that I've heard through the elders themselves, the lady doesn't speak the dialect and that's another thing. The dialect is different from you know, from the southern dialect. The southern dialect has a different way of speaking. And if you come up here you have, if you have that dialect, the elders have a hard time understanding you. That would be like me going over there, they would have a hard time understanding me, right? And a lot of the time, that's the complaint I get here, I don't understand or I don't understand what she's saying, kind of thing right? (Avila)

Tracy stated that at times there are language barriers between the senior and the health care provider where the care provider was not able to explain him or herself to the Aboriginal senior through the translator since medical terminology often does not translate into Aboriginal language.

> And sometimes it could be a language barrier but for the doctors so how to say pee or poop or things like that so I'll just translate a little. I know some of the words but not all of them and if not, I can bring Avila in. Or there's Cheryl that works at the hospital who can also assist with that. So yeah, good resources, very good resources. (Tracy)

Avila noted that Aboriginal seniors need to have a visitor who can speak the language since some seniors cannot speak any English. She went on to communicate that seniors who cannot speak English may feel even more isolated and lonely if they have that language barrier.

> Well you have her program – it's for long-term care and that's what she does. She goes into homes and visits and I'll do the same thing too if I'm asked to go. But I won't go in

> there unless I'm asked or if somebody refers an elder to me and they say the elder needs a visit, needs to talk to somebody or something. Because I speak the language, I'll go there and I bring bannock or something and I sit with them, get stories off them because they are lonely... (Avila)

Literacy is a barrier that was spoken of since some Aboriginal seniors are illiterate and may be unable to follow the directions for taking medications according to some of the participants. They may also be unable to fill out medical forms or read health promotion material and health information brochures particularly if these materials were written in English. Being illiterate in a town where people are expected to know how to read to get through day-to-day life could be overwhelming for an Aboriginal senior with dementia and could lead to isolation of that individual from the outside world, acknowledged one participant. Avila stated, "A lot of them too, they don't read eh? They can understand English but they don't read either. So that's where the problem lies sometimes".

4.3.2.2 Loneliness: an Outcome of Communication Challenges

Another reality for Aboriginal seniors living with dementia in small towns was the feeling of loneliness in the community. A concern noted by participants was that Aboriginal seniors who are coming into a small community from a fly-in or nearby reserve may be very lonely since they may have had to leave all of their family behind during the move. The seniors would have to adjust to living in a larger community that contains a different architectural and social organization compared to the community that they previously resided in and were familiar with, which can possibly result in culture shock, depression and loneliness.

> ...I think a lot of them [Aboriginal seniors] do spend a lot of time alone and nobody pays attention to them. (Avila)

> Yeah, yeah, like you know – you have First Nations coming from off, from a reserve into an urban setting like this to come and see their parents and come look after them and what not and then leave them again. And that's not a very good, what do you call that, it's not a very good situation or setting for that elder. They come in and they come spend time with their parents, or grandparents, whatever it may be and then off they go and again she's left alone or he's left alone. Kind of lonely... but they do it. (Avila)
>
> Family members who maybe don't get to spend as much time with the senior or you know, their relatives. They're just looking to help them get that social interaction. People feel guilty I think when they don't get to go over and spend more time with their Mom or their older aunts and uncles so they try to find substitutes for that, I guess. (Roxanne)
>
> ...introducing them [Aboriginal seniors] to a whole system of care that they're not prepared for... never accessed and unfamiliar with. And it would be very isolating for them. (Joy)

It was voiced that Aboriginal seniors who move into a new community have often left their family and friends behind in their home community or reserve and often find this new adjustment to living very taxing. For example, in some of the apartment buildings, the rules and regulations was a reason stated by participants that may cause a hard transition for seniors moving into these buildings. Mona also speculated that seniors may feel isolated and lonely having to leave their reserves or families behind and having lost that support.

> ...that's the thing you know, you either live in an environment that is very unsafe for you, that doesn't have the basic needs that everybody else has out there but you have your family with you or you move into a senior's apartment that's well set up, everything's good but you're alone. Like, it's sad. (Mona)
>
> ...but then again those are the ones that I find fall through the gap because the apartment building here like I said earlier, you'll see a few of them living there but it's really strict so their family members get to- they can't come and stay with them or anything like that so they got to be there by themselves. So if they don't speak English or anything like that then you know what I mean, they're so isolated. (Mona)

Some participants noted that some Aboriginal seniors have a hard time adjusting to life in a new environment, possibly facing this new challenge alone. Some of the housing and apartment facilities do not facilitate some of the Aboriginal customs and traditions such as having a large family come and stay with them for extended periods of time, voiced one participant. Participants indicated that problems in following the rules and conflicts with non-Aboriginal seniors in buildings have pushed some tenants out of apartments in the past.

> Now obviously they can stay there but the problem is the other residents there start bashing their little culture because you know how the Aboriginals are....for those buildings like just say you have Mrs. So and So, living in the apartment by herself. The families will come in and visit because they like gathering in big groups so if they're coming in from up north, well they have no where to stay so they're going to stay with her for like a week then head back well then the other residents in the building start complaining because they're doing their laundry there and so they end up pushing this poor little lady out of the building because she's not following the rules or whatever, you know what I mean, so they pretty well need... (Mona)

Participants sympathized with the Aboriginal seniors since many of them have family come to visit from northern or fly-in reserves and usually large groups of family come at once to visit the senior and help around the home. Tracy stated that not being able to house family is a huge concern for seniors and also can cause problems with other tenants.

> Yes, families have to sleep on the floor or the couch. And they have to inform Millbrook Housing or through native housing and they're only allowed to stay either a week or two weeks. And a lot of the other tenants because of that age group, they're nosy and they need to know and if you don't tell them they start phoning and tattling on you. So then there's a lot of bickering social wise and in the native community, when they have family come from up north and that, it's not just one person, it could be like 5 coming down. But then you're not allowed to have that with you. (Tracy)
>
> I: Where do they stay?
>
> P: Wherever they can find a place.
>
> I: With the friends somewhere?
>
> P: Exactly, so then it's like, it's called kokum, for Grandma, so if your Grandma is sitting there, and you can't go with and stay with her, instead of like she needs your help. Because a lot of the times when they come down from up north, that's their tradition, they come in and they help you, they clean your walls and things like that. That's then

> their only thing. Maybe they're only allowed to stay a week or maybe two weeks and that's only the one person. (Tracy)

4.3.3 Tailoring Services

Many participants noted that dementia care, services and supports will have to be designed and facilitated in a different manner with the Aboriginal senior population, compared to the non-Aboriginal senior population, to be successful and for programs to be culturally sensitive. Gloria commented, "So I think dementia care in that population would have to look very different for them to be welcoming and accepting."

> I went up and worked on Flameton which is Fraserville and did a program there – a chronic disease self-management program there. And so I got to know the participants pretty well and worked with a nurse there and we had a lot of conversations about that because the approach had to be a bit different and how we presented the program in order for it to be well received. So I think if a barrier is in that regard, the way that they are approached – in their traditional manner, it's more of a very quiet, passive respectful, especially with the elders. And not so much "So you know what brings you here today". It's, I think it's intimidating for a lot of them to come in and of course, their traditional medicines might conflict with something that a practitioner might prescribe or give them and not you know, some are better than others... (Gloria)

A participant who had been working in the field for many years stated that she was not aware of any services or supports for Aboriginal seniors and caregivers to her knowledge and that tailoring these services would be a good start to reaching the senior population.

> Yes. You know, I think that poor housing, poor access to health care, poor socioeconomic conditions means that these people do need to access services and offered at a critical time, you know people who experience profound change. And I think you bring up a good point, I think that tools and screens and all that have to be culturally sensitive and appropriate. And to my knowledge I don't think we have any of that. (Joy)

Participants were asked what could be done to tailor supports and services to try and reach the Aboriginal seniors and their caregivers since, as mentioned above, participants found a poor uptake of services by the population. Responses included ideas such as involving the caregivers and seniors in the planning and implementation process, utilizing elders and translators, scheduling presentations during lunch and providing food, and running events in a welcoming environment that is easy to access.

> Well, I think they could be fine tuned, they could be developed they could be, you know, in collaboration with the caregivers, with the patients and with other health care providers. (Joy)
>
> Well, I use the translator at the Indian Friendship Centre quite a bit... So I always bring her with me because I find they need to be able to talk in their language and just somebody that understands them a little better and then you can get a better picture of how they're coping and what they're doing. So we have that locally which is really nice. (Mona)
>
> Bring food. Yeah, bannock and any kind of food, it doesn't matter. You feed them, they'll come. (Tracy)
>
> ... we're pretty small here that most of them can walk to different places – just make it more in a central area, you know because like a lot of them have it in the hospital board room, not everyone knows where the board room is. Or if it's in the board room, they're like, because I've been there like twice, okay you have to follow the maze type thing, so little things and they're more visual as opposed to read, read, read. (Tracy)

Tracy explained how presentations that are organized and delivered are very important when reaching out to the Aboriginal population. To help engage the seniors, Tracy felt that presenters should involve visual images and try to limit talks to smaller groups.

> They [Aboriginal seniors] like the visual things, seeing things, you know, take the brain apart, you know, that's like when I have mine on for Alzheimer's month, I give them visual pictures and I have them in big colours so they see how it works and things like that. (Tracy)
>
> It [presentations] could help as long as it's more visual, one on one. Because a lot of the Aboriginals are very quiet. And they won't talk about themselves a lot or that but they

> will listen intensely. They will see things but they may not in a big full out presentation in a group but if it's one on one or family one on one then they absorb more. Yeah, but they are very visual people. A lot of them don't read and write so they're getting a lot better with that but they're still trying to keep their traditional that they've grown up with, so they're trying to balance as well. So but as long as we can show them visually, what can happen... (Tracy)

Joy shared a story about a firsthand encounter of what she learned during a presentation in one of the northern communities. She stated that the elders were not interested in the PowerPoint presentation and that they only wanted to have a conversation with her and tell their stories since their culture and traditions encompass story-telling as an integral part of their way of life.

> I know that I went and did a presentation to an elder group a few years ago. I was invited to Trenton and they asked me to come and do this presentation on dementia and, you know, try and build on the capacity for people to identify dementia in some of their communities. When I went to that, it was a real eye opener for me because one of the things we ended up doing we had lunch and I had my presentation all ready. Once I got into it I realized that it was too contrived. These people just wanted to have a conversation. They just wanted to talk and they just wanted to share their experiences. So the moment you brought out a PowerPoint or whipped out a presentation for them to follow, that's not what they wanted. They just wanted to talk and because they story tell, that's how they pass on, you know, their culture and their expressions and things like that. So there's a lot of work to do, there's a lot of work to do in terms of reaching and understanding and finding out from the Aboriginal community how they want to seek services and what they should look like and influencing that, yeah, in a positive way. (Joy)

Participants stated that the Aboriginal community needs to be engaged and included in the design and implementation of services, supports and initiatives and that organizations need to collaborate with the community.

4.4 Crisis and Caregiver Issues

All participants noted the importance that caregivers, especially family, had on supporting Aboriginal seniors with dementia in the home setting. Crisis and caregiver burnout was the number one reason why seniors visited the emergency room or end up in long-term care either within the community or outside the community. Caregiver burnout was attributed to a lack of support and services in rural and remote communities. Aboriginal family dynamics where extended family would live together or in close proximity was voiced as an important aid to caring for the senior in their home even with a lack of services in their community.

4.4.1 Crisis and Caregiver Burnout

Aboriginal families and caregivers were found, for the most part, to be seeking help during the later stages of the disease when the family is already in crisis. Participants stated that when help was sought in the later stages of the disease usually only limited help could be provided at that stage. The participant continued to state that both caregivers and seniors who waited until a crisis point to receive help endured possibly unnecessary stress and hardships than if they came to receive help earlier on during the course of the disease.

> I find with seniors that come in and request placement they are at that point where they've probably been in bed for weeks, you know what I mean, it's past the point of where we can do something to even support them now or help them now. So if that education would have been there, at the beginning when they started noticing these changes, then I think the whole process would have been a lot easier for the caregivers and for the individuals. (Mona)

4.4.2 Experiencing Burnout Due to Lack of Support

Another significant issue when caring for Aboriginal seniors in rural northern communities was caregiver burnout due to a lack of supports and services. Many families have very limited options when they are looking to place their loved ones in respite care or to find services to help that senior live independently.

> But what we're finding is that family caregivers are stressed, they're exhausted. A lot of the people we're serving, you know we're serving people who are 90 years old and their caregiver is 89. And do you know what, they really want to be able to stay at home, in the dignity of their own home. They want to have the choice of how to be able to manage at home, I mean these are people who have, you know, lived their lives and enjoyed their independence as much as they can and so the flexibility of our service seems to be really accommodating that need because they are able to you know, they're experts in the care of their family members. (Charlene)
>
> Well, I think, I think stresses can be similar in terms of, you know, the stress of wanting to keep your family member at home but being exhausted and feeling isolated from your own social opportunities and that sort of thing. I think what' s different is in the region there are fewer services available and we see that as even more clearly the case east of Millbrook, those communities are, I mean there's just not a lot available to support them at all. There's a little bit more available in the west but even in those situations, certainly not to the degree to meet the need. (Charlene)
>
> To date, not many, other than hearing that there's a major gap in providing services to patients with Alzheimer's and dementia and their caregivers, mostly because the caregiver burnout rate is absolutely astronomical. Yeah, but the caregiver burnout rate – there's no support. There's no formal environment where they can connect with one another and feel like, "Okay, what I'm going through is normal" or support groups, for example. (Randi)

Many of the care providers spoke of the reality that caregivers in smaller communities, compared to larger urban centres, may have more duties that can often be very intrusive in nature, due to the lack of supports and services in their community. For example, caregivers with little access to home care options or proximity to a health centre may have to perform duties they are not comfortable with and these types of stressors can lead to caregiver burnout.

> It's like a bitter sweet end, I call it. It's nice that they're passed away and they're not suffering anymore and that they're, you remember them as your spouse, not as a child looking after them – because you have to change their diaper, wipe them down, you now, the whole bit. Feed them, that kind of stuff. So, and a lot of people can't do that - I find in families. And most families they can't. And there are few people understand where a lot of people say, "No, you should just do that" but I have more respect for people when

> they say, "I cannot handle this, I don't know how to do this, I need help" or "I need to place them into a home that will be helping them". (Tracy)

One participant spoke of a son who had to send his father into a smaller rural community from a reserve due to the fact that he was providing care that he was not comfortable with, since there were not enough resources on the reserve. The son was burnt out from providing twenty-four hour care for both his father, who has dementia, and his mother.

> ...he administers his father's insulin so he's responsible for that. It's pretty intrusive care that he has to provide for them and also, he needs to be present in the home for safety concerns and so while he receives this bit of assistance around personal care issues for both of his parents, he is the primary care provider around the clock. And so his explanation to me was when he's not there, you know he remains in contact with them by phone. When he's unable to reach them, his anxiety increases and so he's very much their umbilical cord and 24-hour support. (Joy)

Another participant stated that if supports and services that caregivers need are not provided, then they will quickly burn out and they may have to resort to sending their loved one for care in a hospital or long-term care (LTC) facility prematurely. If the appropriate supports and services were available in the beginning, then the health care system may not have had to be utilized in the first place, discussed the participant.

> And if we don't support family caregivers they become exhausted, they suffer burnout and then we have to rely on those more expensive components of the system that are already overstretched. You know, that's how we run into the ALC issues at the hospital and LTC wait lists. (Charlene)

4.4.3 Aboriginal Family Dynamics and Dementia

Although participants spoke of caregiver burnout and seeking help during crisis, they also talked at length about the benefits of a close knit family when caring for an Aboriginal senior with dementia. A large majority of the seniors lived with family members who were able to take care of them due to a large extended family where many family members reside in the home. Some community care providers noted that Aboriginal families are far more likely to care for their elders than are non-Aboriginal families due to the difference in Aboriginal family dynamics, their culture and traditions and their respect for elders.

> Well I think that they live with family members, you know the seniors, the elders are living with their kids and grandkids so that's helpful, that's something that doesn't always happen in our population anymore. (Gloria)
>
> With the Aboriginals and their culture, family tends to take care of them. They kind of come together and then the parents or the siblings will tend to take their parents in and care for them – usually in their culture which is very nice. So unless they're really at the point where they've deteriorated where the family members are really not coping, then that's when I get involved but if those low level seniors that I would normally see, family usually pitch in and take care of these people. (Mona)

Participants stated that Aboriginal seniors that have family, both close and extended, can usually stay at home longer and fair better compared to the non-Aboriginal population without this family dynamic even when they are faced with dwindling supports and services within their home community.

SERVICE-RELATED ISSUES

All participants spoke at length about the lack of supports and services in rural northern communities. Sub-themes that developed from this main theme included 'mechanical supports' such as transportation and housing, 'social supports' including day programming and support groups and 'instrumental supports' which include respite care and home care.

4.5 Mechanical Supports

At the core of service-related issues for Aboriginal seniors was the inadequate availability of mechanical supports such as transportation and lack of basic and supportive housing needs in all of the communities studied.

4.5.1 Transportation Services

A pressing need that was described by all of the participants was transportation services for the seniors in rural and remote northern communities. Some participants also stated that a large majority of northern communities have serious problems surrounding seniors being able to access transportation services in a timely manner for such things as out of town trips to seek medical attention or to obtain transportation within the community on a daily basis.

> I think one of the biggest areas that needs improvement is transportation services for them– that's definitely a big problem around the region. I've heard it in every community. (Roxanne)

One participant voiced her concern that seniors would opt out of attending out of town medical appointments because the transportation process was too inconvenient. She continued to use the example of how a medical van was used to transport a few seniors at a time to a larger urban centre for medical care. She said that the seniors would have to endure the long trip to the city and then have to wait around all day for everyone's medical appointments to be finished before heading back late at night or having to rent a room for the night. She explained that this process can be very physically and emotionally draining on their clients especially when medical problems are involved.

> But yeah, there's just a shortage of it and a lot of the seniors find it really inconvenient to take those buses because they go down when there's 3 or 4 people and then they're waiting for the other seniors in their appointments and I guess in some cases, there are services available but there not the quality that the seniors are looking for... (Roxanne)
>
> ...certainly transportation seems to be a huge need you know, in all communities, including the city. It's surprising that it's such a need even in the big city, we think we have a good setup for transportation but it certainly again, it's not meeting the need but it's far worse in the region – it's far worse. You know, people have to travel great distances for their medical appointments... (Charlene)

Roxanne stated that some communities had adequate transportation services for Aboriginal seniors within the community; however, transportation for medical appointments and specialists' visits, where seniors had to leave the community, were lacking due to funding. Seniors were not able to afford the extra costs that these trips would entail; some were not able to or did not want to travel such far distances; and others felt the trips were an inconvenience to plan and attend. However, community care providers stated that the organizations had a lack of funding to cover these trips and to maintain the vehicles to make the necessary trips. Planning and execution of out of town medical trips was sometimes a daunting procedure as stated by a few participants.

> Some of the communities operate seniors' vans or medical vans that will shuttle people to and from appointments, especially those in Millbrook so those seniors are getting travel grants but a lot of them can't afford to actually go down and stay the night, pay for accommodations and meals and someone's gas. I mean the travel grant is great but if your appointment is late in the evening and you need to stay overnight sometimes it's not enough for them. Also, just finding someone to drive them is an issue. So as far as out

> of town trips go, the senior's buses that are available are few and far between. Funding has been cut, all over the place. The government funded the initial purchase of a lot of vans and then the ongoing maintenance costs and the replacement costs have been left with the communities to afford. And they're all getting to the age now where they are in need of replacement. Some of the communities just can't leverage the money for that. Not sure why that is and the ongoing maintenance for them. (Roxanne)
>
> If they have an 8am appointment and there's someone with a 4pm appointment – that's a long day. And so if they want to go somewhere they need to get a cab. For some of them it's just too much hassle so they're not going to appointments. Yeah, so we get a lot of requests through our program to fund trips out of town even just short trips where there are no travel grants becomes an issue you know... (Roxanne)

Roxanne continued to imply that for organizations to be able to have the capacity to provide better transportation for Aboriginal seniors there would need to be an increase in available funding since the current demand for transportation heavily outweighs what is available in rural communities.

> Definitely funding for transportation. We get almost daily requests from our volunteers to see if we can provide funding for them to go to another community to bring them down for medical services and things like that. And we just aren't mandated for that kind of intercommunity travel. And we can't fund it. So, we feel bad turning them down constantly, but it's just not something we're able to provide. (Roxanne)

4.5.2 Housing

4.5.2.1 Housing for Aboriginal Seniors

Participants noted evident gaps and areas in the communities that need to be re-conceptualized, when providing all levels of housing to Aboriginal seniors in rural communities, to meet the demand as well as to uphold a higher standard of living for the seniors. These levels of housing included single or multi-family houses, seniors' apartments and supportive housing options in the community.

Participants described that the housing situation for many of the Aboriginal seniors in rural communities was inadequate and some providers stated that they had trouble providing services to seniors in those homes due to the condition of the home. For example, Mona stated that having the occupational therapist go to the home and try to outfit the necessary health care aids was next to impossible, due to the poor condition of the house and other structural problems with the house itself.

> ...so then these poor ladies and men are stuck in these shacks in town that are really- I wouldn't send anybody to live there. So you're going to assess this place and it's brutal, like it's awful. Housing here for Aboriginals, especially seniors, is not acceptable, is not acceptable at all. (Mona)
>
> I guess some housing, better housing for them would really make the whole job a lot easier because then they would be living in an appropriate apartment not in a run down place so then it's easier to get OT to come in and help them, set them up properly, so that they're safe, for their transfers and mobility but it's kind of hard to get OT to come into these old shacks and set them up when everything's such a mess. You know. (Mona)

A few participants in one community talked about the home maintenance program in their community and how it helps seniors be able to maintain their home, thereby allowing them to possibly stay in their home longer before having to move into LTC or another type of living arrangement. The participant stated that such tasks as mowing the lawn or shovelling the snow are crucial jobs that have to be done for many seniors to have the capacity to stay in their own home. Reflecting on the inadequate conditions of the homes that Aboriginal seniors are currently residing in, home maintenance programs can be crucial to help the senior live safely in their own home by doing such jobs as fixing stairs and railings, to repairing electrical or water problems.

> We also have the Home Maintenance Program. So that's to try to help seniors live in their own homes for as long as possible by providing them with a service provider from their community. So those people are also volunteers. They're not paid for their work so we do a police background check, just to make sure we're sending safe people into their homes. They're not necessarily tradesmen, so they are just doing sort of handyman type

> things whether it's cutting the grass or installing a faucet or something like that. Just to help reduce the costs and burdens of maintaining a home for seniors. (Roxanne)

Gloria explained that through a housing organization there are good options in the community for growing families to retain adequate housing options, but since these units are geared more to larger families, these units are not suitable for many seniors. "I know through Millbrook Housing they have some native housing but it's very limited and they're bigger homes so they're good for like families, or younger families with kids but for single seniors there really isn't much".

Another disadvantage of homes for Aboriginal seniors was the fact that they are not receiving funding or resources to equip these rentals with the necessary aids to facilitate the senior to stay in the home for as long as possible.

> And who's going to pay for that? The renter, the guy that owns the apartment, won't help them out so on certain things you can get funding through NIHB but ramps and stuff like that it's usually the building that will provide that for you. So it's, yeah, it's tough. It's tough for them. (Mona)

Mona continued to explain that some of the senior apartment complex owners will not rent to Aboriginal seniors due to racial and stereotypical beliefs towards the Aboriginal culture, thereby leaving run down rental homes as the only option for some Aboriginal seniors.

> Yeah, just you know, a lot of people with – they're just labelled so people because you know they have their way, they have their culture and a lot of people can't respect that. And they don't want their home whatever, neglected, so they won't rent to natives. The better apartments are not rented to them so then these people that own all these shacks that should be torn down are rented to them. (Mona)

A lack of funding or income was discussed by Tracy as a barrier for Aboriginal seniors accessing adequate housing in rural communities.

> There's not a true service that's out there and if there is they don't have any money to do it because whatever money they get, because they're on low income, for the rent and everything, they have to have an assessment every year. So your rent may stay the same or go up. So like last year for instance, all the seniors for the whole year got $50 more on their cheques and all the rents went up $50 more. (Tracy)
>
> There's very few of them that have any CPP or pension plan because they didn't work that generation, they stayed home, they looked after their kids. The husbands worked and not all husbands had a pension plan. Some of them did, but most of them didn't so then they're only usually getting OAS or geared to income. (Tracy)

Participants explained about the lack of housing for seniors and also noted that there are not enough seniors' apartments available in rural and remote communities for the increasing aging population. "Well that is a big lack. We have the two senior's buildings..." (Mona)

> There's one unit here that's not accommodating because of the stairways and a lot of them can't use that so it's really hard for them. I don't know why they make units with stairs especially for elders because some of them are in wheelchairs, some of them you know are in walkers – yeah, it's hard. And they don't build elevators for them to go up and down either. They can't afford that I guess. (Avila)

Avila noted that wait-lists for seniors to get into the apartments was also long in many of the units in one of the communities.

> You hear a lot of elders complain that they have to move down because they can't go up and down their stairways. And the sad thing is, they can't because they fill up so fast too. They have a waiting list if somebody wants to get in and I don't think it's not only for natives it's also for non-natives. (Avila)

Another issue regarding senior's apartments in some communities, as stated by participants, was the fact that many of the apartments were very small — too small for seniors to live comfortably and to have a good quality of life. One participant talked about what she would like to see in a senior's apartment complex and stated that the residence would have to be a lot larger.

> No its not, if I could have a dream place for seniors, I would have each senior have 2 bedrooms, 2 full bedrooms, not just enough for a bed and a dresser, a full kitchen and a full living room, not just a little kitchenette and a little kitchen because here, the size of my office is 9 x 13, and that's just the size of their kitchen and their living room. It might be a little bit bigger in the other one. Yeah, so it's like you go in the door and you got right away, you have a window here so there goes a whole wall right there. The door opens this way- you only get a partial there so some people would like a couch but they can't put a full couch because if they do then the door hits the couch. (Tracy)

Participants voiced their concern that some or all of the apartments, depending on the community, needed updating or improvements and that some are not fit for seniors to occupy them. When Avila was asked how she would feel if she was an elder having to leave her home on or off the reserve and move into a senior's apartment she responded, "So, can you imagine, when all these elders had a home sometime, somewhere along the way, they have their own home. They have their own way of looking after their home to have something like that [seniors' apartment]...no".

Another concern from care providers was that in one community, the seniors' apartment had a mix of seniors and disabled people and stated there have been problems in nearby communities before when both inhabit the same building. There were not enough buildings to house the seniors separately so the only available option at the moment in the community is to allow them to reside in the same building but on different floors.

> You can't live in the top of that building it's pretty well just disabled healthy people because you can't get seniors up there so that building is kind of scary because it's a mix, you have a few seniors, on the main floor so the upstairs could be like mental health, disabled people so you know, we all know about cases that have happened in Millbrook with mixing seniors and mental health people. It's just not a good thing I think. So people will choose not to stay at that building... (Mona)

4.5.2.2 Supportive Housing

Every participant mentioned the need for the option of available supportive housing for seniors in rural and remote communities. In one community, Gloria said that the district had established a committee and that supportive housing was a future initiative.

> Not at this time. I think it's [supportive housing] on the radar something that the municipality is looking at or the hospital is looking at partnering with because it's an absolute necessity. (Gloria)
>
> Oh and I'm not in that sector anymore so I'm feeling a little more free to say that's it's on the radar and hopefully not too far down the road. Hopefully it will be built before I need it – that's basically where I'm at... (Gloria)

Joy reiterated the fact that rural communities need to have a continuum of care options built into the community's infrastructure from housing to senior apartments to supportive housing. This way LTC does not have to be the only option in many cases.

> I think that [supportive housing] is woefully lacking, for instance, they don't have their own supportive housing in a lot of instances, like senior housing or a LTC type facility. I'm not sure if that's feasible but we need some sort of continuum of housing, social supports… social supports and housing. (Joy)
>
> ...once they move in to the senior's apartment then, they don't have to worry about the roof or the pipes leaking or you know all that kind of maintenance stuff. But they still, there's no services so they still have to qualify for CCAC. There's no place where it's a supportive type of living where they have the kind of inclusive services – there's none of those options up here. (Mona)

The need to build supportive housing facilities for seniors in rural communities was a real need expressed by all participants. Helping seniors have a good quality of life and a nice place to live were also voiced by participants as crucial steps for the future. Tracy noted, "I think housing facilities would be wonderful. That would be an awesome thing".

> I've always visualized for the elders here, it didn't matter if they were native or non-native, put them into a very nice, to build for them a very nice unit for all of them and to put their laundry right on the same floor and they have a recreation right on the same building, in the same place, because you may as well give them a good life while they're still here at the end of their life, at the end of their life cycle. That's the kind of thing those people need. Something they can feel good about, you know, and something they can look forward to... (Avila)

4.5.2.3 Long-term Care (LTC) as a Last Resort and Only Option

Participants stated that in all of the communities the only option for Aboriginal seniors who are not able to live with family or who cannot support themselves in a house or apartment, is to end up in a long-term care home since none of the communities presently had any form of supportive housing infrastructure. Waiting lists of up to three years to get a placement in LTC were discussed by participants in many communities. Gloria stated, "Long term care, what is it, 2 ½ - 3 year waiting list? Yeah, I think that's it".

> If they can't cope for themselves and bathe themselves and things like that then that's where they end up is the hospital. (Roxanne)
>
> I would I have to say, that there are pockets of people, within LTC, a lot of Aboriginal people I think remain at home for as long as possible. Certainly they're being managed by their communities certainly. (Joy)

Having LTC as the only option can possibly be even harder on families and on the senior as it may mean the senior will have to take an opening in a LTC bed in another town far away from family and friends. Extreme stress on both parties can result when having to move a senior out of their home community, however, many families have no other choice. One participant noted that moving a parent to another vacancy in a LTC facility can cause two to six hours of driving time in the region and this distance only multiplies when Aboriginal seniors are flying in from remote reserves to see their parents or grandparents.

> For sure - the remote communities just don't have the range of services that are required so yeah absolutely… if you don't have the services you need, you go to what's available which is often an institutional model of service and it might not be the model of choice. And it might not be in their home community either and that's a problem as well. (Charlene)

Participants also stated that many of the seniors that end up in LTC do not require the level of care provided, but must live there because of a lack of alternatives. Participants suggested that if supportive housing was available, many seniors would be able to postpone entering LTC and remain in the community longer or possibly indefinitely.

> And the other option is long-term care if they're at that point – a lot of the seniors that are still functional. They really don't need to be in long-term care and if they had maybe a senior's apartment building or little complex just for Aboriginals, you know what I mean, I think they would co-exist a lot better. Like in Eagleland they have a little senior's apartment, I forget, there's about 8 or 10 apartments that are... and that's really well done because they each have their apartment so they have each other to support each other – but that's on reserves so there's not many services. (Mona)

Although participants could appreciate that LTC facilities in small communities have access to limited resources and funding, many voiced their concern about not having enough beds for seniors who are in desperate need of LTC. This means the seniors' only option was to stay in the hospital in alternative level of care or acute care until a LTC bed became available in their community or another community. Tracy noted that these acute care beds are in hospitals where often there are no locked doors, potentially causing security issues. "So if you have like, for Alzheimer's' there's not anything specific here like the hospital, they don't even have a section that Alzheimer's can go in to be safe".

> They have the extended care which is a locked wing but at the same time, if some of the patients who can come and go, that person can leave too. Because, like if they're all coded, you open up the door and you leave. And if you don't make sure the door is closed behind me, then they'll come out with you. And if you don't know if that person has, you know, dementia of any sort, then that becomes an issue and sometimes it's hard

> because, like here, the extended care, they don't have, like in Millbrook, they have sections where it's just a wing for Alzheimer's or dementia or something similar like that and the people there they understand, they get it, they know how to work with them. (Tracy)

Participants stated that LTC was a last resort for Aboriginal seniors and their family members and/or caregivers. Tracy described how a rapid decline in memory was often evident when seniors moved into a LTC home away from their familiar surroundings, such as from a northern reserve.

> No, they don't normally run and go and get a diagnosis. And actually, to me I find, as long as they're in their environment, they take care of their own and understand that they have lots of memories. As soon as you take them out of that environment and you put them somewhere else, then they're like, they want to remember, but they're in 4 walls, a window and a door, as opposed to out in the bush. Bring them to the bush, and 99% of them will say, "That plant there, you don't eat", like "That one there is good". Where it's a whole different generation, a whole way where they're looking at life. (Tracy)
>
> Yeah. And we know with Alzheimer's, if they get into long-term care, they're not going to remember you anymore because you're not there 24/7. So that could be also heartbreaking on the family as well. It's a double edged sword for it. (Tracy)

Joy talked about the options that she presents to families, caregivers and the seniors and how all of the options available may mean that the senior has to leave the community and move to a larger centre and how complex this situation can be for all who are involved in the decision making process.

> They make all the decisions. I will simply provide them with information about resources but it may mean that they need to come to live in Millbrook to take advantage of services that would allow them to live, still live independently. It may mean moving off reserve or moving into supportive housing where they can get some light support or it may mean separation of the couple by illness whereby she may move into LTC and then the husband can remain on the reserve. So there's a lot to talk about, a lot of complexity involved and, like I said, they make all the decisions in their circumstances so it's really just to give them an idea of the range of services they can participate in. It would mean changing a lot about their circumstances. (Joy)

Tracy noted that some seniors have a difficult time adjusting to the strict rules and regulations that are present in LTC facilities, even if it does not reflect their wishes or their culture. She also states that she herself would have trouble following such a schedule and that seniors should be given more flexibility when in LTC.

> ...most extended cares like here they tell you, you need to get up now, you need to have a bath now, you need to do this, you need, you need, you need. That's really hard on a lot of clients. They're going, like I've had clients in the past, that used to live there and their nurses would phone and say, "Traci, we need your help, got a fight going on, there's swears and everything". "Yup, no problem", so I go, "So what's going on"? "I don't like being told what to do, when to do it and how to do it" I go "Yeah, that would piss me off too!" Because realistically it's true. So I go up to their assistants, "Really, what's the big issue?" "Well they didn't have a bath for two days" and I said "Really? Tell me, what have they done to earn that bath for two days, other than lay in bed, get up go eat, go back to bed". I said, "Well you know give them a sponge bath, that's what they're asking. Give them a bucket in the bathroom, they want to do it themselves instead of making it a fight". (Tracy)

Tracy continued to note that the facilities that are already present should be reorganized to downsize the amount of administrative space and devote more room for extra LTC beds or build an entire building just for LTC.

> I think a bigger extended wing would be even better as well or just a whole new building just for extended care people because like, our building's pretty big over here but how they revamped and did things like that, I know they've changed so many times, it's chaotic. There are more administration offices than there are beds. I call it the top heavy syndrome. (Tracy)

4.6 Social Support Programs and Services

4.6.1 Support Groups

A few participants noted the lack of programs and support groups for Aboriginal seniors and their caregivers. If support groups were available, according to Gloria, they were only for the caregivers and they had limited turnouts.

> I think it's kind of sad because there isn't a day program, there were no groups… It was just the caregivers for now, because there was a real stress, a real need... The caregivers, they weren't communicating, they weren't having coffee, they weren't taking time for themselves, and we actually had one woman completely burn out and crash. Her dad had Alzheimer's and Parkinson's and her mom had Alzheimer's. Her mom was not verbal, like, it was just, it went from bad to worse and she had no support. And she, was the beginning for me of, okay, these people need some help so, yeah. (Gloria)

Gloria's community did start up a support group for caregivers in the area but currently did not have any Aboriginal caregivers attend any of the groups.

> ...so putting together the support group was a way to share and Marleigh came and did a… learning series for us through telemedicine and Robert was doing one through the First Link, we through the First Link, with the participants and I had about four people that would come all the time, every week. We ran it once a week every Monday afternoon because it worked best for the group. (Gloria)

4.6.2 Day Programming

Participants stated that day programming was available in many of the communities on certain days. Many of the day programs were put on by Aboriginal organizations and included culturally specific crafts and other related programs for seniors. Transportation was provided free of charge for most of the programming. Tracy noted that her organization would tailor the activities to help improve the memory and coordination of seniors, especially those with memory problems or dementia.

> And they pick them up with the handicap bus and they come from 10 until 2 so we play games that will help with anything from limbering the arms to memory games, to up and walking around or just staying and sitting. We also, every once in a while, switch it up and I'll throw in chair exercises in to help them do it or else we just starting doing the Wii. Yeah so, I try because most seniors like you know, with dementia, their memory goes so we play a lot of numbers or things to get their memory going so with the Wii, we do like bowling or even boxing so they know – oh yeah, I can lift my arm up. (Tracy)
>
> We'll have different tricks, sometimes we'll use flashcards and things like that. So even like our bingo, we'll do number bingo or I'll do a nutrition bingo which is all pictures. So they can recognize different pictures to match and to help that way. (Tracy)

4.6.3 Friendly Visiting Program

As mentioned by participants previously, seniors in rural and remote communities need social interaction; without it they can become lonely or withdrawn. Participants stated that the friendly visiting program in communities is crucial for social interaction as well as the overall health and well-being of all seniors in the community.

> Through Erie Agency we have a senior's volunteer kind of friendly visiting thing, so it's not maybe hands on assistance but just, you know, company, visiting, play cards with them, stuff like that. There's that which is kind of nice. That was here a while back and then it kind of fell through the gaps and now it's up and running again so I can see that being very beneficial because a lot of them are lonely. Besides that I know that there's some private help out there besides, that's about it really. (Mona)
>
> The volunteers themselves are seniors so age 50+ and they go into the homes of seniors in their own community and offer companionship. So they go in, they can play cards, they can visit, participate in hobbies, so knitting, playing cards, whatever it is. They often take them out into the community and encourage them to interact with others, at senior's clubs, at different community events, they can help them with grocery shopping and we will reimburse the mileage for that. (Roxanne)

4.7 Instrumental Supports

4.7.1 CCAC and Home Care

Home care options were stated as a great need for seniors and their caregivers in rural communities, by participants.

> They're available, like I said, we don't go on reserves, so if they live anywhere in Stonewall, that is provincially funded and they have a health card, and then they have to qualify so they need to require assistance with personal care and stuff like that before we'll provide a PSW because the focus is not housekeeping, the focus is personal care so bathing, dressing, the feeding, the medications, that becomes priority over the housekeeping. (Mona)

Many participants stated that the amount and the availability of home care options in the communities was inadequate and that seniors were not able to access enough home care services or did not have the money to be able to afford to have providers come in and clean their home, thereby forcing many seniors out of their homes prematurely.

> It's inadequate and even with cleaning, they have Homecare but Homecare used to do housecleaning and they don't anymore. It's not in their description anymore - personal care only. So a lot of these seniors they can't wash the walls. (Tracy)

Participants referenced the CCAC as being a crucial service for seniors in rural and remote communities, to provide personalized care to the senior population.

> Well if they have no trustworthy caregiver to come in to help them with that, then that's when I look at the family and say they need to be placed because if they're forgetting to take their medication then there's an issue because they don't have a family member that's ensuring to make sure that their medications are taken care of. And then, they're obviously not going to be eating then as well because they can't remember. Sometimes when they're not taking their medication, they're not eating as well. So, it's almost crucial to start the process. I'll talk to CCAC because most of them are under that umbrella as well so okay, I've noticed this, this and this so what should we do... (Tracy)

Roxanne explained that seniors are desperate for more services such as the ones that the CCAC provides and that she knew that some seniors were putting themselves on waiting lists before they necessarily needed the service because, if they were not on the list until they were in crisis, they may not be able to cope with having to wait to receive the required services.

> CCAC provides a lot of services to the seniors in the area, you know a little bit of housecleaning, a little bit of, kind of whatever the senior needs. They come in and do that, especially for disabled seniors but I believe there's a waiting list even for that. You almost need, I've heard from seniors, that they feel that they have to put themselves on that waiting list even before they really need the service just so that when they do need it – it's available. So they're starting to learn how to work the system I guess. It's too bad that they have to resort to dishonesty just to get themselves on the list. They need to get services though. (Roxanne)

4.7.2 Respite Care

Participants said that there is a lack of available respite services for caregivers in rural communities and, in most cases, only one organization provided this service on a provisional basis. The only other option for caregivers according to participants was to put their loved one into the hospital.

> There's a lot of trouble with respite care here, there's not enough of that. I know people who have got their parents living with them and when they need a break, there's really just, aside from putting them in a hospital bed, there's no place really for them to go. An organization provides services here but it's really limited- very limited. They end up in a hospital, nobody wants to put their parent in a hospital and then feel comfortable having a weekend out of town, you know? So, yeah, I would say there are not a lot of options. (Roxanne)

Some participants communicated that there was a need for respite services in the rural communities and that these services must look a lot different than they do in urban centres to accommodate the unique needs of remote northern communities in providing respite care.

> So they can use more than one model of service but in order to replicate that kind of service throughout the region, there's just no way we can have the funding to do that because of the sparse population and the vast geography. That's why we came up with the family directed respite funding. (Charlene)

An organization that provides respite care in the north developed a pilot project to develop family directed respite funding where residents in smaller communities can tailor the service to fit their needs as described by one participant.. The participant also stated that it allowed caregivers, such as a caregiver for an Aboriginal senior, the flexibility to hire a trusted family member or friend to provide respite care for their loved one. She continued by saying that this type of model is, in itself, a culturally competent and culturally sensitive model of care.

> ... what we did was we tested out an innovative pilot project of the Aging at Home Strategy to provide services in the region and we do it through family directed respite funding. So what family caregivers do is they access the type of respite that they want. Often they're hiring a neighbour, you know, a trusted friend, or someone like that. You know, maybe it's they're best friend's daughter or somebody that they can hire that person to come in and take care of the person, their loved one at home and they can take a break that way. Or they can do a lot of creative things with the respite, it's amazing. If you encourage people to be creative and make the service work for them, they really take advantage of that. (Charlene)

Charlene stated that despite respite services being extremely good and directed and implemented to fit a complex catchment area, the wait-lists for caregivers were quite long in the region, ranging from a few months or even years to receive services, due to a lack of funding. She stated that these wait-lists are difficult for caregivers since they routinely seek these services when they are at a crisis point and need the service immediately to either 'take a breather' or to look after their own health needs.

> There's never enough funding. So we do have waiting lists, actually for all of the services that we provide, both in the city and in the district of Millbrook as well as Cape and Midtown River district. And in all the districts we do have waiting lists but it's just

> wonderful to be able to provide some services and actually our waiting list situation has actually improved quite a bit through the Aging at Home Strategy again in all the areas including the city. So there's been an improvement but does it meet the demand? No, the demand always outstrips our abilities to respond. (Charlene)

> We have different lengths for each of our waiting lists because they're all under different funding categories from the government so, for example... In the communities east of Milbrook, we're probably looking at, I would say under a year, probably measurable in a couple of months. (Charlene)

Charlene continued to explain that respite services are one of the most important community care services that can be available to help seniors stay longer in their own homes, to increase the quality of life and to reduce caregiver burden. Keeping seniors out of LTC and out of the emergency rooms were reasons stated by participants that initiatives such as family directed respite funding need to have more funding and support.

> You know they, they know what they need, and they know how best to have that need met. I think that that's one of the things, one of the reasons for the success of the service is that it really is a fluid service that can take on the shape of whatever the family needs. And, you know what, we're trying to meet the same goals as the government ministry is trying to meet and that's just to try to keep people at home. They're staying out of the emergency department and out of hospital and out of LTC for as long as they can. (Charlene)

4.8 Challenges to Accessing and Using Health Services

This theme encompasses some of the difficulties of receiving medical care in the north from the perceptions of community care providers that work with Aboriginal clients with dementia. Issues regarding continuity of care between the Aboriginal client, physicians, locums and practitioners were discussed. Finally, retention of health care providers is voiced as a concern in rural dementia care.

4.8.1 Accessing Health Care in the North

Participants explained that small communities experienced many barriers in accessing health care and that wait-lists are a large concern. The amount of time required to get an appointment with a physician or nurse practitioner as well as extremely long wait times in the emergency department in many communities were described. Tracy commented, “and the wait-list of course, you know for seeing emergency or that stuff, that’s across the board. It’s like that for all seniors”.

Mona shared the fact that she once conducted assessments up in northern reserves but the health and safety concerns became too great over the years and she could no longer provide this personal service; subsequently, she conducts her assessments through teleconference or over the phone.

> I used to fly out there and do assessments out there but it just became very unsafe, health and safety and all that so now we do them through either video conferencing or audio which you don’t have that connection anymore so it’s really tough. (Mona)

Some participants have also experienced cases where seniors have been overlooked when accessing health care in the north, due to barriers in accessing the health care services that they required. As Roxanne stated, “I’ve heard of some cases where seniors have gone in and sort of been... I don’t want to say neglected but they haven’t been cared for in a way that they should have been”.

> Yeah, so there’s cases like that and I’m sure they have them everywhere but they stand out. You know, when you think about the lack of care seniors are getting, yeah, actually that’s, I think that’s happening across the area. (Roxanne)

Joy stated that her organization is working with the system to help deliver and integrate senior's services in the region to better care for and support seniors in rural and northern communities as well as in urban centres.

> So we had that integration and with that, we introduced a new role for being more accessible to the LTC community. We're having people assigned in a liaison person role and with that we're building the capacity for those folks to use my services as well. And that person's getting introduced to the culture, like when we have a person working in that environment, and have their finger on the pulse for what's needed in terms of specific client need and they can pull me in as a resource I think much more readily than before and a lot of that's being driven by the new LTC act… (Joy)

4.8.2 Continuity of Care and Retention of Health Care Staff

Continuity of care was a significant system challenge for people with dementia and care partners mentioned by many participants. Continuity of care was related to a number of factors, the most pressing being issues related to physicians. A lack of available physicians, high rates of turnover in physicians, and the use of locums were all described as challenges. Participants pointed to the addition of nurse practitioners to health care teams as a way to increase continuity of care. Retention of health care staff was also seen as a challenge to continuity of care.

4.8.2.1 Continuity of Care

In many communities, participants noted that they have a lack of available physicians for the entire population and that people have to change doctors on a regular basis due to the lack of steady physicians in the communities.

> I haven't heard any complaints, but then again, the doctors and stuff, doctors are not one of the best services we have here. Because you know, we have a doctor that's been here like forever, and that's the only one. And then we have doctors that are coming up – I don't know how many times I've changed doctors already. I don't have a steady doctor

> and I refuse to have a steady doctor because you don't get one anyway. They keep changing right? (Avila)
>
> Absolutely. Like I don't have a family physician here in Trenton. I've still got one in Millbrook because we can't get one in Trenton. And I actually live in Drowning, so it's even worse. If you need to see a doctor you really need to come down to Trenton. And even then you're not even guaranteed to see one. We've made appointments to see doctors and ended up seeing nurses because there were no doctors. (Roxanne)

Participants expressed that in some communities, few physicians practise on a permanent basis. New, younger full-time physicians and locums that came to the community brought new initiatives and a different outlook on health and health care.

> ...but yeah we have some fine doctors that are here for longer term and very attentive and very young and they're, they seem to be catching a lot of this and making referrals to Dr. Bell and such much more quickly. (Gloria)
>
> Yeah, it is because like we have, I think we have two fresh doctors that are here permanently and then we have a NP and then we have the regular doctor whose been here for 99 years I call it – everybody has one of those doctors and sometimes that can be good and sometimes it can't be good. Because sometimes it's like, "Yeah, yeah, yeah, okay here" and then you got the newer ones where they'll all "Oh yeah, okay, yes, we're going to change everything about you and this is what we're giving you". And they're [the senior] like, "Okay what does this mean?" (Tracy)
>
> Or you're just getting old, not necessarily, or if it's all in your head, like for mental illness and stuff, you know what, I think you'll see the younger doctors today coming out and they're more open. I think there's more education going on in those medical schools. Overall I think any professional nurse, doctor, physio, anything, you need to have that open mind. You need to look, you have to look at that person and not put them in a box, you need to look at them individually and see what works best for them. (Mona)

All communities experienced a large number of locums providing front-line care both as family physicians and in the emergency room in rural communities. A problem noted was that many locums are not from the north and are not accustomed to the diversity of northern populations and the community's unique needs. Not having access to a steady physician can hinder the continuity of care continuum when seniors are seeing a different physician each time they are in.

> ...but we do have a large portion of our medical staff are locums will come and do emerg. So they're from the big city, you know, they're just here to fix people and get out and I think sometimes there's some cultural insensitivity in that regard – only due to ignorance and not because they're just trying to make, you know, their system fit, but because they don't know any differently so I think elders and dementia population is a real tricky one to work with. (Gloria)
>
> What they call locums or whatever, so they come in for a few weeks so if you're sick and you need to see a doctor, then you see that one and then you're sick again, maybe it's the same illness, and then you'll see a different one. (Avila)

Participants believe that locums are not the answer to help aid in the delivery of health care and community care in the north but they are definitely a necessity in providing front-line health care. Gloria stated, "...it's a bandaid for the system to have locums but it's certainly not the answer – especially with seniors".

> The best doctor in the world wouldn't be able to pick that up. Being a locum, you know. They're good for the emergency, for covering the emergency and doing that kind of thing, but for the family practise stuff, it's hard for them, they can only do what they can. (Mona)

Participants voiced that having locums treat seniors with dementia can be an issue due to lack of continuity. Locums may not get to know seniors and may not follow them for prolonged periods of time, thereby not noticing changes in memory and personality and so forth. The need for continuity of care in the health care sector was described as a necessity for seniors and dementia care.

> Absolutely, yeah, it's a big problem because, as we know, with dementia, it changes so quickly from one day to the next, if you know one person with dementia you don't only know one person, that sort of thing so they may present completely fine on one occasion and have complaints of this, that, and the other, and then they get treated for just that

> snapshot moment that they're in emerg and then the next time they might be in about a different complaint but you know, they're not going back in the files and seeing, they're not asking family members, maybe they're not you know, putting the whole picture together, which I think, if you have continuity of care, that happens. (Gloria)

> Yeah, that's really unfortunate. You know that's always bad for anybody, if you don't have a consistency. Locums are great because they're filling the gap, but for long term reassessments and stuff like that they, they, you can't blame them, they see people in and out that – how can they really get to know you. It's really unfortunate, they don't have time to skim – all the charts are computerized so it's not even that you can open it and flip through quickly. They're trying to figure out the system so they're trying to figure out, "Who is this"? You know what I mean? It's difficult, we need to have permanent practitioners; I think that's the only way that you truly get that whole circle of care because you have somebody that gets to know you, knows your diseases, knows your medication, knows if you're addicted, like if something's going on with you a locum will never pick that up. They don't know you. (Mona)

> Not just seniors, because they need that continuity. They may not always remember one thing to the next, and locums don't always have time to read the file because they're just filling in. (Randi)

Tracy noted that she goes with her clients to appointments if they do not have family or another caregiver to accompany them, thereby enforcing continuity of care informally on the part of the care provider. She makes sure that the senior understands what is happening during the appointment with the physician and can also write down directions and explain medications and their side effects to the client. The care provider can also keep prior notes and explain the seniors' medical problems to the locum so that the physician has knowledge of how the senior has been progressing at home.

> So a lot of times, like if my clients are seeing new doctors or they're seeing a locum, I go with them and I bring their medications with them and sit down and explain. They talk to them but I'm listening and then I look at them, "Do you understand"? And I put it in layman's terms, you know. (Tracy)

Participants stated that many communities are adding nurse practitioners to their health care teams to offer a greater continuity of care to people with dementia in the community and for people to access from surrounding communities.

> Yes, Carla – she's very, very, very busy. I know I refer a lot of my seniors to her because of the consistency and the pills and just so they're followed up properly. And then she gets to know them and it's so much easier but a lot of them are old school and they want to see a doctor. (Mona)

Roxanne stated that some seniors do not understand the role of the nurse practitioner and still request to see a doctor instead as they are accustomed to only seeing physicians for their medications and other health care needs.

> I: There was no doctor on call, or?
>
> P: There was no doctor available. So we ended up seeing nurses. And I mean, they're whatever the highest form of nurse is...
>
> I: Nurse practitioner?
>
> P: yeah, we would see a NP and she'd give us the prescription or whatever we need and make the referrals but it's still not the same as seeing a doctor. (Roxanne)

4.8.2.2 Retention of Health Care Staff

In essence of health care in the north and the problems with continuity of care between health professionals and Aboriginal seniors, one of the encompassing problems is health care retention of staff. All communities were noted to have difficulty with retention and recruitment of health care and community care staff. Reasons voiced for lack of recruitment and retention of staff included the remoteness of locations, financial reasons, lack of jobs for the person's significant other or extended family, wanting to experience a larger centre with more amenities, and no physical attachments to the rural location.

> I think recruitment and retention is especially difficult here because most people want to go to the major centres so I think that's a classic problem of any profession in a small town. (Gloria)

All of the community care providers were perplexed by how to recruit and retain health professionals in northern rural and remote towns. Roxanne stated, "... I think people would be a lot happier with the medical services if there were more physicians available here. How to get them up here... How do we train them and keep them. Yeah, that's the question". Tracy also stated, "To get more doctors but that's a struggle right across the board".

Mona encompassed the entire sub-theme of health care professional retention in a rural community when she said:

> We could have had a lot more stay but the Health Team here I don't think is providing the financial support that maybe, I don't know somebody in Millbrook is or so of course if you don't have any of the attachments that's here, or kids or a spouse, you're going to go where you're wanted first of all. Then you can do a full scope of what you've been taught. But I find, yeah, not many, I find the local people here if they go away they take nursing or I haven't heard of any of them taking... being a doctor or anything, they're not sticking around. But you haven't seen many that are, I know it's just to try to encourage people, local people to take it but unless in your mind you want to stay local, doesn't matter what you take you're going to stay, but if you want to go and you can't blame them if they've been isolated for all their teenage life so some of them want to go see what's out there. So it doesn't matter what you provide for them, they're going to go. They might stay for a year or two because you gave them a little bit of funding but, at the end of the day, they're gone as soon as they can. (Mona)

4.9 Providing Culturally Sensitive Programs and Services

Taking into account the lack of continuity of care as well as the 'revolving door' of health practitioners coming in and out of rural northern communities strengthens the need to have practitioners that are culturally sensitive to Aboriginal culture and lifeways to be able to better access and serve the Aboriginal senior population who have dementia. Some strategies mentioned included educating the Aboriginal population and seniors on dementia, tailoring services to the Aboriginal population and finally, facilitating organizations to work together to achieve the best possible supports and resources for their community.

4.9.1 Educating the Aboriginal Population about Dementia in Culturally Relevant Ways

Participants listed ‘education surrounding dementia’ as one of the first steps needed in the Aboriginal population to create an awareness around the disease and to open communication lines between care providers, families and the seniors. These educational initiatives cannot look the same, nor can they be facilitated in the same way, as they are for the non-Aboriginal population, stated all participants. Education was described as an essential way to bring awareness of dementia to Aboriginal people.

> I think so, I think we need to get out there and educate the Aboriginal population itself because those caregivers are just siblings of these, you know what I mean, elders and I think if we go to them, if you go to their community, and do education and maybe have some of their, their nurses out in those reserves, so if you bring it to them and bring it to their communities, I can see people listening a lot better than trying to send them information. You need to, I think, meet with them and bring the tools when you meet with them and introduce it that way. I think that’s the only way you’re going to truly get them interested. Because material coming in, I don’t think it’s going to work for that population. They don’t understand it, they need to be able to ask the questions, or you need to provide those examples of, you know the little old lady who has changed mentally and, yeah, it’s not getting old, this is not the normal ageing process, this is somebody with dementia and that’s when they’ll click – holy man, that’s what Mom went through, or you know, so I think we need to meet with them. (Mona)

> No, I think the big one is education. I think bringing it to their communities and then we’ll start seeing them – once they realize that this is not normal, what’s going on with their parents, then you’re going to see them seeking help. So if there’s no help there, then they will start calling. But, unless they know, what’s going on, they’re not going to do it. And once they have that education, then the providers need to provide, like the CCAC, then they’ll understand why they need to call us now. And, it’ll all come together for them. (Mona)

Some participants stated that educating the Aboriginal population will help to alleviate stress on the health care and community care system by getting supports and services to the seniors and caregivers earlier, before they experience a crisis situation. These educational initiatives would potentially eliminate extra stress and complications for both the person and the acting organization. Mona noted that practitioners need to be culturally sensitive and respectful of Aboriginal culture and traditions when educating the families and seniors about dementia and not attempt to conform them to a biomedical view of the disease.

> So if that education would have been there, at the beginning when they started noticing these changes, then I think the whole process would have been a lot easier for the caregivers and for the individuals. Because a lot of them are coming in with... because they have moved. And it's nobody's fault of their own, you know what I mean, if the knowledge isn't there, the education isn't there. What are they to know? It's not fair but that's the way it is. So, we need to catch them early. And then, hopefully, they'll ask for help or support. (Mona)

4.9.2 Complexity of Cultural Sensitivity and Education for Community Care Providers

Participants were asked whether or not they thought that the local health care and community care providers were culturally sensitive to Aboriginal culture and traditions. The majority of respondents noted that they thought that both sectors were doing a good job when it came to being respectful of, and sensitive to, Aboriginal culture in rural and remote communities.

> I think yeah, I believe they are. I haven't run into anybody who hasn't been and they also pull in a lot of support if they don't understand so that's a big plus compared to years ago that they were like big deal, but the medical has changed so much over the years so it has helped a lot. Yeah, it's a big difference. (Tracy)
>
> I don't think there's a lack of sensitivity. I think there's a lack of services and that might create a lack of sensitivity within the health care system where people are maybe overrun with clients because there's not enough services for them all so maybe people are being rushed through different services. (Roxanne)

Participants explained the types of educational initiatives that are currently provided in their communities. Not only were community care providers receiving education regarding aging and dementia, some were also receiving cultural sensitivity training. Also, the volunteers who worked for some organizations were also receiving training, thereby equipping them to provide better services to the senior population.

> ...the volunteers themselves actually identified it as a topic that they would like more information about on. Because they are seeing some of their clients suffering from these things - they want information on it. (Roxanne)
>
> But training is also good – when we can partner with places, like the Alzheimer Society to bring in training for our volunteers. Some of the hospitals have kind of partnered with us to provide some training for our volunteers so that they can provide better services to the seniors that they're working with. Whether it's an understanding of falls prevention or, you know, just understanding scams and things that are targeting the elderly – elderly abuse, things like that. Any kind of training that other agencies can partner with us to provide is great because I can't provide all the training to them. I'm not an expert on any of those topics so when we can bring people in it's better for their training. (Roxanne)

A few participants noted that in some communities they have witnessed a lack of cultural competency and believed that there is an ongoing need for cultural competency and sensitivity training for health care providers and community care providers so they can deliver culturally competent health care.

Joy noted the need for cultural sensitivity training due to the large percentage of the Aboriginal population in the north and the need for care providers to be able to serve diverse populations.

> Yes I think that there's, there needs to be a focus certainly on Aboriginal culture because I think I read somewhere very recently that within our LHIN over 20% of the people identify as being Aboriginal or Métis so that's very significant in terms of population. And then I think just, you know, patient voices are supposed to be driving health care

> more and more, we're supposed to be patient-centered, and patient centric and I think we're only going to get that way through teaching our, you know, building our workforce and teaching people to be sensitive to diversity for all cultures and being sensitive to that. (Joy)

Joy communicated the need for dementia screening tools to be culturally specific and sensitive to the Aboriginal population. She was not aware of any initiatives regarding culturally specific tools being developed for the Aboriginal population in the north. "I think that tools and screens and all that have to be culturally sensitive and appropriate. And to my knowledge I don't think we have any of that".

4.10 Hoping for a Bright Future

4.10.1 The Future of Community Care Services

Participants were asked what they would like to see in the future in terms of shaping community care services in rural and remote northern communities. Care providers noted that there needs to be a flexible network of services that can be moulded to the diverse and dynamic northern population, thereby meeting their needs and keeping seniors in their home for as long as possible. Participants also voiced that the need for community care services will substantially increase as the baby boomer population ages. Care providers realized that the care needs of the senior rests squarely on the shoulders of families and caregivers first and that the system needs to have a framework to help support them and to provide the services that they require to stay at home, thereby refraining from overwhelming the healthcare system.

> But I think a really well developed basket of flexible services to keep people at home... the community support services are really the answer. I mean for a long time, we've known that the answer isn't always the hospital to meet healthcare needs but what we haven't had is the community services in place to really fill the void. I think we've come

> a long way in the last few years but we've got a much longer way to go yet especially as you mentioned, on the horizon, we know there's going to be a lot more people needing that kind of support. (Charlene)

> Well I sure would like us to be able to meet the growing need of families. I think, in terms of the future, I think there's going to be a growing demand for services. We've just seen the tip of the iceberg, you know in terms of the ALC situation in hospitals, and waiting lists for LTC and so we know the answer is community. I think more and more, responsibilities are going to rest with family caregivers where they haven't out migrated and so that's going to be part of the expectation. So we have to be prepared to support those family caregivers to continue their role. You know, without family caregivers, the health care system would collapse and so we need to make investments in that area. (Charlene)

Charlene adds that although there have been steps in the right direction to support care at home, much depends on the political agenda and what the government is planning to invest in for the future.

> In the last few years, we've seen significant steps taken and it always saddens me that so much depends on the political agenda and when an election's going to be and when it isn't going to be and what party comes in and so on so that always concerns me. But I mean certainly in the last few years we have seen investments in the community support service sector and that's very, that gives me hope. Has it been enough? No - it hasn't been enough. But it's certainly a step in the right direction. (Charlene)

4.10.2 Working Together- Health Care and Community Care

Participants stated that in rural and remote communities, health care sectors and community care organizations need to work together to best serve the community and that this should be both a present and future initiative for organizations. Responses were split between communities who were doing a good job and partnering with each other and communities who needed a lot of work to achieve a level of collaboration.

Gloria said she felt she was in a silo and did not feel connected to other organizations to build partnerships with and promote the growth of initiatives.

> Also working together because of the over 3 years that I was at the Family Health Team and going to conferences and all these you know, initiatives and team work and everybody working in their silos and that has to stop and that's happening in a lot of areas but in a small town it's still kind of, I don't know, there's still some territorial stuff that I don't understand. I think maybe in a rural, and they always say we're better at it, but, we're better at it when it's convenient for us. So I came to learn that one very quickly whereas I'm more, "Why aren't we all working together here". If you don't know about dementia well then, send them off to someone who does or you know, go and inform yourself. You're one click away from knowing everything you need to know. (Gloria)

> I would say it's frustrating for me and that was one of the reasons why I got out of health care in a small community because we really do need to work together, we need to make a difference, we're all these people have – they can't go bouncing around from one place to the next. Sometimes this is all that they have, you know, so... (Gloria)

4.10.3 Working Together- Success in a Rural Community

There was an overwhelming response by participants in certain communities and sectors that stated that their organizations or sectors are working together with others in the community to form strong partnerships and that they are breaking out of their individual silos. Participants stated that organizations were building partnerships to help share resources and to also educate each other or provide support when needed.

> I know I see it every so often and like the different groups do provide and now it's good because they have that inter-agency group, that, it's a bunch of people from different agencies. We meet every 6 to 8 weeks to talk about local issues and what other programming was going on and usually that's a good place that they'll bring some of this education and you have hats from everywhere. From RCMP, ambulance, like the different organizations, hospital, so it's kind of nice because you get a, you kind of get a whole professional group there and you've got them so that's the time to start educating that kind of stuff. And some of them will bring it to their agency. (Mona)

> Well that's why they call me if something happens over there. We have this relationship that if you know they can call me anytime, if they need a translator they'll call right away. (Avila)

> That's actually how the federation in which our funding comes through our big umbrella to stop the silos, to interact, to work together and even amongst ourselves as well. So we do a lot of inter-agency meetings and mixing it up and sharing information as long as the client is okay with that but it also enables the client to go to what they would call the

> mainstream and not get shut down. They go, "Oh I remember you, you know, I feel comfortable with you", things like that. (Tracy)
>
> I have a wealth of resources at my fingertips, I have a lot of people that I can consult with, case managers, team leaders, geriatric psychiatrists and geriatricians. (Joy)

Promoting 'working together' in a small community was voiced as being a necessity and something that takes a lot of work and dedication. It was noted that this initiative is especially challenging when people in the organizations change and it feels like community care providers have to start all over again building those connections.

> No, we try to promote as much as, it takes a lot of work, it does, and we're still working on it and we'll probably always work on it. It's just because it's just how it works in any place and in any agency. You know, and it depends on the, like if you get a new ED [executive director] and the hospital gets a new CEO and they change things so have you start all over again. So which is good and bad because things work and now, oh you have to go change again. You know, and we work well with the school too so everybody, it's like the whole full circle of the medicine wheel as we call it so from one generation right up until the next. So everybody has a balance and that's what we try to promote and work together. (Tracy)
>
> Yeah, it has to be done because you just can't do it all yourself. There's not enough funding for you to hire staff to do it all. We can kind of use each other. It works to everybody's advantage I think. Trenton's pretty good about that. (Roxanne)
>
> In a timely and accessible way, I think when we work in silos and very separately, that's a waste of time and resources. I think this is a way more collaborative approach and, like I said, I think puts the person in that environment, in that culture, has their finger on the pulse of what's going on and I think when we have roots on the ground like that, I think people are way more responsive and visible, accessible- you know I think it promotes honest communication. You are able to test out ideas and all kinds of things that leads to a lot of good stuff. (Joy)

There was also a large response by participants regarding Aboriginal organizations working together with the health care system and with the community care sector to blend Aboriginal culture and traditions into health and health care initiatives in rural and remote communities.

> We have open sweats and then we have closed sweats so for instance, if you've never been to a sweat, you can contact the Friendship Centre and usually Avila puts on the sweats and before you get to go to the sweat she will go through the steps of what it is and you would have to tell why do you want to know, is it just off the cuff, or is it just because or whatever, you would just have to say why you would need it, because it's very sacred ceremony. We've gone in, we've done drumming, we've done openings with just our drumming and that so like whatever they need and they ask for it we'll go in and do that and vice versa, if they find out things, we'll go in there and because we have health fairs where we all connect and work together and things like that. (Tracy)

> Yeah, I think our hospital has come a long way in a short time and does really well in that regard. But it's like I say, the locums, the individuals, I think the organization as a whole does well having Cheryl and her program and they really do try to make, I guess extend the olive branch... (Gloria)

4.10.4 Working Together- The Alzheimer's Society

Participants had overwhelming positive experiences working with the Alzheimer Society. Care providers stated that they believed that the Alzheimer Society was doing an excellent job reaching out into the communities and providing supports and services such as setting up presentations and information sessions. The utilization of teleconferencing and providing support to the caregivers was a welcome experience and was mentioned by several participants.

> Well, I can't think of anything that they could try to do more of – my experience with the Alzheimer's Society was super positive. They wanted to do absolutely everything from setting up a lap top to Skyping with a social worker if somebody needed to, you know, having all these fabulous ideas that went nowhere because the infrastructure's not there, like the connections aren't there. (Gloria)

> Well, what I've seen they've been doing very well because they come up here every, you know they do a lot of programs, or they're trying to get seniors out so there's lots of advertisements and you know little workshops here and there that for promotion so it's getting more and more well aware out there and because it's so new right now, like people are accepting and not saying that Alzheimer's hasn't been here all these years – but it's getting more acceptable so it's a lot easier for people to say, "Oh yeah, I'm going to go to that presentation", you know, not saying I have it or you have it, I want to learn that. (Tracy)

> I think that the Alzheimer Society right now is taking steps to expand their support groups, right – their doing teleconferencing or whatever they're doing to hold these groups in the different communities. (Roxanne)

4.10.5 Working Together- Aboriginal Specific Health Care/Community Care Services

Participants voiced how wonderful it was to have local Aboriginal based health care and community care services either in their home community or nearby. Centres were said to provide excellent local services to Aboriginal seniors in the communities where they existed.

> There is we... they have a wonderful Eagle Friendship Centre here – part of the Indian Federation of Friendship Centres – they are fabulous. They have wonderful programs , they have a couple of senior's programs and then in Cedar Falls, so that's locally here in Trenton, Cedar Falls they have Dearhurst Family Services and they do a lot of community care and they have a lot, a lot of cases there... (Gloria)
>
> ...but her program translates, goes and meets with them, will assist them with services or whatever they need, there's a palliative elder, then they will make special considerations like smudging and things like that. She's implemented a lot of good cultural policies – culturally appropriate right in the hospital. (Gloria)
>
> I do have a few and they will call and the Indian Friendship Centre is a good support for the Aboriginals and Traci is the care and she goes and sees them and helps them with appointments, making sure their medications are filled, stuff like that. And then if they, if she's notices that they're deteriorating and they're needing more help then she involves me so we'll go together because they already know her and trust her and then brings me in and we start talking about services so I do have a few that will accept help here. (Mona)
>
> I know with the Indian Friendship Centre they have every Thursday they do day programming, and they do all kinds of cultural stuff there. She does meals and tries to accommodate what they do, you know, like the bannock and all that stuff. So they live in Trenton, she will come, they'll pick them up and bring them to that day program. So they do the social thing and provide lunch and activities so it's good. (Mona)

Gloria noted that one of the excellent features of the Friendship Centres and Health Centres that are designed especially for Aboriginal people is the fact that services and supports are provided and designed by an Aboriginal staff.

> I think community care is really fortunate that it's a lot of these Aboriginal organizations, with Aboriginal staff doing the home care and community care and running the programs. But certainly in the regular everyday health care, there would be a lack of cultural competency. (Gloria)

4.10.6 Future Initiatives in Rural Dementia Care

Future health care and community care initiatives in the north were explained by participants as becoming more patient-centered and client-focused.

> There are some pieces of legislation that are also driving the changes for much more client focus, patient- centered, and because of that, we're trying to address client needs better I think and so we want to be accessible to LTC. (Joy)

Utilizing Telehealth to a greater degree as well as in different forms was also described by participants. Joy stated that the use of medical transcribers, that are being educated in the north, are being utilized to help bridge the gap between health care providers, community care providers, and the Aboriginal population, when it comes to language and medical terminology.

> I think Telehealth could be used a lot more for just teaching and mentoring and coaching and education. I think a lot more can be done that way because we have a lot of isolated communities and you know, I think that people who move to city centres, they will access services more readily because they're in need but I think there's a lot more outreach that could be done, in terms of sustaining health and keeping people healthy for a lot longer... I think just this past spring in Bruce Mines I went to provide something called Gentle Persuasive Approaches to the first class of the medical interpreters that were graduating from the college there. So these people were being trained to interpret healthcare dialogue and discussion, appropriate to Oji-Cree, Ojibway dialects. So that's exciting and I know, I think we're building some innovative health care and that's certainly a good example of that. And you mentioned the First Link, so it's those kind of innovations, I think… you know with Telehealth or telemedicine, I think all of those things are worthwhile. And strategically how they're going to locate them, six of them in hospital and the other people were dedicated to other areas. And I think some reserves with health centres and other folks were going to go back to serve in their communities so those are the kinds of things I think that will be the transformers in healthcare. (Joy)

Finally, participants strongly recommended that, going forward, the Aboriginal community needs to be involved and engaged in planning and facilitating services to their seniors. Towards the end of my interview with Joy she explained her thoughts of what she would like to see for the future regarding services and supports for Aboriginal seniors with dementia in rural and remote communities.

> I think there has to be a lot of engagement along the way and I think that they have to be the drivers of it. Their leaders from a standpoint of communities and tell us what they need so I think there has to be a lot, a lot of engagement throughout the entire process and, like I said, I think some reserves vary in terms of their health and the structure of the community, the health, the vibrancy and commitment to making some of those changes. So it will have to be on a very individual, highly engaged basis that we have to try to help these people and I know that they have an aging population and so the incidents of dementia… and certainly they have a lot of cardiovascular risk factors and diabetes so there's, like I said, there's a lot of work to be done. I think that there's a lot of potential for collaboration so I'm hopeful that studies like yours will be the precursor or lead into some of that… because it's woefully needed, yeah. (Joy)

Utilization of culturally sensitive and appropriate resource tools, supports and services, as well as engaging and involving the Aboriginal community in developing, planning and implementing dementia services to rural and remote communities, will help to foster the beginning of a relationship between community care, Aboriginal seniors and their family. Participants in this study sought a model of dementia resources and support where care is more person-centered by combining the holistic care model with the westernized view of medicine and services to best suit the individual and their respective community.

Chapter Five: Discussion and Implications

5.1 Introduction

The purpose of this study was to explore the experiences of community care providers' perceptions of dementia in Aboriginal seniors that lived in rural and remote communities in northern Ontario. The study focused on the following overarching questions: 1) What types of services and interactions do community care providers in rural northern Ontario provide to persons with dementia and their family members?; 2) What are the experiences of community care providers who work with Aboriginal seniors with dementia?; 3) What are the needs of community care providers who work with Aboriginal seniors with dementia in rural northwestern Ontario?; 4) What are the challenges faced by community care providers working with Aboriginal seniors with dementias in rural northwestern Ontario?; 5) What types of services and/or supports are needed for community care workers to better care for Aboriginal people with dementia in rural northwestern Ontario?; 6) What are the perceptions of community care providers of the needs and issues surrounding dementia in Aboriginal communities in rural northwestern Ontario?

The findings of this study mirror the results of the limited current studies regarding dementia in Aboriginal seniors (Alzheimer's Australia, 2006; Cammer, 2006; Lanting et al., 2011; Morgan et al., 2009; Smith et al., 2011). Much of the current literature on dementia in Aboriginal people has occurred in northern Saskatchewan and in Australia over the past five years. Smith et al. (2011), in their study regarding dementia in the Torres Strait Islander population of Australia, stated "Many issues described are not unique to Indigenous Australians and have been documented for other Indigenous populations and rural communities" (p.11). In light of the findings of this study I believe that these issues are not unique to Aboriginal Canadians in rural northern Ontario, and, therefore, we can learn from research that has been conducted in other countries.

The discussion is divided into three main sections which include: Medicalization of Dementia, Providing Necessary Supports and Services, and Communication and Coordination. Finally, an overview of Implications for Future Research and Study Limitations will be presented.

5.2 Cultural Sensitivity and the Medicalization of Dementia

A key issue that my study raised was the view of the medicalization of dementia and dementia care in the Aboriginal population. Medicalization is "defining behaviour as a medical problem and mandating the medical profession to provide some form of treatment for it" (Bond, 1992, p.399). The biomedical model "sees dementia mostly as a neuropathology" (Power, 2010, p.77). Iliffe and Manthorpe coined the term the 'Alzheimerization' of old age to describe the medicalization of dementia in the western world (2004, p.103). Bond (1992) stated that science and medicine have provided us with a limited understanding to the cause or causes of dementia let alone the variation of the disease between individuals. Bond (1992) also stressed that dementia is socially constructed with blurred guidelines between a normal aging brain and an abnormally aging brain. "In the absence of specific biological markers, the accurate identification of early stage dementia is complex and problematic" (Milne, 2010, p.69). In my study, some participants voiced the concern that Aboriginal families and seniors are not seeking medical care during the early stages of dementia to receive care and supports. Some also noted that most seniors and family members reach out for help in the end stages of the disease when medical intervention can do little to help the disease. Is it right for the health care and community care sectors to push the medicalization of dementia and the use of drugs in the early stages of the disease onto the Aboriginal population? Should the biomedical view of westernized medicine be projected as the "correct way" to help Aboriginal seniors with dementia? I believe, going forward from this study, that health and community care sectors need to closely look at whether essentially pushing these views of dementia onto a culture that believes in holistic care and the medicine wheel may have dire consequences for future relations (Hansen, Hughes, Routley & Robinson, 2008). Bond (1992) stated that one of the first steps to demedicalizing dementia is to "understand the social context as well as the clinical uncertainty of the illness trajectory of dementia" (1992, p.401). The Aboriginal culture has already experienced many historical breaches of cultural ways and identity as discussed in the literature review, such as loss of land and residential school experiences. Is it the right thing to do to base the dementia care platform on the westernized biomedical model of care and further feed the disconnect between them?

One participant noted that the health sector must be careful in pushing pills, thereby trying to get the Aboriginal population to submit to the biomedical model of care and the "individualization of behaviour" (Bond, 1992, p.400). The participant went on to state that she had experienced physicians getting upset in the appointments with the seniors and the family when they did not want to follow the 'prescribed treatment plan'. There is a need to respect people's choices and their rights to their own beliefs when reflecting back on preserving personhood in dementia care. According to Whitehouse (2008), although current drugs available for Alzheimer's disease have shown some improvements in cognitive function in some people with dementia, the drugs do not work for everyone, especially in the later stages of the disease, and they may also have a range of side effects. Other risks of prescribing drugs for seniors include the risk of polypharmacy and negative drug reactions as well as the placebo effect where the patient will not come off the drug as they may fear they will get worse without it (Whitehouse, 2008). Therefore, an intertwining of biomedical and holistic services should be used to conceptualize a program of care for Aboriginal seniors that encompasses their traditions and their beliefs (Jervais, Jackson & Manson, 2002). Cultural priorities could focus on sustaining the person's dignity and integrity while empowering the individual and their caregivers to seek a care path that aligns with their world views (Jervais et al., 2002; Whitehouse, 2008).

Whitehouse (2008) stated that health care for aging clients should be focusing on depathologizing dementia and looking into ways of supporting a person with dementia through the journey of aging instead of labelling them as having Alzheimer's disease. He goes one step further stating that AD is a myth and that the symptoms of AD are just the natural effects of the aging brain from a combination of genetic, environmental and behavioural factors (Whitehouse, 2008). Whitehouse (2008) stated that labelling a person with dementia is detrimental to their psychological and social well-being and the fear of the disease along with the notion that there is "no cure" is a large burden on aging people with dementia. This topic of the direct negative effects of diagnosing dementia was not covered in depth by any of the participants in my study, however, some participants noted that the stigma of the diagnosis could be a reason why diagnosis was not sought. There is also the fact that early diagnosis may lengthen the period of illness and impair the quality of life of the individual and the carers than if they were diagnosed later on in the aging process (Iliffe &Manthorpe, 2004). In light of these opinions, one might wonder whether a diagnosis of dementia is beneficial.

Study participants noted that this logic of AD being a myth or non-existent in Aboriginal culture was voiced by all participants. Participants noted that the majority of Aboriginal people that they have been in contact with, believed that cognitive changes are a result of old age and were not willing to 'label' Alzheimer's as a single disease entity. In Cree, there is no word for the disease 'dementia' (Lanting et al., 2011). "By making the choice not to allow yourself (or your loved one) to be brought into the medicalized myth of AD you can preserve your humanity, age with greater dignity, and add quality to your later years (Whitehouse, 2008, p.19). This raised the notion of what if the health care community explained the aging brain as a "change in self" rather than labelling it as Alzheimer's disease? (Whitehouse, 2008, p.25). Does diagnosing and medicating a person with the signs of Alzheimer's disease create a negative personhood and a "perceived loss of self"? (Whitehouse, 2008, p.25). In essence, who are we to force the medicalization of variable aging of the human brain onto the Aboriginal culture if they seem unwilling to participate? I wonder whether labeling cognitive decline in Aboriginal seniors will actually help them to seek supports and services that we "feel" are a necessity for seniors and their caregivers with dementia. Taking a step back and looking at brain aging, personhood and culture, in a holistic sense, seems like it may be a good place to start. The uniqueness of the aging brain and dementia is summed up nicely by Whitehouse who states " Once you've seen one person with Alzheimer's, you've seen one patient with Alzheimer's (2008, p.76).

The medicalization of dementia sets limitations of viewing the socio-cultural context as well as the personhood of the individual (Nygård, 2006; O'Connor, Phinney & Hulko, 2010; Pratt & Wilkinson, 2003). O'Connor et al. stated that Aboriginal people can look at dementia through a cultural lens and not see it as the beginning of cognitive decline but as "growth and connection" instead of part of an illness category (2010, p.37).

The above issue of the medicalization of aging and trying to introduce or impose a medicalized framework of dementia care, or "medical intrusion", along with related supports and services onto the Aboriginal population, was debated (Milne, 2010, p.73). In Canada, there is a very low reported prevalence of AD in the Aboriginal population which leads to either poor detection or a truly lower prevalence of the disease compared to the rest of Canadians (Lanting et al., 2011; Morgan et al., 2009). First, should we even be, in essence, advocating for supports and services for Aboriginal people and their caregivers when these services may look far different than what they may need or even want? This research found that, at least in some communities, Aboriginal organizations along with other local community care organizations, provided some services and supports to Aboriginal seniors and their caregivers but the population were not seeking and utilizing these services. Does this mean that they do not want the help or are they not aware that these services and supports exist? Participants, both from Aboriginal and non-Aboriginal organizations, were unsure why this uptake was so minimal and they were also unsure at times how to inform and attract the Aboriginal population to utilize their services. However, the analysis of the study data suggests some possible reasons for minimal use of these services which include: differing views of health and dementia care; the stigma associated with dementia; communication challenges; transportation issues, etc...

One question that can be discussed is whether changing the current biomedical template of dementia services and supports to reflect a more holistic culturally sensitive type of model would help to better serve the Aboriginal population. "The development and provision of care for elderly Aboriginal people should reflect their holistic needs, including their spiritual, emotional, cultural, physical and mental wellbeing" (Smith et al., 2011, p.2). Would a different take on current services available in the north serve the residents more effectively, along with, help to attract the population to seek these new supports and services? The uptake of the First Nation First Link program, after the reorganization and implementation of this initiative, grew substantially. Facilitators believed this uptake increased due to a combination of cultural traditions, views and lifeways into the dementia support and services in the First Link model (The Canadian Press, 2010). A possibility would be to make these types of services available nation-wide and provide a framework for this program by researching and involving the Aboriginal population in the north to participate in the design and utilization of these supports and services. The Aboriginal people would be the 'drivers' in this type of community framework. Alzheimer's Australia (2006) believes that by developing culturally sensitive and appropriate assessment tools for dementia in Aboriginal and Torres Strait Islander people, in both rural and urban communities, is a first step to reaching out to the Aboriginal population. Alzheimer's Australia (2006) is currently designing and implementing the Kimberley Indigenous Cognitive Assessment project (KICA) to help Aboriginal people and their families with diagnosis, referral and treatment of Aboriginal people with dementia. The project focused on reaching Aboriginal clients in the early stages of dementia to offer supports and services, ensure services are tailored to individual needs, develop referral pathways and provide a range of in-home care options for the Aboriginal community (Alzheimer's Australia, 2006). The use of these tailored services and supports were all suggested by the participants in my study as well to reach out to Aboriginal residents in the north.

Another important concept during the research study was the need for cultural awareness and sensitivity education for community care providers in rural and remote communities. The research reflected the current literature on dementia in Aboriginal seniors by stating that Aboriginal people need to feel welcome and understood in the health system and that care providers who are sensitive and respective to their culture and lifeways is an important part of the process. It is important that the community care workforce is trained and skilled in cultural awareness and sensitive of the Aboriginal population (Alzheimer's Australia, 2006). There needs to be "a concentrated emphasis on strengthening and bolstering the participation of the Aboriginal aged care workforce in the rapidly increasing field of Dementia within Aboriginal Communities of both urban and regional / remote Aboriginal communities..." (Alzheimer's Australia, 2006, p.35).

Rosenberg et al. (2009) exemplified many aspects of Aboriginal views of Western medicine and how these views could act as barriers to receiving a medical diagnosis, and subsequent supports and services.

> The 'colonial presence' of non-Aboriginal people in Canada, the power of non-Aboriginal physicians and the power structures inherent in Western medicine all act as barriers to effective formal treatment. Traditional healing methods using nature as a base frequently conflict with the 'culture of colonization' associated with a medical system that uses complicated machines and advanced artificial treatments. By excluding the worldviews of Aboriginal Peoples, Western medical practices are often viewed by Aboriginal Peoples as dehumanizing as they separate Older Aboriginal Peoples from their communities and involve an individual-style decision making that can run contrary to traditional Aboriginal belief systems. These anxieties can be particularly amplified amongst Older Aboriginal Peoples due to the higher rates of those who are monolingual Aboriginal language-speaking and stronger attachments to traditional Aboriginal views on health and healing. (p.17)

Building on the view of the medicalization of dementia, participants noted that many Aboriginal seniors and families were not stepping forth to seek help and support with dementia or cognitive impairment for the fear of being placed into a long-term setting and taken away from their family and friends. Participants stated that seniors felt that long-term care was an extreme last resort when the family could not cope anymore in looking after the senior. Smith et al. (2011) noted that long-term care was recognized as a last resort because community members viewed it as "a place where people are sent to die" (p.6). This fear of institutionalization emerged as a prominent concern by community care providers as to why seniors and their families were not seeking help earlier in the course of the disease. The fear of institutionalization by seniors and their families may also lie within the socio-political past including residential schools, the implementation of reserves and the Indian Act.

> The generation of Aboriginal Older Adults currently at greatest risk of dementia is also the generation that experienced residential schools, limited freedoms and virtual imprisonment on reserves, and attempts at cultural assimilation. For people who have experienced these oppressions, distrust of Western healthcare systems is not an unrealistic or pessimistic outlook. Fears of being moved from family and friends to be placed in a nursing home take on a heightened meaning as this may have been experienced earlier in life or experienced when children were taken. (Cammer, 2006, p.78-79)

Rosenberg et al. (2009) stated that another reason why Aboriginal seniors would have to leave their community in rural and remote locations is the lack of trained or available homecare and community care workers, therefore, forcing families to look outside the community for resources. The research supported this fact since all communities faced a lack of health care workers and had trouble retaining these workers due to geographical isolation, lack of other available jobs for the worker's spouse and/or family and the out-migration of young people to pursue an education or find alternative work. Jervais et al. (2002) study of American Indian communities found that most care for seniors with dementia was provided by the close or extended family on an unpaid basis, which supports the findings of this study. Jervais et al. (2002) continued stating that although many families are still able to care for the senior, there are currently " several trends, including increasing life spans, smaller families, and the geographic dispersion of potential family caregivers that may decrease the likelihood of an older person obtaining adequate support from family alone" (p.298).

Jervais et al.'s (2002) study found that,

> Families, though, may at times find themselves unable to function as primary caregivers due to competing family and/or work responsibilities. This no doubt puts them in a bind, given the cultural obligation that many Natives feel to take care of older family members. This is likely worsened by families' awareness that there may not, in fact, be any acceptable alternatives to informal caregiving. (p.308)

The respondents all stressed the importance that dementia initiatives as well as supports and services need to be available in smaller rural and remote communities. Teel (2004) mirrored this finding by stating that it is important that the senior with dementia should be able to stay in their home community and have access to early diagnosis if desired, if at possible, as it has benefits to their memory and overall general health and wellbeing.

Lanting et al. (2011) stated that appropriate supports and services need to be available to caregivers early in the disease process to reduce caregiver's and family member's stress levels and reduce the stress experience by the carers. If treatment, planning and the decision making process are initiated early in the disease progression, then quality of life for both the person with dementia, carer and/or family can be heightened (Lanting et al., 2011). A direct result of intervening early in the process and providing support in the community setting is decreasing the overall cost to the health care system and preventing many people from having to resort to long-term care at all or at least for a shorter period of time (Cammer, 2006; Lanting et al, 2011).

The recommendations that came out of the findings of my study was the need for educational initiatives and community awareness and prevention programs for care providers and for the Aboriginal population, focusing on dementia (Alzheimer's Australia, 2006). Alzheimer's

Australia (2006) recommended that Aboriginal people and caregivers have easy access to education and training in dementia awareness and that non-Aboriginal people have access to cultural awareness workshops promoted by their workplace, thereby promoting cultural safety (Innes, 2001). In all of the communities, education was seen as a crucial need for workers to become more aware of the signs and symptoms of dementia as well as the care and support needs for people who have dementia. Some participants noted that the health care sector does not receive enough education during their programs of study in college and university regarding dementia and that these curriculums need to be altered in the future to include dementia and dementia care, especially since rural and remote populations are aging quickly (ASC, 2010). One participant continued to reflect the greater need for professionals trained in dementia and dementia care as the population ages and to have these specialists available in a timely manner to rural and remote communities in the north. Smith et al. (2011) also stated that the community, caregivers and staff should also be trained in elder abuse.

There is a tension between the medicalization of dementia and the current research and literature calling for the Aboriginal population to have access to education surrounding recognizing dementia and caring for someone who has dementia. This study's findings supported previous studies which found that a large portion of the Aboriginal population, along with some health providers, still view dementia as a normal part of the aging process (Cammer, 2006; Morgan et al., 2009). If families and seniors were aware of the signs and symptoms of the disease earlier, they may have the capacity to seek help earlier before the situation went into a crisis mode. This education may be even more important as the Aboriginal population is starting to have a longer life expectancy, closer to the Canadian average than in previous generations. "Given that formal healthcare services in isolated communities are already limited, difficulties in terms of quality and access are likely to only get worse as the number of Older Aboriginal Peoples living in these communities continues to increase" (Rosenberg et al., 2009, p.17). The increase of ageing in the population contributes to one of the largest risk factors of developing dementia (ADI, 2010). Community care providers in this study expressed that education could help to alleviate the caregiver burnout that occurred when families waited until later on in the disease course to seek help. Although this study supported previous research that recommended education and early diagnosis, it goes against other current studies that suggest early diagnosis could have ill effect such as prolonging the disease period, stigma as well as physiological and socio-cultural ramifications for the person with dementia, family and caregivers (Milne, 2010; O'Connor, Phinney & Hulko, 2010). Still, ensuring that people with dementia and caregivers are able to plan, access and receive services is important. It is also important that awareness and education are part of that cohesive process, however, it is crucial not to overstep boundaries and force the medicalization of dementia onto the Aboriginal population. This contemplation sets a tricky balancing point for communities when trying to support the Aboriginal population while still providing culturally sensitive and appropriate care.

5.2.2 Providing Necessary Supports and Services

All the respondents reported the need for more dementia supports and services within their respective communities for both Aboriginal and non-Aboriginal seniors, not only with dementia, but also in general. Community care providers stated that having these services in place and connecting with the individuals and their families early in the disease process could help to prevent crisis and caregiver burnout later on. The lack of supports and services found in the three rural northern communities included transportation services for seniors, supportive housing and seniors apartments, support groups, day programming, homecare, and respite care which is supported by relevant literature (Cammer, 2006; Jervais et al., 2002; Lanting et al., 2011). Jervais et al. (2002) noted that these problems are often exaggerated by poverty, rurality, and culture in American Indians. This lack of services was found for the entire senior population in the host communities studied and not just for Aboriginal residents. A few participants noted that there seemed to be more services available to the Aboriginal senior population compared to the non-Aboriginal population, however, this finding was not supported in the current literature on the topic (Alzheimer's Australia, 2006; Cammer, 2006; Morgan et al., 2009; Smith et al., 2011).

Alzheimer's Australia (2006, p. 7-8) stated that the following Action Points should be implemented to help Aboriginal people and their caregivers regarding dementia supports and services.

- Adopt person centred care approaches.
- Implement service standards through accreditation to meet the needs of Aboriginal and Torres Strait Islander people with dementia.
- Develop cultural protocols for implementation across service settings including hospital, primary healthcare, outpatients, emergency, geriatric, psychiatric and drug and alcohol relief.
- Develop strategies to better support carers who support people at home, in acute care and other service settings as well as for those who live alone and cannot access respite care.

- Where possible implement innovative solutions to improve accessibility to services. These innovations may include mobile services (a travelling information bus), delivering health messages to people living in rural and remote locations (computer animation); and activities that support localised action (carers support meetings).
- Ensure culturally appropriate information, advice and counselling services for Aboriginal and Torres Strait Islander people with dementia and those who care for them.

5.2.3 Communication and Coordination

Participants stated that it is crucial for health organizations, care workers and the community to work together to best serve Aboriginal seniors and their caregivers in rural and remote communities. Working together, which includes communication and cooperation between agencies, services and the community as an initial step is supported by the literature (Jeffery, Abonyi, Labonte & Duncan, 2006). Smith et al. (2011) stated that if services and agencies work separately, it will result in unnecessary duplication of services, gaps in services, poor case management and decreased positive patient outcomes. My study found that distance between organizations and services in rural and remote communities was one cause why community care providers sometimes felt like they were in a 'silo'. This finding is supported by Alzheimer's Australia's 2006 national study as well as by Smith et al. (2011) which stated that communication and cooperation can be hindered by distance as well as inflexible care options and support models. It is important that there is regular communication among services and organizations as well as between services, supports and the community.

In Australia, Smith et al. (2011) found that Aboriginal community members were often unaware of what types of services and supports were available to them, how to access these types of services or how to follow up with care services that were referred to them at a health centre or community organization. Respondents of the research posit that some reasons why Aboriginal people were not aware of services available in northwestern Ontario could be related to a lack of education regarding dementia and the fact that many Aboriginals see cognitive impairment as a normal part of aging. Additionally, language barriers and the fear that seniors may have of being taken out of the community and placed into long-term care were suggested as other contributing factors.

The views of participants in my study agreed with the current literature that dementia supports and services for Aboriginal seniors must be driven by the community and involve Aboriginal people in the planning, design and implementation of dementia supports and services (Alzheimer's Australia, 2006; Jeffery et al., 2006; Lanting et al., 2011; Morgan et al., 2009; Smith et al., 2011). Smith et al. (2011) suggested that having a community-based dementia advocate that is trusted and easily accessible to help seniors and families navigate through the system and connect them with services, would be beneficial. The research reflects the need to train Aboriginal staff in the community, which is supported in the literature, to promote cultural sensitivity and safety along with utilization of traditional healers. Smith et al. (2011) study found that employing trained Aboriginal staff in the community was found to be the best way to improve dementia care and support for Aboriginal seniors and their families. Alzheimer's Australia (2006) also recommended that best practice care models be incorporated into all settings and be flexible and adaptable to local and regional needs of Aboriginal seniors and their caregivers.

5.3 Implications for Future Research

This study was one of the first in northwestern Ontario to look specifically at community care providers' perceptions of dementia and dementia care for Aboriginal seniors, focusing on northern rural and remote communities. The goal of this project was to lay a foundation for further research with community care providers, health care providers, caregivers and Aboriginal seniors with dementia to develop the capacity to be able to deliver well designed and implemented services and supports for the Aboriginal population in the north. As such, further research is a necessity in the north due to the lack of data and knowledge of dementia in Aboriginal populations, not only in northern Ontario, but across Canada and even worldwide. The only study, to my knowledge, being conducted on rural and remote Aboriginal seniors is occurring through the Northern Ontario School of Medicine by Dr. Kristen Jacklin. Dr. Jacklin is focusing on the caregiver and Aboriginal seniors' perceptions of dementia in the Aboriginal population in both rural and urban settings (Jacklin, 2010). Both studies will lay a starting foundation for future research and what steps should be taken by the health and community sectors in Canada.

This study should guide future research in the north to expand the limited knowledge of dementia in the Aboriginal population and what their needs are regarding supports and services, and how best to meet those needs. Research should be conducted on a larger scale that this study was not able to fulfill due to funding constraints. Interviews with community care and health care providers should simultaneously be conducted to obtain more information on what supports and services are most needed in northern communities and how these services can be delivered in a culturally sensitive and effective way (Innes, 2001; Innes, Blackstock, Mason, Smith & Cox, 2005). This foundational research needs to be completed first since there is a lack of data on the Aboriginal population and dementia, as proven with the limited amount of current studies available in the literature review conducted for this study (Alzheimer's Australia, 2006; Cammer, 2006; Lanting et al., 2011; Morgan et al., 2009; Smith et al., 2011).

Further research should be conducted with Aboriginal seniors and their caregivers following the completion of Dr. Jacklin's study (Jacklin, 2010). This first hand information of what the seniors and caregivers need will help to steer what services are available, what supports are needed and how to tailor services for Aboriginal people. Since my study recognized that, in some northern communities, there are services that are available that are not being utilized, the research community needs to analyze why this phenomenon is happening. Future research initiatives should explore how to access these populations to help provide these supports and services effectively and in a timely fashion. Prevention initiatives should also be explored such as identifying modifiable risk factors for dementia as well as to determine and track the prevalence of dementia in the Canadian Aboriginal population. It is vital to incorporate Aboriginal people in all levels of planning, designing and implementing of dementia services and to hear first-hand what they believe they need to care for a senior with dementia in rural and remote communities (University of Alberta, 2010).

Morgan (2007, p.1) suggested that dementia services can be improved for Aboriginal seniors by:

- Improving the *availability* of specialized personnel and services for assessment and management of dementia
- Enhance the *accessibility* of programs supporting formal and informal caregivers of persons with dementia
- Improving the *acceptability* of services for persons with dementia and their caregivers

Future research studies should look into ways that community care and health care organizations in the north can work together and avoid the "silo" effect. Working in a collaborative fashion ends the duplication of services and supports, enables person-centered care, promotes change and decreases the drain on resources in the communities (Cammer, 2006). Since this research found that there is a lack of dementia supports and services in rural and remote communities, it is crucial to find ways for organizations to collaborate and share knowledge and strategies together. Health and community care centres that are on the forefront of collaboration, such as the Memory Clinic in Saskatchewan, should be used as working examples of how to provide these supports and services (Cammer, 2006; Morgan et al., 2009). This sharing of knowledge across organizations would hopefully help to increase the quality of care and services for Aboriginal seniors who have dementia.

From an educational perspective, research should also focus on what educational initiatives are needed to train community care and health care staff on dementia and cultural sensitivity. The research found a large requirement for education of health providers on dementia in rural and remote communities and also recognized the problematic issue of delivering this education over such a vast geographical area. Studies should look at ways of delivering this education to health care providers in a way that could reach a large audience, be cost effective, as well as fit the lifestyle of providers from rural communities. Educational initiatives should take into account such issues as health care retention and understaffing in small communities. Alzheimer's Australia (2006) suggested that future research should focus on examining the benefits of having an increased Aboriginal workforce in dementia care as well as focus on determining the effects of culturally adapted cognitive screening tools. Finally, Alzheimer's Australia (2006) also suggested the need to develop a link and open dialogue between national and international literature and researchers to strengthen the knowledge on dementia in indigenous populations around the world.

5.4 Study Limitations

Although this study was conducted using qualitative research that was appropriate for the objectives of this study, there were possible limitations to the study as to how it was designed and implemented.

It is possible that the lack of complete anonymity may have caused some participants not to share their true thoughts on the study questions. Although all identifying information was removed from the interviews, there may still be a concern by participants that certain experiences or information may allow the reader to identify the interviewees, especially since research was undertaken in small communities where everyone seems to know everyone else. Since the study was conducted in three small rural northern communities, I ran the risk of participants feeling that sharing stories or their personal opinion could cause them to become identifiable, thereby limiting the amount of in-depth information they could share with me. Coming from a small community myself, I am well aware that everyone in a small town knows almost everyone else. This knowledge of people and their experiences could easily run the risk that participants would feel hesitant or even reluctant to share thoughts, feelings and stories. This risk is even more evident when talking negatively about supports, services or organizations in the community. To counteract this possible situation, I had each participant read over the information letter as well as the consent form (see Appendix C and D respectfully). Each participant was made aware that all identifying information would be removed from the interview which included names of people and organizations as well as places. Each participant was assured that if I had any doubts that a quote could identify a participant that I would bring that quote back to the participant to ask permission on whether they felt comfortable enough for me to include it in the report.

Participants may have been reluctant to share their views of the Aboriginal population due to fear of possible stigmatization or cultural insensitivity issues regarding that population, such as a fear of sounding racist or insensitive. Participants were made aware that I was not of Aboriginal descent and this factor may have been a limitation in recovering interview data. Aboriginal or non-Aboriginal participants may have felt guarded to share information because I was not of Aboriginal descent or vice versa. Also, this research study focused only on community care providers' perspectives and not from the aboriginal communities first hand perspectives of dementia in rural settings.

Data quality could have been affected due to the lack of experience that I, as a graduate student, have at conducting qualitative interviews. Although I have worked on conducting interviews with caregivers, health care providers and community care providers for over two years, I have a lot of knowledge to gain and techniques to master in the qualitative interview and coding process. I may have made errors in probing or guiding participant questions or missed windows of opportunity to engage the participants more on certain subjects. These types of interviewing techniques take time and practice and, therefore, could have hindered the quality of data obtained from the participants interviewed as well as how the study data was conveyed in the write-up of the findings.

Finally, the number of participants that I interviewed for this report could have been higher even though I felt that data saturation was achieved. There is always the chance that I may have missed acquiring different opinions or stories regarding the perceptions of community care providers.

5.5 Final Reflections

The qualitative research approach that was used in this study gained insight into the perspectives of community care providers' perceptions of dementia in Aboriginal seniors in rural and remote communities in northern Ontario. This study sought to understand the experiences and needs of community care providers working directly with Aboriginal seniors in these communities. This research also brought to light the challenges these providers faced in delivering care along with what supports and services they believed that rural and remote communities need to facilitate dementia care best practices to Aboriginal seniors and their families.

This research was conducted to provide baseline data on dementia research and Aboriginal seniors in northwestern Ontario. To date, there is a gap in research and literature regarding Aboriginal people and dementia. I believe compiling front line care providers' experiences and needs in this area will help to further inform the district on what supports and services can be offered or changed. This research hopes to start the dialogue to better facilitate continuous and culturally appropriate dementia care for Aboriginal seniors and their caregivers in the north.

This research, through a cultural lens, addressed the importance of the growing concern in the Canadian health care system regarding the rise of dementia cases and the decreased availability of current dementia supports and services. The themes that emerged from this research suggest the need for a re-organization and redefining of dementia services for Aboriginal seniors. Seniors and caregivers need to have the supports available in their community during the early stages of the disease so that the chance of the situation escalating into a crisis may be averted. Dementia services and supports should be tailored to the Aboriginal population to try to reach the 'inaccessible population'.

The results highlight the need for rural and remote communities to build the capacity to have mechanical, social and instrumental supports for people with dementia and their caregivers. Providing continuity of care for Aboriginal seniors, as well as providing an environment of cultural sensitivity, is key to supporting people who have dementia. Finally, the community and health care organizations need to work together to best support and serve seniors who have dementia, their families and their caregivers.

The findings suggest the need for further research that focuses on the Aboriginal population and dementia, not only in rural and remote communities, but across the country. If strategies and programs are not designed and implemented into these communities, as the Canadian population continues to age exponentially, the system, as it stands, will become overwhelmed and reliance on emergency and acute care will soar (ASC, 2010).

> Please learn and understand from us the carers, for one day this could be you, the one with Alzheimer's or the one caring for your loved one; for this disease knows no age, no race and no status. (Faye Kingston in Alzheimer's Australia, 2006, p.53)

By fostering the development of culturally appropriate and timely access to dementia supports and services, Aboriginal seniors will be able to age successfully in their home community by having access to the requirements they need to facilitate living with dementia while holding onto their personhood.

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Appendix A

http://www.comeexplorecanada.com/ontario/regions/northern_ontario/

Appendix B

Amy Gusul
(807)620-1433
argusul@lakeheadu.ca

INFORMATION LETTER FOR PARTICIPANTS

Dear Potential Participant,

The purpose of this letter is to ask you if you would like to participate in a research project I am doing for my master's thesis in the Master of Public Health Program at Lakehead University. The study is titled Community Care Provider's Perceptions of Dementia in Aboriginal Seniors. My goal is to identify the needs and challenges and to explore the experiences of community care providers who treat and care for Aboriginal seniors living with dementia. I am conducting this research to develop a body of knowledge related to dementia and Aboriginal seniors in northwestern Ontario and to start filling the information gap that currently exists in this area. This research is focusing on community care providers who reside in rural northern Ontario in the Thunder Bay district and their perceptions of Alzheimer's disease and related dementia in Aboriginal seniors. This research is funded through the Thunder Bay Alzheimer Society Local Research Grant and through the Ontario Research Coalition Early Researcher Award Program in partnership with Lakehead University's Centre for Education and Research in Aging and Health (CERAH).

Your participation in this project would include sharing your knowledge, thoughts and experiences of dementia in a rural northern community, focusing on Aboriginal seniors. Participation would include an audiotaped interview lasting approximately 30 to 60 minutes. The presentation will occur at a place and at a time that is convenient for you. All information that is gathered for this study will be kept completely confidential and will only be able to be accessed by me and my advisor, Dr. Elaine Wiersma. All audiotapes will be destroyed once the research is completed, and interview transcripts will be kept in a locked filing cabinet at Lakehead University for a minimum of five years.

If you decide to participate in this study, I will be asking you to sign a consent form to participate in the interview. Participation in this study is completely voluntary and you may choose not to participate or you may choose to withdraw from the study at any time. Should you choose to withdraw from the study, any information relating to you will be removed from the analysis. You may decline to answer any of the questions asked during the interview and you may decide not to have the interview audiotaped. It is not anticipated that you will experience physiological or psychological harm related to participation in this study.

This study has been approved by the Research Ethics Board at Lakehead University and can be contacted at (807) 766-7289 or Fax (807) 346-7749 if you have any concerns or comments.

Should you have any questions or concerns about this study please feel free to contact me, Amy Gusul, at (807) 620-1433 or my advisor, Dr. Elaine Wiersma, at (807) 766-7250. A research summary of the findings will be available upon completion of the study in 2011 and will be distributed to all participants.

Thank you very much for your time and interest in this study. I look forward to your potential involvement in this research.

Sincerely,

Amy Gusul

Candidate, Master of Public Health Program
Lakehead University
Thunder Bay, ON

Appendix C

Amy Gusul

(807)620-1433

argusul@lakeheadu.ca

INFORMED CONSENT

I have read the information letter provided by Amy Gusul, Candidate, Master of Public Health (MPH) program, Lakehead University, regarding the study: Community Care Providers' Perceptions of Dementia in Aboriginal Seniors. My consent to participate in this study is made under the following conditions:

1. That I have read and understood the information in the study cover letter.
2. My voluntary involvement includes participating in an interview that will take approximately 30 to 60 minutes and will be scheduled during a time and place that works best for me.
3. My participation is completely voluntary and all data collected will be used solely for research purposes.
   All data will be kept strictly confidential and will only be accessed by the researcher and advisor. Pseudonyms for the community and all participants involved will be used on all documents pertaining to the study and in all oral and written reports of the project. My name will never be used.
4. I may withdraw from the study at any time by simply notifying the researchers or research assistant, and may refuse to answer any questions during the interview or ask to have the tape turned off at any time. All information pertaining to my participation, including audiotapes and interview transcripts, will be destroyed. My withdrawal from the research will have no impact on my experiences and access to present or future services in my community.
5. The research findings will be published for use at professional conferences and a Master's thesis.
6. All data will be securely stored in a locked filing cabinet at Lakehead University for a minimum of five years. Files linking interview transcripts to any identifying information will be kept for five years at which point they will be destroyed. Audio tapes will be kept for five years. Transcripts containing no identifying information will be kept indefinitely in electronic format on a password protected computer for future review/analyses.
7. That there is no anticipated physiological or psychological harm resulting from participation in this study.
8. I will be provided with a research summary of the findings upon completion of the study in 2011.

This study has been approved by the Research Ethics Board at Lakehead University.

I consent to participating in an interview.

Name of participant____

Signature of participant______________________________________

Date (mm/dd/yyyy)____

I consent to having the interview audiotaped.

Name of participant____

Signature of participant______________________________________

Date (mm/dd/yyyy)____

Signature of Researcher_______________________________________

Appendix D

Interview Guide for Community Care Providers Treating and Caring for Aboriginal Seniors Living with Dementia

Experiences of Community:

1) Tell me a little bit about your community. What is it like to live here?
2) How long have you lived in this community?
3) What brought you to this community?
4) What do you like about living here? What are the benefits of living in this community?
5) What are the challenges living and working in a northern rural community?

Professional/Work Experience with Dementia:

6) Can you describe your work and role in this community? Can you tell me a little bit about your organization?
7) What are your experiences working with people with ADRD in this community?
8) What are some of the challenges faced when working with Aboriginal seniors with dementias in the north?
9) How might these challenges differ from those you face in other aspects of your job?

Experiences of Alzheimer's Disease and Related Dementia (ADRD) Regarding Aboriginal Seniors:

10) From your perspective, how would you describe what it is like to live with ADRD in this community?
11) Are there any supports or services that are available for people living with ADRD in the community? Are there any supports or services directed specifically for Aboriginal people living with ADRD?
12) What supports or services are available for people living with ADRD in the community?
13) What supports or services are designed specifically for Aboriginal seniors diagnosed with dementia?
14) What is your perception regarding the experiences of Aboriginal families in trying to access needed supports and services in the community?
15) How can community care workers support self-management of dementia for Aboriginal seniors?

Challenges and Needs of Community Care Providers Caring for Aboriginal Seniors Living with ADRD in the Community:

16) What are some of your organization's needs when working with Aboriginal seniors with dementia in your community?
17) What types of services and/or supports would assist you in better meeting the needs of your Aboriginal clients with dementia? What do you need to do your job well?

18) From your perspective, how would you describe the level of cultural competency among mainstream health and community care providers when dealing with Aboriginal clients in the north?
19) What do you think is needed in the community to address issues around cultural competency, if they exist?
20) Do you think there is a need for cultural training and education initiatives for the community and service providers? If so, how do you think more education will benefit the type and quality of care delivered to Aboriginal people in your community?
21) What types of culturally appropriate tools might help you in your work with Aboriginal seniors with dementia?
22) Are you aware of any research that is directly related to Aboriginal people and ADRD?
23) Do you have anything else you would like to add? Have we covered everything?
24) Do you have any questions for me?