

MEANINGS OF MEMORY: AGING AND DEMENTIA IN MANITOULIN ISLAND FIRST
NATIONS

MEANINGS OF MEMORY: UNDERSTANDING AGING AND DEMENTIA IN FIRST NATIONS
COMMUNITIES ON MANITOULIN ISLAND, ONTARIO

By JESSICA E. PACE, B.A., M.A.

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the
Requirements for the Degree Doctor of Philosophy

McMaster University DOCTOR OF PHILOSOPHY (2013) Hamilton, Ontario (Anthropology)

TITLE: Meanings of Memory: Understanding Aging and Dementia in First Nations Communities on Manitoulin Island, Ontario AUTHOR: Jessica E. Pace, B.A. (University of Waterloo), M.A. (Memorial University) SUPERVISOR: Dr. Wayne Warry NUMBER OF PAGES: xiii, 266

ABSTRACT

This thesis reports results from my PhD research investigating experiences of aging and dementia among First Nations seniors on Manitoulin Island, Ontario. Dementia has been identified as a growing problem in Aboriginal communities by researchers and Aboriginal stakeholders. However, little research has documented First Nations peoples' explanatory models of dementia or aging. In this thesis I explore Manitoulin Island First Nations people's knowledge, attitudes, beliefs and behaviours related to healthy aging and dementia. I present data that documents explanatory models of successful aging and dementia, issues surrounding help-seeking and treatment, and practices relating to care-giving.

This research uses an ethnographic approach following a community-based participatory action research design. In-depth, semi-structured interviews were carried out with seniors, people with dementia, informal family caregivers, health care providers, and traditional healers in seven First Nations communities on Manitoulin Island. Focus groups were carried out with nurses and personal support workers. A total of 59 participants were involved in this research. Participant observation was used to enrich interview data. A hermeneutic phenomenological approach was used to interpret participants' lived experiences of aging and dementia.

This research demonstrates that First Nations seniors strive to remain healthy and engaged in life as they age. However, it also demonstrates that dementia is a growing problem in First Nations communities. Although First Nations people are generally accepting of memory loss in old age as a natural occurrence, a conflicting perception of dementia as pathological was also present. This research demonstrates that changes to culture and ways of life are perceived to have a significant impact on First Nations peoples' ability to age successfully and on the emergence of dementia as a growing health concern. I conclude that improving access to culturally safe supports and services is needed to ensure that people can better cope with the challenges of aging and dementia.

ACKNOWLEDGEMENTS

I would like to extend my heartfelt thanks to the kind and generous people of the seven First Nations communities on Manitoulin Island whom I worked with over the course of this research for welcoming me into their communities and sharing their stories and experiences. I am grateful to each of the participants who invited me into their homes to share their experiences with me. Without those individuals this research would not be possible. To my good friend Mary, thank you for the laughter and the hours and hours of Scrabble. I consider myself so lucky to have met you and learned from you during my time on Manitoulin. Your friendship and generosity made me feel at home.

Thank you to my supervisor, Wayne Warry, for your support and guidance throughout my Ph. D. education. I appreciate the time you put in to read my many drafts and the insightful feedback you provided. To Kristen Jacklin, thank you for all of the work you did in organizing the project, for introducing me to the community and for being a sounding board when I needed a different perspective on the data. I am also grateful to my committee members, Tina Moffatt and Jenny Ploeg for their feedback, guidance and support.

I would also like to extend my appreciation to the other members of our research team. Lisa Boesch and Agnes Kanasawe, thank you for all the behind the scenes work you did to make this project a possibility. A special mention to my research assistant on Manitoulin Island, Karen Pitawanakwat. Karen, I learned so much from you. Thank you for your wonderful work, the many lunches you and your family shared with me, and for your insights to the data. Your enthusiasm and dedication are noticed by everyone around you. To Debbie Selent, I greatly appreciate all the work you put in to organizing interviews for me and your friendship during my stay on Manitoulin. Thanks also to the advisory committee for their feedback and insights.

This project would not have been possible without the generous funding provided to me by the Canadian Institutes of Health Research, the Indigenous Health Research and Development Program, and the McMaster School of Graduate Studies. This project was also made possible by funding from the Alzheimer Society of Canada and the Ontario Mental Health Foundation.

To my wonderful husband, Greg. Thank you for always being by my side through all the ups and downs of life. You are my soul mate. I truly could not have gotten through this process without you. Thanks also to my family for all of their love and support. To my parents for always encouraging me to follow my dreams and supporting me in pursuing so many years of education. To my sister Kaitlin, thank you for being a listening ear and providing me with perspective and comic relief. To my Aunt Anne and my Aunt

Barbie and all of my wonderful girlfriends, thanks for the lunches and the long talks – they were a much needed respite from writing.

And finally, I would like to extend my utmost gratitude to my grandparents, Elisabeth & William Pace and Winifred & Frederick Snow, each of whom in their own way has influenced this thesis. You are my inspiration. You have helped me to see that aging can be a difficult time but also a wonderful time. I miss you all. Knowing you has enriched my life and my ability to understand this topic.

Table of Contents

Abstract	iii
Acknowledgements	iv
List of figures and tables	xii
List of abbreviations and symbols	xiii
Chapter One: Introduction	1
Introduction.....	1
Situating the research	2
Aging and health.....	3
Dementia	7
Risk factors and prevention	9
Treatment and care	10
Cultural safety and personhood	13
Research setting	14
Theoretical orientation.....	17
Significance.....	19
Significance to the researcher	19
Significance to the communities	20
Significance to the literature	21
Guide to the thesis	22
Chapter Two: Methodology	26
Introduction.....	26
Research with Aboriginal peoples.....	26
Phenomenology.....	30
Sample	33
People with dementia	34
Seniors	36
Caregivers	37
Key informants.....	37

Methodology	39
Identification of participants (sampling)	40
Consent.....	41
Interviews and focus groups.....	41
Participant observation	43
Analysis	45
Dissemination and knowledge translation.....	47
Conclusions.....	48
Chapter Three: What makes for a good old age? First Nations seniors’ perceptions of a successful old age	49
Introduction.....	49
Context	50
Understanding aging	50
Aboriginal peoples’ experiences with aging.....	53
Results	56
The experience of aging	56
Explanatory models of successful aging.....	58
Factors that influence healthy aging: Behaviours, barriers and enablers.....	60
Biological	60
Physical health	60
Cognitive health	62
Psychological health.....	63
Attitude and adaptability.....	63
Autonomy and control.....	65
Behavioural	67
Cognitive stimulation	68
Physical activity.....	68

Healthy eating	70
Alcohol and smoking	71
Socio-cultural	72
Poverty	72
Transportation	73
Housing and home maintenance	73
Safety and security	74
Social support and stimulation	75
Culture	78
Interpretation	81
Conclusions	89
Chapter Four: Understanding dementia: First Nations peoples' explanatory models of forgetfulness in old age	91
Introduction	91
Context	91
Prevalence	92
Cultural constructs and explanatory models	94
Results	96
Prevalence and rates	96
Emergence of a new disease	97
Causes of memory loss	99
Physiological factors influencing memory loss	100
Age/Natural	100
Head injury	101
Medications	102
Heredity	103
Biomedical risk factors	104

Psychosocial factors influencing memory loss	107
Alcohol	107
Trauma, stress and grief	108
Indigenous interpretations	110
Environmental and food contamination.....	111
Eating habits and food preparation	112
Lack of cognitive and social stimulation	113
Supernatural causes.....	115
Describing dementia	116
English words and phrases for dementia.....	116
Ojibwe words and phrases for dementia.....	117
Dementia as a natural part of aging	120
Dementia as a second childhood	122
Dementia as frightening.....	123
Living with Dementia	125
Interpretation	130
Conclusions.....	135
Chapter Five: Coping with age-related memory loss: Care seeking, diagnosis and treatment.....	136
Introduction.....	136
Context	137
Factors that affect help seeking and diagnosis.....	137
Diagnosis and testing	139
Results	141
Health care professionals' perceptions of diagnosis	141
Community awareness of diagnostic procedures	143
Reasons people seek diagnosis and care	144
Safety	144

Changing or inappropriate behaviours	145
Inability to cope	147
Reasons people do not seek diagnosis and care	148
Belief that memory loss is natural	148
Distrust of western medicine and concern for privacy.....	150
Treatment	152
Biomedicine	152
Traditional approaches to treatment	154
Barriers to prevention, care-seeking, diagnosis and treatment.....	157
Lack of biomedical knowledge.....	157
Access to health care	159
Cultural inappropriateness/Language	161
Interpretation	163
Conclusions.....	168
Chapter Six: Caring for a person with dementia: Formal and informal care strategies	170
Introduction.....	170
Context	171
Aboriginal experiences with care-giving.....	171
Results	175
Informal family care-giving	175
Reasons for providing care	177
Onset of care-giving: Identification of a need for support	178
Care strategies	180
Social stimulation, visiting, and communication	180
Redirection.....	182
Respect and focus on abilities.....	183
Challenges and caregiver stress.....	185

Round-the-clock care	185
Unmet needs and access to resources	187
Physical and emotional strain	189
Coping	190
Strengths and benefits	191
Formal care-giving.....	193
Lack of biomedical knowledge, education, and training	196
Nursing homes	197
Cultural safety	200
Interpretation	201
Conclusions.....	208
Chapter Seven: Conclusions	210
Introduction.....	210
Research questions and approach	210
Discussion of research findings	211
Limitations	220
Possible areas for future research.....	221
Conclusions.....	222
References	224
Appendix A	240
Appendix B.....	245
Appendix C.....	252
Appendix D	256
Appendix E.....	260
Appendix F.....	263

LIST OF FIGURES AND TABLES

Figure 1. Map of Manitoulin Island, Ontario	17
Figure 2 Amikook Senior's Centre, Wikwemikong	45
Table 1. Warning signs for dementia, Alzheimer Society of Canada	8
Table 2. The Stages of Alzheimer's Disease, Alzheimer's Society of Canada.....	12
Table 3. Number of Seniors in Manitoulin Island First Nations Communities	15
Table 4. Interview and Focus Group Participants	34

LIST OF ALL ABBREVIATIONS AND SYMBOLS

AD - Alzheimer's disease

ADRD - Alzheimer's disease and related dementias

AOK - Aundeck Omni Kaning

CEGEP - Collège d'enseignement general et professional

CIHR - Canadian Institutes of Health Research

IM - Indigenous Methodologies

MCI - Mild cognitive impairment

PAR - Participatory Action Research

PI – Principal Investigator

PSW - Personal Support Worker

RA – Research Assistant

RN - Registered Nurse

RPN - Registered Practical Nurse

Chapter One: Introduction

Introduction

The Aboriginal population in Canada has historically been demographically young. However, there is a rapid aging trend in this population and the number of Aboriginal adults over the age of fifty is growing steadily. This is reflective of a larger worldwide trend towards aging. As the population ages, there is an increasing need for research that considers Aboriginal¹ peoples' understandings of and experiences with aging and associated age-related health problems. Alzheimer's disease and related dementias (ARD), in particular, are emerging as a growing concern. It has been projected that by 2038, nearly three percent of the Canadian population will have dementia and the cumulative cost of caring for these people will be 872 billion dollars (Alzheimer Society, 2010). It is, thus, important that the needs of individuals living with the condition be well understood. Knowledge about experiences of dementia is particularly lacking for minority populations, including Aboriginal peoples. The need for research related to cultural understandings of ARD has been recognized by researchers and Aboriginal people alike. In this thesis I address this gap in knowledge by examining perceptions and experiences of aging and age-related memory loss of First Nations people on Manitoulin Island, Ontario.

In order to best understand First Nations peoples' experiences with dementia, I first look at their experiences with aging. I argue that understanding seniors' perspectives of aging can provide valuable insights for understanding the impacts of age-related cognitive decline. Further, these insights can aid in the development of dementia care practices that are respectful of the person experiencing memory loss. I build on the knowledge gathered about aging by also considering local perceptions of dementia. I consider the ways in which perceptions of aging and memory loss shape behaviours relating to dementia including prevention, help-seeking, treatment, and care. I suggest that broadly understanding experiences of aging can shed light on the full impacts of dementia. This understanding can also be used as a tool to maximize quality of life. This is because having a better understanding of peoples' aging experiences can lead to the

¹ Throughout this thesis the term Aboriginal is used to refer to the descendents of the original inhabitants of North America. In Canada, this term encompasses three groups: Indians, Métis, and Inuit. The term First Nations is used to describe people of 'Indian' descent, as this is the term preferred by First Nations peoples themselves. When citing American literature, I also utilize the words American Indian or Alaska Native in reference to the original inhabitants of what is now the United States.

development of care and support practices that support seniors' values and reflect their understandings of personhood and meaning in old age.

In order to achieve these goals, in this research I consider several key questions: How does culture shape aging and the specific experience of dementia? What does it mean to be and become old in contemporary First Nations communities? What constitutes "successful" and healthy aging for First Nations seniors on Manitoulin Island? How are Alzheimer's disease and dementia identified and explained? When, where, and how do First Nations people seek help for dementia? How are people with dementia cared for in First Nations communities? What are the unique needs of First Nations patients relating to ADRD treatment and care? What culturally appropriate care strategies can/need be developed for this population to be integrated with existing services and improve the dementia experience for both caregivers and people with dementia?

In this Introduction I situate the research by considering background information about Aboriginal seniors, aging, and health. I then move on to describe biomedical understandings of Alzheimer's disease and related dementias, including definitions and descriptions of different types of dementia, risk factors, and biomedical practices for the treatment and care of people with dementia. Next, I describe my justification for pursuing this topic by considering the significance of this subject matter to myself, the communities I have worked with, and the literature. Finally, I provide a guide to the thesis.

Situating the Research

In 2001, the Canadian census identified 39,900 Aboriginal adults aged sixty-five or older. That number has been projected to more than double by 2017 (Statistics Canada, 2005). Although the Aboriginal population in Canada is demographically younger than the non-Aboriginal population, declining fertility rates coupled with improving health status and life expectancy are contributing to a significant aging trend in the Aboriginal population (Statistics Canada, 2005). As this population grows older the incidence of age-related health concerns, including ADRD, is expected to rise.

As dementia has emerged as a problem facing North American Aboriginal people, so too has an interest in studying this issue. To date, published research in Canada and the United States has primarily focused on prevalence (H. C. Hendrie, Hall, & Pillay, 1993), epidemiology and genetics (H. C. Hendrie, et al., 1993; Kramer, 1996; Rosenberg, Richter, Risser, Taubman, & Prado-Farmer, 1996), risk factors (Henderson & Henderson, 2002; H. C. Hendrie, et al., 1993), cognitive testing (Griffin-Pierce et al., 2008; Hall, Hendrie, Rodgers, & Prince, 1993; H. C. Hendrie & Hanson, 1972; Whyte et al., 2005), and caregiver burden (Hennessey & John, 1995; Hennessey & John, 1996). Other work

related to normal aging, dementia, and dementia care-giving among Aboriginal people is largely exploratory (Lanting, Crossley, Morgan, & Cammer, 2011). Few studies have concentrated on the cultural construction of ADRD (Henderson & Henderson, 2002; Henderson & Traphagan, 2005; Hulko et al., 2010; L. L. Jervis & Manson, 2002; Kramer, 1996) and, to my knowledge, none have considered the intersection of perspectives of successful aging and dementia.

Early research on dementia in Aboriginal contexts has called for better understanding of explanatory models (Kleinman, 1978) and cultural constructions of dementia in this population (Henderson & Henderson, 2002; L. L. Jervis & Manson, 2002). Further, the need for this research has been identified by Aboriginal communities. One key example that relates directly to this project is a 2007 roundtable conducted in Sudbury, Ontario. This meeting brought together representatives from Aboriginal communities, Aboriginal and non-Aboriginal health care providers, and other individuals with experience relating to the provision of services for ADRD in an Aboriginal context. This meeting resulted in a report that called for further exploration into the prevalence and experience of ADRD for Aboriginal people, identified gaps in current knowledge about dementia and dementia care, and drafted an action plan for improving dementia-specific services for Indigenous communities (Sutherland, 2007). My PhD research stems, in part, from the inquiries and recommendations that emerged from this roundtable. This roundtable was the stimulus that led Dr. Kristen Jacklin to develop a multi-sited program of research funded by the Ontario Mental Health Foundation and Alzheimer's Society of Canada. Manitoulin Island was one of these sites; and my thesis research, in part funded by this study, is complimentary to and distinctive from, this Ontario study.

Aging and Health

In order to understand the impacts of dementia in Aboriginal communities it is important to first consider broader constructs of age and aging in an Aboriginal context. In most research on old age, human aging is defined in a biomedical framework that focuses on biologically-based functional decline accompanied by increasing susceptibility to disease and death (Hayflick, 1994). Under this paradigm, aging is considered to be a problem of biology and the importance of broader social, cultural, and economic pressures that impact the aged are overlooked. Despite the dominance of biomedical constructs of old age in western society, many social researchers have recognized that aging is a much more dynamic process shaped as much by psychosocial factors as biology (Tulle-Winton, 1999).

Attempts by gerontologists and anthropologists to present a more holistic biopsychosocial model for aging have demonstrated that the process and experience of aging vary widely across cultures. The experience of aging and the way people age are

strongly shaped by the views and expectations of their larger society about what being and becoming old means, how people are expected to age, and their roles in larger social structures (Clark & Anderson, 1980; Gelfand, 2003; Skinner, Teresi, Holmes, Stahl, & Stewart, 2002). Alternative models to the biomedical construct of aging have focused on more positive views of aging and the use of critical frameworks that are less reductionist and consider the ways that race, class, and gender intersect with aging. A holistic or “wholistic” perspective of aging is much more appropriate for use in research with Aboriginal people than a deterministic, biomedical model of aging because a holistic model more closely parallels Aboriginal peoples’ own beliefs about health.

Limited research has considered contemporary Aboriginal peoples’ understandings of health, how they address their health concerns, and the barriers they perceive to impact their health (Graham & Stamler, 2010). However, there does seem to be an overall shared perspective that health is holistic and relates to a combination of the physical, mental, emotional and spiritual realms. As a part of this belief system, aging is understood as a natural process that is part of the circle of life (Assembly of First Nations, 2007). All people begin as infants, move through childhood, adolescence, adulthood, and, finally, to old age before returning to the spirit world. This understanding is sometimes viewed within the context of the teachings of the medicine wheel (N. Adelson, 2005; Graham & Stamler, 2010). Aboriginal Elders are perceived to have important knowledge and wisdom and are respected and valued for their ability to teach and offer guidance to younger generations (Assembly of First Nations, 2007:6) Family care for elders as they grow older and require assistance is a strong cultural value (Habjan, Prince, & Kelley, 2012).

A 1997 report by the National Indian and Inuit Community Health Representatives Organization (NIICHO) suggests that essential elements of healthy aging include well-being in physical, mental-emotional, social, and spiritual spheres; empowerment (the ability to make decisions about one’s life); awareness of and access to information about available programs and services; easy access to medical, social, and support services; aging in place, with respect and dignity, for as long as possible (independent and interdependent living); a supportive social environment; continued community involvement and participation; financial security; adequate and affordable housing; and accessible and affordable transportation (Ship, 1997). As I demonstrate later, these recommendations for healthy aging closely echo the desires of my research participants. The Assembly of First Nations (2007:7) argues that “When these pre-requisites of aging well are applied in today’s First Nations socio-economic context, it is apparent that very few First Nations people are aging well.”

This statement is based in part on several factors that we know impact older Aboriginal people’s health. We know that Aboriginal seniors have higher levels of poverty, lower health status and significantly increased levels of chronic disease and co-

morbidities compared to their non-Aboriginal counterparts (Cooke, Guimond, & McWhirter, 2008; Kathi Wilson, Rosenberg, Abonyi, & Lovelace, 2010). These challenges result from cumulative life events and barriers such as socio-economic conditions, education, health, and social support. Although Aboriginal seniors people face many challenges that impede their ability to age well, it has also been documented that they have generally positive perceptions of old age (Cooke, et al., 2008).

I believe it is important to take into account perspectives of aging well and recognize that many older people actively take strides to achieve a healthy old age. We must be careful not to suggest that the increased challenges faced by older Aboriginal adults reflect unwillingness, lack of interest, or lack of knowledge on the part of these individuals with regards to aging well. Instead, we must consider that for many people the opposite is true; they are very knowledgeable about their desires for their old age and take active steps to achieve or maintain a positive and healthy aging experience. However, life history and structural barriers are powerful influences that often impede their efforts. Improvements must be made to the circumstances in which Aboriginal people live throughout all stages of the life-course if we hope to see a significant improvement in the health and experience of these people as they age. Because of the importance of a holistic approach to aging, and a consideration of the cumulative effects of the life course on experiences of aging and dementia, a life course perspective is central to my analysis of aging and dementia in Aboriginal communities. I consider these barriers and the life course perspective again later in this section in relation to social determinants of Aboriginal peoples' health.

Dementia may be the result of cumulative stresses on the body and brain over the life course and must be considered as an outcome of an entire life lived. Risk factors include low socioeconomic status, large household size, father's occupation (unskilled manual labour), poor nutrition, limited education, and chronic disease (Glymour, Errel, & Berkman, 2009; V. M. Morceri et al., 2001; V. M. Morceri, Kukull, Emanuel, van Belle, & Larson, 2000). All of these factors are shaped across the person's entire life course, and become embodied. Life course research considers how inequalities across the lifespan shape health in later life (Fuller-Iglesias, Smith, & Antonucci, 2009). Similarly, life course epidemiology suggests that "current health reflects a lifetime of past exposures" (Glymour, et al., 2009:27). These perspectives can be useful in the development and implementation of interventions to modify risk factors for the development of disease. Interventions in childhood and adulthood have been shown to be beneficial to health and cognition in the long term (Glymour, et al., 2009). If the goal is to prevent dementia, and to promote "optimal development" throughout the life course, including old age (Fuller-Iglesias, et al., 2009:4), then it is important to think about dementia in a life course perspective and beginning interventions early in the life course, so that their full benefits might be experienced.

Many of the factors discussed in the previous paragraphs are known social determinants of Aboriginal peoples' health (Loppie-Reading & Wein, 2009). Social determinants of health are factors that are known to impact the health of individuals and populations. Inequalities in social determinants of health lead to health disparities. These factors operate at several different levels: distal, intermediate and proximal. Proximal determinants are factors that have a direct impact on health. Proximal determinants include a person's health behaviours (alcohol use, smoking, diet, exercise) as well as their physical and social environments. Poverty, education, food security, and housing are all examples of proximal determinants of health (Loppie-Reading & Wein, 2009). An example of how social determinants impact health at the proximal level is poor education. Individual who lack education often also have low levels of literacy and fewer skills than people with higher educational attainment. A lack of literacy restricts peoples access to information (including health information) and can limit a person's opportunities for employment, which can then lead to poverty and social exclusion (Loppie-Reading & Wein, 2009). These factors act as stressors that can lead to increased vulnerability to infection, mental health issues, and chronic disease (Loppie-Reading & Wein, 2009).

Proximal determinants of health are influenced by higher level factors, called intermediate determinants of health. Intermediate determinants of health are the direct causes of the smaller-scale proximal factors discussed above. Intermediate determinants include a lack of community infrastructure, inadequate or inaccessible educational and health care systems, and cultural continuity (Loppie-Reading & Wein, 2009). Finally, high-level political, economic, and social contexts including colonialism, racism, social exclusion, and repression of social determination are known as distal determinants of health (Loppie-Reading & Wein, 2009). These factors directly influence proximal and intermediate determinants of health and have the most significant impact on the health of populations because they cause all of the smaller factors that lead to increased risks of adverse health conditions (Loppie-Reading & Wein, 2009).

Social determinants impact a person at any moment in their life, but it is important to recognize that the effects of inequalities in the social determinants of health can build over a person's life course. The adverse effects of social inequalities can grow and compound. When considering seniors, then, we must look not only at the social determinants that they are experiencing in the present, but also the determinants they have been exposed to from birth (or even conception) onwards, which have all acted to shape the person's life and health (Loppie-Reading & Wein, 2009). I have previously discussed the increased risk factors for dementia and the higher levels of chronic illness experienced by Aboriginal peoples. These are inextricably intertwined with social determinants of health.

Although Aboriginal Elders² have long been considered to be important contributors to research, especially by anthropologists, past research has relied on these elders for their knowledge about culture and language and has almost never considered their own experiences with aging. Very little research has considered aging and the aged in an Aboriginal context, and even less has attempted to understand their perceptions of dementia. In light of the increasing population of Aboriginal seniors, it is important that researchers now turn their attention to documenting the experiences of seniors and utilizing their subjective knowledge to address the problems they encounter as they age. By listening to the voices of Aboriginal people relating to their expectations, experiences, triumphs, and challenges as they grow older researchers gain the ability to understand what problems need the most attention and achieve insight into the type of solutions that are the most meaningful.

Dementia

Within the biomedical model Alzheimer's disease and related dementias are understood as progressive and degenerative age-related syndromes that affect the brain (Alzheimer Society, 2010). These syndromes are characterized by memory loss, confusion, changes to behaviour and personality, and difficulty with communication (Cohen, 1991). It can be challenging for people with dementia to make decisions, think through complex ideas, carry out activities of daily living, or learn new skills. Psychiatric symptoms such as agitation, anxiety, and depression may be present, and physical symptoms including incontinence and loss of the ability to swallow often emerge as the disease progresses (Thornton & Winkler, 1988). Table 1 presents ten warning signs for dementia published by the Alzheimer Society of Canada.

Dementia is an umbrella term that encompasses many different conditions. Some dementias, such as those caused by infections, drug abuse, dietary deficiencies, or depression are reversible, meaning that they can be treated and cured (Alzheimer Society, 2010). Other dementias including Alzheimer's disease, vascular dementia, fronto-temporal dementia, Lewy Body dementia and Creutzfeldt-Jakob disease are caused by progressive neurodegenerative diseases. These dementias are irreversible and cannot be cured (Alzheimer Society, 2010). The distinction between reversible and irreversible forms of dementia has significant implications relating to the identification and treatment of cognitive decline.

² The term seniors will be used throughout this thesis to reference Aboriginal adults over the age of 50. The term Elder is used in some places to represent the specific sub-set of seniors who are recognized to have a special role in their communities because of their cultural and spiritual knowledge.

Table 1. Warning signs for dementia, Alzheimer Society of Canada

Ten Warning Signs	
1	Memory loss that affects day-to-day functioning
2	Difficulty performing familiar tasks
3	Problems with language
4	Disorientation of time and place
5	Poor or decreased judgment
6	Problems with abstract thinking
7	Misplacing things
8	Changes in mood and behaviour
9	Changes in personality
10	Loss of initiative

Alzheimer’s disease has captured the public imagination as a ‘thief’ of memory, competence, and individuality. In western society, Alzheimer’s disease (AD) can be used as a metaphor for the entire aging process, representing part of the human life course that is associated with decline, dependency and a loss of personhood. Alzheimer’s disease epitomizes what western culture fears about old age; a negative, medicalized and valueless period of a person’s life associated with a loss of autonomy and productivity. Dementia is the ultimate example of decline and dependency in old age where one loses not only physical and cognitive capabilities, but also their core identity. One author suggests that dementia, along with AIDS and cancer, is one of the most feared of all modern diseases (Bond, 1999).

The western biomedical construction of Alzheimer’s disease is predominant. However, in the last several decades, there has been considerable advocacy among researchers and organizations that are involved with dementia research and care to

combat these negative representations of people with dementia and re-frame our perspectives of their capabilities (Dewing, 2002, 2007; Kitwood, 1997). Further, anthropologists have demonstrated that Alzheimer's disease, like other health issues, is perceived differently across cultures (Cohen 1994; Henderson and Henderson 2002; Kleinman 1980). For example, Aboriginal peoples are generally more accepting of symptoms of dementia, and perceive memory loss to be a natural part of the aging process (Henderson & Henderson, 2002; Sutherland, 2007). Recognizing how a particular group understands age-related memory loss is an important first step in devising culturally-appropriate education and interventions to address the challenges brought on by dementia.

Risk Factors & Prevention

Several factors can influence a person's risk for developing dementia. These risk factors do not cause dementia, but they can increase or decrease the probability that a person will develop the condition. The two primary risk factors for Alzheimer's disease are age and genetics (Alzheimer Society, 2010). These are non-modifiable, that is, there is nothing a person can do to change them. As people age, they become more likely to develop Alzheimer's disease. One in twenty Canadians over the age of 65 develop AD, while as many as one in four older people over the age of 85 have the condition (Alzheimer Society, 2010). Family history plays a significant role in determining whether a person will develop dementia, but not all forms of dementia or Alzheimer's disease are influenced by genetics.

There are also many risk factors which are modifiable. These include Type 2 diabetes, head injury, strokes and ministrokes, high cholesterol, high blood pressure, mild cognitive impairment (MCI), chronic inflammatory conditions, a history of clinical depression, lack of cognitive stimulation and obesity (Alzheimer Society, 2010). Other factors that have been linked to a possible increased risk for developing dementia include a lack of formal education, low socio-economic status, smoking and alcohol abuse (Alzheimer Society, 2010). As discussed previously, (Loppie-Reading & Wein, 2009) social determinants of Aboriginal peoples' health over the life course influence the risk factors for dementia that Aboriginal seniors have been exposed to, and help to explain why Aboriginal people may be at a higher level of risk for developing dementia. In the context of Aboriginal peoples, it may also be important to consider the long-term effects of colonization and intergenerational trauma when attempting to understand why people develop the disease.

The Alzheimer's Society of Canada (2010) recommends healthy lifestyle choices as a means of reducing the risk of developing ADRD. A healthy diet, aerobic exercise, cognitive stimulation, and active social life are all considered to be beneficial in preventing the onset of dementia. Preventing head injury and seeking adequate

treatment for medical conditions such as diabetes, high cholesterol, and high blood pressure are also factors that can aid in the maintenance of brain health (Alzheimer Society, 2010). However, these recommendations may be difficult for Aboriginal people to achieve since they may live in remote locations, have less access to services, and face financial and structural barriers that prevent them from engaging in these behaviours. They may also be inadequate because they do not reflect cultural understandings of the disease.

As is perhaps evident, many of the risk factors for ADRD are more prevalent in the Aboriginal population compared to the rest of Canada. The prevalence of ADRD in the Aboriginal population is not known and is difficult to estimate. It has been suggested in the literature that the prevalence of all dementias is about the same, appearing in approximately eight percent of adults over age sixty-five, for Aboriginal and non-Aboriginal Canadians (H. C. Hendrie, et al., 1993). Alzheimer's disease is believed to be less common for Aboriginal people. However, it is believed that because of the higher incidence of certain risk factors such as diabetes, cardiovascular disease, and alcoholism that Aboriginal peoples may be more susceptible to other types of dementia, especially vascular dementias (H. C. Hendrie, et al., 1993). New data suggests that there may actually be a higher prevalence of dementia among First Nations people in Alberta than their non-First Nations counterparts (K. Jacklin, Walker, & Shawande, 2013). For this reason, it is especially important to consider how to devise relevant strategies to reduce modifiable risks for Aboriginal people.

Treatment and Care

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

The care needs of a person with dementia increase substantially over the course of the disease. Table 2 depicts the symptoms commonly associated with each stage of the disease and the type of care that is required to support a person experiencing these symptoms. In the early stages of dementia, symptoms are generally mild and the person

with memory loss is often able to continue on with their normal life with little or no assistance from others. During the second stage, many more symptoms emerge and their severity may increase. It is during this stage that care and support become a necessity. The type of support a person with dementia requires in the middle stage of dementia may range from reminders and emotional support to assistance with activities of daily living and supervision to prevent dangerous behaviours. The final stage of dementia requires round-the-clock physical care. At this stage of the disease people with dementia have often lost the capacity to communicate verbally, maintain urinary and bowel continence, and control their physical abilities (Alzheimer Society, 2010).

Family caregivers are a crucial component of care for persons with dementia. It has been estimated that 231 million hours of care are provided in Canada each year by informal caregivers. This number is expected to triple within a generation (Alzheimer Society, 2010). Informal care for Aboriginal seniors is primarily provided by resident daughters, sons, or spouses, or by non-resident daughters, sisters, and sons (Buchignani & Armstrong-Esther, 1999). Extended family members, friends, or neighbors may also provide care. Women are the most frequent providers of informal care. However, rapid population aging, high levels of chronic illness and co-morbidities, and changing roles of women are putting pressure on traditional Aboriginal models of eldercare, and increasing the need for formal services and supports (Habjan, et al., 2012).

Traditional extended family structures are under pressure since many young Aboriginal people seek employment outside of their communities. Middle-aged women, who most commonly fill the role of caring for their elderly parents, also have high migration rates away from their communities (Habjan, et al., 2012). With more than half of Aboriginal women living and working off-reserve, and a growing elderly population living on reserve, traditional intergenerational care patterns are breaking down. As this happens, families are relying more heavily on formal services to provide care for elders (Habjan, et al., 2012). Unfortunately, in many Aboriginal communities there simply is not enough in the way of health service resources to ensure that seniors are being well cared for. Often, health service personnel lack appropriate training and have limited opportunities to receive further education (Habjan, et al., 2012). Further, there is a concern that a disconnect between seniors and youth is leading to a decline in respect and “intergenerational mutual aid” (Habjan, et al., 2012:216).

While demographic shifts have increased the need for home care services such as in-home nursing, homemaker and personal support worker services, and nursing homes, family care is recognized as the most effective and beneficial type of care for persons with dementia. This is demonstrated in mainstream literature which shows that supportive family care can delay admission into long term care, keep families intact, and ensure longer survival for persons with dementia (McClendon, Smyth, & Neundorfer, 2004, 2006; M. S. Mittleman, Haley, Clay, & Roth, 2006). It is also a well documented

preference in Aboriginal communities, where there is a strong value of helping seniors to age and die in their own homes and communities (Habjan, et al., 2012).

Table 2. The Stages of Alzheimer's Disease, Alzheimer's Society of Canada

	Early Stage	Middle Stage	Late Stage & End of Life
Common Symptoms	Forgetfulness Communication difficulties	More pronounced memory loss Less ability to concentrate Confusion Disorientation to time and place Problems with language Difficulty making choices Changes in mood Sense of loss or insecurity Withdrawal Wandering Repetition Delusions and hallucinations Uninhibited behaviour Changes in sleep and appetite Spatial problems	Loss of ability to communicate verbally Difficulty swallowing Loss of continence May lose physical abilities such as walking, sitting unsupported
Care and assistance needs	Requires little to no assistance	Increased need for care Use reminders and cues Speak slowly and clearly Stick to concrete subjects, avoid abstraction Provide emotional support Encourage a healthy lifestyle Prevent dangerous behaviours Help needed for activities of daily living including dressing, eating, bathing and using the toilet	24 hour care Full physical care Decision making about life-prolonging treatments and a comfortable death

Although informal care has many benefits, it also has risks. Dementia caregivers face intense physical, emotional and financial strain and are at high risk for depression and diminished health as the needs of the care recipient increase (Alspaugh, Stephens, Townsend, Zarit, & Greene, 1999; Alzheimer Society, 2010; Dunkin & Anderson-Hanley, 1998). Caregivers who lack education, training and support related to dementia are at higher risk for adverse effects related to care-giving and are likely to provide lower quality care. Highly stressed or depressed caregivers may engage in behaviours that have the potential to harm the care recipient including neglect, yelling, threatening and rough treatment (Williamson, Shaffer, & The Family Relationships in Late Life Project, 2001). However, harm can also be done if the caregiver does not take a person-centered approach to care which recognizes the care receiver's capacities alongside of their deficits and respects their identity (Kitwood, 1997; Sabat, 2001). This may lead to the care recipient experiencing "excess disability" which can lead to accelerated decline (McClendon, et al., 2004; Sabat, 2001).

The information about family care-giving cited in the previous paragraphs relates to all Canadians, but is relevant for Aboriginal families as well. In fact, understanding and supporting family care-giving may be even more important in an Aboriginal context because dementia care-giving is often compounded by the presence of co-morbidities and Aboriginal people often lack access to the same level of services available to mainstream Canadians. Further, family care-giving is the preferred mode of care for Aboriginal people because caring for elders is a strong cultural value (Habjan, et al., 2012).

Cultural Safety and Personhood

Cultural safety is a concept that emerged from nursing research with the Maori of New Zealand. The focus of cultural safety is on the "fluidity of culture" and power relations that characterize all cross-cultural interactions (Hulko & Stern, 2009:72). Cultural safety is distinct from cultural sensitivity or cultural competence in that the latter ignore the influence of power and generally conceive of culture from an essentialist perspective. Cultural safety can be differentiated from these other notions by its consideration of a shift in power from the service provider to the service recipient (Wepa, 2007 cited in Hulko and Stern 2009). Cultural safety recognizes that health care providers need to be "respectful of nationality, culture, age, sex, political and religious beliefs, and sexual orientation" (NAHO, 2008). Cultural safety is important because it can counteract negative experiences with the mainstream health care system and lead to better care and patient outcomes. The implementation of culturally safe care is a step towards improving Aboriginal peoples' health and narrowing the gap between Aboriginal peoples' health status and the health status of mainstream Canadians (NAHO, 2009). When striving to achieve culturally safe dementia care protocols for Aboriginal people it is important to keep in mind an appropriate understanding of personhood in

addition to recognizing other unique characteristics of Aboriginal seniors with dementia and their family caregivers.

Beliefs about personhood are a fundamental building block for the design of dementia care strategies. Having an appropriate understanding of how a cultural group understands personhood has important implications for the development of treatment and care protocols for people with dementia. From a western perspective, personhood is often defined around understandings of autonomy. Kitwood (1997:8) explains personhood as a “standing or status that is bestowed upon one human being, by others, in the context of relationship and social well-being”. Conceptions of personhood in other cultures do not always align with the criteria and values forwarded by Western philosophers. While Euro-American cultures tend to value an egocentric and individualistic conception of persons, Aboriginal “personhood” criteria are different (Kirmayer et al. 2003).

In order to conduct ethically sound dementia research with Aboriginal groups, researchers must become aware of Aboriginal peoples’ values relating to personhood. These are often more relational, and may have communalistic, ecocentric (relating to land or animals) and cosmocentric (relating to the spirit world or ancestral lineage) elements. Relationships with family, larger kin and community groups, the natural world, spirits and ancestors must be considered when applying personhood theories to research with Aboriginal peoples (Kirmayer et al. 2003). It has been suggested that collectivist cultures envision their sense of self to be embedded in the community rather than in the individual (Waid & Frazier, 2003). The Aboriginal (collectivist) worldview assigns value to a person based on who they are rather than what their abilities are (Hulko & Stern, 2009).

Research Setting

This multi-sited research was carried out in seven First Nations communities on Manitoulin Island, Ontario. Manitoulin Island is the world’s largest freshwater island. It is located on the north shore of Lake Huron in northern Ontario. Manitoulin Island is 2,766 km² in size and approximately 135 km in length. Manitoulin has two incorporated towns (Northeastern Manitoulin and the Islands and Gore Bay) and six First Nations reserves (Wikwemikong, Sheshegwaning, M’Chigeeng, Zhibaahaasing, Sheguiandah, and Aundeck Omni Kaning). A seventh reserve, Whitefish River is located just across the North Channel. Manitoulin can be accessed by the mainland by a swing bridge over the North Channel or by ferry from Tobermory. The closest urban center is Sudbury, which is anywhere from a 100 km to 225 km drive from the island depending on the community. The population of Manitoulin is approximately 13,000, and is made up of both Aboriginal and non-Aboriginal peoples. The Aboriginal population, who are primarily Ojibwe,

Odawa, and Potawatomi, make up close to half the population. In the summer months, the population increases by several thousand as tourists come to stay on the island.

Table 3. Number of Seniors in Manitoulin Island First Nations Communities (On-reserve), 2012

Community	Population Age 50+	Total Population	% Population 50+
<i>AOK</i>	82	356	23.03%
<i>Sheguiandah</i>	27	148	18.24%
<i>Sheshegwaning</i>	29	92	31.52%
<i>Whitefish River</i>	84	347	24.20%
<i>Zhiibaahaasing*</i>	20	76	26.32%
<i>M'Chigeeng**</i>	245	900	27.22%
<i>Wikwemikong</i>	738	3,146	23.45%

*Estimated number, detailed statistics not available

**Data from June 2013

Manitoulin was selected as an ideal location for this research in part because of the diversity of the seven First Nations in size, language use, adherence to traditional culture, remoteness and availability of services. In addition, key stakeholders at the community level had expressed an interest in engaging in research about dementia. The principal investigators on the larger project (Jacklin and Warry) also had well-established relationships with the First Nations on Manitoulin which facilitated my entry into the communities.

Research participants were selected from the seven First Nations communities on Manitoulin Island. These communities range in size from 76 people to 3000 people (Table 3). A local research assistant (Karen Pitawanakwat) was hired to assist with locating and interviewing participants in Wikwemikong. I carried out the remainder of the interviews in the six United Chiefs and Councils of Mnidoo Mnising (UCCMM) communities (Aundeck-Omni-Kaning, Sheguiandah, Whitefish River, M'Chigeeng, Sheshegwaning, and Zhiibaahaasing). I also conducted focus groups and participant observation in both Wikwemikong and UCCMM communities. Throughout this thesis the data from Wikwemikong and UCCMM communities are considered together to provide a picture of the experience of dementia on Manitoulin as a whole. However, in some

places, where notable differences are present I discuss Wikwemikong and UCCMM communities separately.

There are several health services available to First Nations people living on Manitoulin Island. The three main agencies on Manitoulin that I worked with were the Noojmowin Teg Health Access Center, Mnaamodzawin Health services, and the Wikwemikong health center. Mnaamodzawin Health Services and the Noojmowin-Teg Health Access Center are located at a shared site in Aundeck Omni Kaning. Mnaamodzawin provides programs including Home Community Care, the Community Health Program and the Community Mental Health and Cultural Program to five communities (Aundeck Omni Kaning, Sheguiandah, Sheshegwaning, Whitefish River, and Zhiibaahaasing). Noojmowin Teg services all seven of the First Nations communities as well as off-reserve First Nations people on Manitoulin Island. Noojmowin Teg provides services including nurse practitioner, family physician, and psychologist services, community nutrition, FASD programs, children's programs, diabetes wellness, as well as aging at home and traditional medicine. The Wikwemikong Health Center, located in Wikwemikong, offers a variety of services including children and youth services, mental health, primary care, medical transportation and home care. I primarily engaged with individuals who worked in Long Term Care and Home and Community Care. All three of these organizations provide services in both Ojibwe and in English. Noojmowin-Teg and Mnaamodzawin are centrally located, but are still a 95 km drive from the furthest community. Alongside of these more global services, each of the reserves also has its own small health center, and many also have a drop-in elder's center with activities for seniors.

In addition to the organizations that I worked with for my interviews, there are several other service providers serving the whole of Manitoulin Island. There is one nursing home on reserve, located in Wikwemikong. This nursing home was closed to new patients during the time of my fieldwork. Since the completion of my fieldwork the Wikwemikong Nursing home has again been opened to new patients. There are also two other nursing homes on the island, one in Gore Bay and one in Little Current. There are two hospitals on the island, located in Little Current and Mindemoya. Travelling to these services from some of the reserves can involve driving over 100km. Accessing specialist services requires even longer distance travel as they are located in Sudbury (over 200km from the most remote community) or as far away as Toronto (700km from the most remote community).

Figure 1. Map of Manitoulin Island, Ontario



Theoretical Orientation

This project was designed around theoretical foundations based in critical medical anthropology (CMA) and participatory action research (PAR). These two approaches were chosen because they are widely accepted to be appropriate and ethical frameworks for research involving Aboriginal peoples. They were also selected because they are consistent with the design and goals of the larger project within which my research occurs. These two approaches have been widely used in Aboriginal health research and have been demonstrated to be effective in eliciting new information relating to Aboriginal peoples health and well-being (K. Jacklin, 2007).

A critical medical anthropology framework (Scheper-Hughes, 1990) recognizes inequalities in health care and services to marginalized groups. According to Baer, Singer and Susser (2003:38), critical medical anthropology:

Understands health issues within the context of encompassing political and economic forces – including forces of institutional, national, and global scale – that pattern human relationships, shape social behaviours, condition collective experience, reorder local ecologies, and situate cultural meanings.

Further, this approach considers how health and well-being are “culturally constructed, negotiated, and re-negotiated in a dynamic process through time and space” (Lock & Scheper-Hughes, 1990). Because this research focuses on Aboriginal people, seniors, and people with dementia – groups that are all in some way disadvantaged and marginalized – it is important to consider the multi-scalar factors that influence their health.

CMA, as well as critical gerontology, often takes a political economy standpoint. In critical gerontology, political economy has the strength of considering the way that race, class, gender and aging intersect (Minkler, 1999; Minkler & Estes, 1991). A political economy framework considers power relations and problems of aging related to inequalities of power, income and property (Kart, 1987). This interdisciplinary approach focuses on “interlocking systems of inequality” (Stoller & Gibson, 1997) that offer insight into the social construction of aging that shape and determine the experience of aging and growing old (Minkler 1999). An approach that considers health from a political economic vantage point is also useful in Aboriginal health research because of the impacts of past and present policies of the Canadian government on First Nations, Inuit, and Métis health (RCAP, 1996). This framework allows me to locate my analysis in an appropriate socio-political framework that recognizes higher level structures that shape the experience of aging and dementia for Aboriginal peoples on Manitoulin Island.

As I discuss in more detail in the next chapter, this research is also oriented within a participatory action framework. Guidelines for research involving Aboriginal peoples established by the Canadian Institutes for Health Research (CIHR) recommend that Canadian Aboriginal communities should be offered the option of community-based participatory action research (PAR) before any research is begun (Canadian Institutes of Health Research, 2006). Participatory action research focuses on research partnerships and promotes empowerment, inclusivity and respect (Dickson & Green, 2001; Ermine, Sinclair, & Jeffery, 2004). Within this paradigm, researchers involve community stakeholders at all levels of the research process from the inception of the project and continuing through the research design, implementation, and dissemination stages of the research. The combination of PAR and CMA is useful because both approaches support community empowerment and self-determination. This is important in Aboriginal health research because these factors have been demonstrated to be important components in improving the health and well-being of Aboriginal communities (Warry, 1998).

Significance

I now consider several facets of the potential significance of this research. First, I speak to why this research is important to me on a personal level, and how I came to be interested in working with people with dementia. I then move on to a discussion of the relevance of this project to the communities I work in and the academic literature.

Significance to the Researcher

Although I have made an effort to remain as objective as possible in the analysis of the data gathered for this thesis, my personal experiences with older people with Alzheimer's disease and dementia shape my understanding of the needs of this population and how I relate with people coping with condition. Here, I share my background experiences and interests in dementia so that I can identify to the reader any possible biases that I carry relating to this research and my beliefs about the rights of people with dementia and their caregivers.

My first experience with dementia was with my maternal grandfather. When I was a young teenager, my grandfather, then in his mid-80s began to exhibit signs of cognitive decline. He had trouble remembering and occasionally repeated himself. These symptoms seemed to emerge shortly after the sudden death of my uncle, my mother's oldest brother. What I remember most about his memory loss was his tendency to get up in the night. Sometimes he would do things that made us fear for the safety of him and my grandmother, like making toast in the oven late at night. Over time, my grandmother became run-down from the demands of caring for him and in the interest of preserving both of their health, my family made the difficult decision to enroll my granddad in a nursing home. It was a decision no one wanted to make, but that was necessary for safety reasons. As a family we continued to regularly visit my grandfather while he was in the nursing home. Over time he gradually lost more of his ability to remember, and shortly before his death he even had trouble recognizing some of the members in our family, including me. I did not realize it at the time, but seeing my grandfather decline, observing the difficult decisions that had to be made about his care, and knowing how unhappy he was to be in a nursing home made a real impact on me.

A few years later, I had an opportunity to take a communication and community course at John Abbott College, a Collège d'enseignement général et professionnel (CEGEP), in Ste.-Anne-de-Bellevue, Quebec. The major component of this class was learning about the impacts of dementia and spending two hours a week as a friendly visitor to a veteran with dementia. I was paired with two veterans, and came to enjoy my weekly visits with them. I learned how to communicate with them despite the impacts of cognitive decline and to find activities that they were interested in and enjoyed. That experience taught me a lot more about dementia and interacting with

people with cognitive decline. I learned to empathize with these individuals, and to see that they were still individuals with unique interests and personal histories. Getting to know the two gentlemen I worked with as part of this Psychosocial Enhancement Program and later volunteer work as a Mall Walking companion to an older woman with Alzheimer's disease further solidified my interest in dementia, and convinced me that there were many ways that the quality of life of people with dementia could be greatly improved if the people around them would take the time to recognize them as unique individuals who retained interests, emotions, and personalities.

My strong feelings about the importance of family support, successful aging, and the ability of older people to remain active and engaged as they age are further shaped by the environment I was raised in. My grandparents were always a big part of my life and I was fortunate enough to be able to have relationships with them that lasted well into my twenties. Two of my grandparents lived into their late eighties and two into their mid-nineties. My grandparents were all very engaged in their lives to a very old age. One grandfather worked until he was 84, and my grandmothers were very involved socially and with their hobbies until they passed away. My grandparents were always at the centre of large family gatherings and extended family provided them with assistance when it was needed. I recognize that this is not the case for all older people or their families, but see it as a valuable model that has positive and lasting effects on multiple generations.

Over time, the feelings I developed through volunteer and family experiences took root and grew into ideas for an undergraduate research project in a medical anthropology class, which evolved over time into the basis for this PhD research. At each stage of my education about dementia and getting to know people coping with the condition I have become more and more convinced that people with dementia and their caregivers have a right to better information, better support, and better experiences with dementia and dementia care. Work on this thesis has continued to solidify this belief, and I hope that by taking the time to gather and share the stories of First Nations people with dementia, their families, and communities, this thesis will act as a resource that will provide insight for people to design and implement educational materials, care strategies and support systems to improve the quality of life of people with age-related cognitive impairment.

Significance to the community

This project is significant to the Manitoulin First Nations population in several ways. Importantly, this research responds to a need they have identified for a better understanding of Alzheimer's disease and related dementias (Sutherland, 2007). The information that has been gathered during this project allows for an evaluation of the quality of life of individuals and families affected by Alzheimer's disease and dementia

and has the potential to be put to use as a measure of the appropriateness of educational and diagnostic materials related to ADRD.

This research gives a voice to many types of people who are dealing with dementia as well as relatively healthy seniors. Bringing these voices together provides an opportunity to identify the biggest challenges that are associated with aging, dementia, and dementia care in this context. The combined perspective of seniors, people with dementia, family caregivers, and health care providers provide multi-faceted data that have the potential to be used to influence future efforts to design policy and programs that address the needs of First Nations communities on many levels. Because this information has been gathered, the developers of policy and programming will have access to data about how to provide relevant and culturally appropriate supports that reflect the needs and desires of actual people. Programs and services that reflect the needs of the people who will be accessing them, as well as their language and culture can improve the chances of people coping with dementia to have a higher quality of life.

Further, this project emphasizes the voices of older people, and in doing so highlights their strengths and encourages them to pursue a successful and healthy old age. Gathering perspectives of successful aging and the measures that older people take to age well has underscored the importance of health promotion related to aging. First Nations seniors' beliefs about behaviours that contribute to a healthy old age are similar to recommendations for the prevention of dementia in the literature (Alzheimer Society, 2010). As such, promoting these behaviours has the potential to not only minimize the impacts of dementia, but also to improve the quality of life of all seniors and strives to make a better future for this demographic.

Significance to the literature

The results of this research contribute to the literature by addressing issues related to contemporary First Nations peoples' beliefs about health, aging, and different types of age-related memory loss, all of which are underrepresented in the literature. The aging process and subjective experiences of older people have routinely been overlooked in social research and in structural and government planning and minority populations are particularly underrepresented. In published research, "the elderly" are often presented as a homogenous group and the significant impact of gender, ethnicity, culture, and socioeconomic status on aging are frequently neglected. Individuals with dementia have been further marginalized as research participants. Studies focusing on the subjective experiences of people with dementia have only emerged in the past two decades (Downs, 1997, 2000; Hubbard, Downs, & Tester, 2002). The results presented in this thesis address the lack of literature that represents perspectives on aging and dementia by giving a voice to a minority population (First Nations peoples), to seniors,

and to people with dementia and privileging their understandings of growing old and cognitive decline.

This project contributes to the theoretical literature in medical anthropology and helps to shed light on the ways that culture shapes experiences of aging and ADRD. The qualitative data gathered in this research contributes to a clearer understanding of the way that Aboriginal people in Ontario understand and experience Alzheimer's disease which will be useful to Aboriginal people with dementia, their families and caregivers, as well as their health care providers. The aging component provides context for expectations and roles of elders in an Aboriginal setting that can serve as a starting point for other studies related to health issues faced by Aboriginal seniors. This data is relevant to academic researchers in anthropology and other disciplines such as gerontology, health studies, and medicine and Indigenous studies. Moreover, the project has the potential to lead to the development of a model for applied, culturally appropriate strategies for the care of First Nations people suffering from Alzheimer's and dementia.

The inclusion of non-impaired seniors, health care providers, and informal caregivers provides highly contextual data about the experience of ADRD and how they interact in a web of individuals, families, community and culture. Further, this research presents broad observations that extend beyond Aboriginal communities and have relevance for other minority populations as well as mainstream Canadians. These observations have the potential to influence health, social policy, and the delivery of health care programs related to seniors and people and families who are coping with dementia.

Guide to Thesis

In Chapter Two I explain the theoretical and methodological approach of this research in detail. The chapter describes the characteristics of each of the categories of participants (people with dementia, caregivers, seniors, focus groups, key informants). It also situates the community-based ethnographic research approach in the context of participatory action research and Indigenous methodologies. Within this chapter I discuss the ethics and approval processes as well as the development of community relationships. Finally, I discuss data collection and analysis procedures, with a particular focus on phenomenology.

Chapter Three examines First Nations seniors' subjective experiences of aging and attempts to understand what they perceive to be the key characteristics that define a successful old age. The chapter begins with a review of relevant literature relating to theories of aging and successful aging before presenting current knowledge about Aboriginal seniors. In this chapter, I privilege the voices of the seniors who were

interviewed, using direct quotes from their interview transcripts to highlight their explanatory models of aging well and the behaviours that they believe to contribute to a healthy old age. I then proceed to examine some of the barriers that inhibit older peoples' efforts to age well and the challenges that older people face on a daily basis. The chapter concludes with a discussion of the complex issues that relate to older people and considers why it is important to understand their subjective experiences of old age in the context of dementia and the importance of promoting and supporting healthy aging practices for older people across the board.

Chapter Four describes First Nations peoples' explanatory models of forgetfulness in old age. Here, I consider not only Alzheimer's disease and dementia, but all forms of memory loss and the range of responses to different levels of severity of cognitive decline. The chapter begins with a review of relevant literature relating to dementia among Aboriginal peoples. I consider what is known about the prevalence of dementia in this population as well as the importance of utilizing local explanatory models and cultural constructs of disease. I demonstrate in this chapter that the perceptions of dementia gathered during my research parallel the findings of other research that has attempted to understand cultural perceptions of memory loss and dementia. In the results section of this chapter, I again consider the prevalence of dementia in a Manitoulin-specific context and the idea that dementia is an emerging disease. Participants perceive the emergence of dementia to be caused by a shift away from a traditional lifestyle towards a way of life that is more sedentary, relies more heavily on store-bought foods, and has less clearly defined roles for seniors. I then present my participants' perceptions of the causes of memory loss and the ways they describe dementia in both English and Ojibwe. Three predominant perceptions about age-related memory loss held by First Nations people are then presented: that it is a natural part of the aging process, that it represents a second childhood or return to infancy, and that it is a frightening or worrisome occurrence. My interpretation then considers a question put forth to me in one of my focus groups, "When do you start counting dementia?" I consider in detail the importance of knowing when to "start counting" dementia and how to differentiate normal memory loss from the more frightening, pathological form that leads to rapid decline.

Chapter Five deals with coping mechanisms including help-seeking, diagnosis and treatment for dementia. This chapter presents a review of the literature relating to help-seeking and diagnosis among Aboriginal people and considers some of the challenges associated with diagnosis and cognitive testing in this context. Following the discussion of the literature, I examine the reasons that participants in this project seek diagnosis and care including concerns about safety, changing or inappropriate behaviours, an inability to cope with the needs of the person with dementia, or the recommendation of health care providers. I also examine the reasons that people do not seek out diagnosis and treatment. These most commonly relate to the belief that memory loss is natural

and a distrust of biomedicine. In order to get a complete picture of diagnosis and treatment, I present the perception of physicians and care workers relating to diagnostic tools. I also discuss how poorly understood diagnosis and diagnostic procedures are among people with dementia and their family caregivers. After the discussion of diagnostic procedures and experiences I move on to present both biomedical and traditional approaches to treatment. I conclude by presenting the barriers to dementia diagnosis and care in the communities I worked in. This chapter builds on the importance of knowing when to distinguish “normal” memory loss in old age from problematic forgetfulness caused by dementia that I began to explore in chapter four by considering the relevance of diagnostic tools and whether a formal diagnosis of dementia changes the outcomes for dementia care and support.

Chapter Six considers the primary issues surrounding care for people with dementia, both for informal family caregivers and formal, trained care providers. The chapter begins with a review of the literature relating to care-giving for people with dementia, specifically focusing on Aboriginal peoples’ experiences with care provision. This chapter largely focuses on informal family care-giving, since this type of care emerged from the interview data as the dominant and preferred mode of care for a person with dementia. I present family caregivers’ reasons for providing care, the factors which indicated to them that the person with memory loss was in need of additional support, and the challenges and stresses of care-giving. That is followed by a discussion of the pressures that are impacting traditional care practices. I then consider the experiences of formal health care providers such as nurses and personal support workers in providing dementia care. Strengths in dementia care that emerged from my interviews and observations are also discussed. The chapter concludes with a discussion of optimal care-giving practices and the importance of relevant education, training, and support for caregivers in ensuring that people with dementia are receiving care that supports their personhood and quality of life.

Chapter seven contains a final discussion of the overall thesis findings and presents my conclusions. In this chapter I present an overview of the key themes and findings of this thesis relating to successful aging, explanatory models of dementia, diagnosis and treatment, and care-giving. I demonstrate that knowledge of perceptions of successful aging has significant relevance to the study of dementia, and highlight the importance of changes to traditional lifestyles and the disruption of cultural continuity as a key factor that impacts First Nations seniors’ ability to age well and that is perceived to be influential in the increasing prevalence of dementia. I also suggest recommendations for dementia support, services and care in this community. These include developing culturally appropriate education and training interventions for informal family caregivers as well as health care providers at multiple levels. In addition, there is a need for the development of a dementia support group run by Aboriginal people for Aboriginal people and available in Ojibwe, culturally appropriate health promotion materials, and

increased support for people and families coping with dementia including evening, overnight and weekend home-care support and increased hours of respite for caregivers.

Chapter Two: Methodology

Introduction

This chapter describes the theoretical and methodological approach that was taken to gather and analyze data for this thesis. This project was a community-based research project that used ethnographic methods including interviews, focus groups and participant observation. An important aspect of this research was its participatory, community-based design that involved working with community stakeholders at all stages of the research design including the identification of a need for this research, design of research questions, data collection and dissemination. A phenomenological approach to data analysis was used to elicit understandings of participants' lived experiences with aging and dementia. The combination of ethnographic and participatory approaches and phenomenological analysis were chosen because they suited my goals to discover how Aboriginal people experience and interpret dementia. A description of research methods, ethical protocols, characteristics of the research participants, and analytical approach follows.

Research with Aboriginal Peoples

Engaging in ethical research is important in any context, but research with Aboriginal peoples necessitates special consideration of ethical research design that respects Indigenous values. Aboriginal peoples have been studied extensively for hundreds of years, and too often, research involving Aboriginal peoples was carried out without the consent of the communities who were being studied and did not reflect their needs. Further, Indigenous peoples were rarely informed of the results of the research, leaving them disenfranchised from the knowledge they had shared with researchers (Kovach, 2009). Today, it is widely recognized that research with Aboriginal communities must reflect their desires and needs, and must have meaningful benefits for the people who are involved (Ermine, et al., 2004; K. Jacklin & Kinoshameg, 2009).

Guidelines for research involving Aboriginal peoples established by the Canadian Institutes for Health Research (CIHR) recommend that Canadian Aboriginal communities should be offered the option of community-based participatory action research (PAR) before any research is begun (Canadian Institutes of Health Research, 2006). Participatory action research focuses on research partnerships and promotes empowerment, inclusivity and respect (Dickson & Green, 2001; Ermine, et al., 2004). It is recognized that PAR can also be complementary to Indigenous research methodologies (Evans, Hole, Berg, Hutchinson, & Sookraj, 2009). Indigenous methodologies (IM) are an

alternative way of conceptualizing research processes that have traditionally been grounded in positivistic paradigms (Berg, Evans, Fuller, & The Okanagan Urban Aboriginal Health Research Collective, 2007; Louis, 2007). They are intended to give a voice to peoples who have been marginalized by traditional research practices (Berg, et al., 2007; Evans, et al., 2009). Indigenous methodologies promote research by and for Indigenous people, privileges their voices, and values research approaches drawn from Indigenous traditions (Evans, et al., 2009). This research is primarily designed around the principles of PAR, but with an awareness of Indigenous methodologies and their importance.

Jacklin and Kinoshameg (2009) suggest that when participatory research is conducted properly, community members are engaged in the research process from the inception of the project. This means that they are actively involved in defining the research questions, planning and designing the project, and implementing and evaluating the results. They further recommend eight principles for research that is culturally and community appropriate. These are: partnership, empowerment, community control, mutual benefit, wholism, action, communication, and respect. These recommendations are in line with recommendations for ethical research with Aboriginal peoples outlined by the *Tri-Council Policy Statement on Ethical Conduct for Research Involving the First Nations, Inuit and Métis Peoples of Canada* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010), the *Canadian Institute of Health Research (CIHR) Guidelines for Health Research Involving Aboriginal Peoples* (Canadian Institutes of Health Research, 2006) and the National Aboriginal Health Organization principles of ownership, control, access and possession (OCAP). This research was designed to respond to a need for research about Alzheimer's disease and related dementias that was articulated by key community stakeholders on Manitoulin Island (Sutherland, 2007) and community engagement was sought during all stages of the research including the research design, development of questions, and evaluation of results. This process is described further in the methodology section later in this chapter.

Evans et al. (2009) argue that key aspects of PAR and Indigenous methodologies intersect and that the two are compatible. Margaret Kovach (2009) also suggests that IM shares certain characteristics with relational qualitative approaches such as PAR, because they both value process as well as content. Both PAR and IM share a goal of counteracting the Western positivist research paradigm (Ermine, et al., 2004; Haig-Brown & Dannenmann/Kaamatweyaashiik, 2002; Louis, 2007). Instead, the focus of IMs is on cultural relevance and coming to indigenous ways of knowing. To achieve research that meets these guidelines, researchers focus on engaging in projects that are useful and beneficial to the communities in which they are carried out, culturally-relevant, defined by partnerships and collaboration, and founded on an Indigenous worldview (Ermine, et al., 2004; K. Jacklin & Kinoshameg, 2009; Smylie et al., 2004). Increasingly,

there is also a call for “insider” research, which involves including one or more individuals from the target community on the research team, and involving other Aboriginal “insiders” in all stages of the research from design to implementation (Ermine, et al., 2004; K. Jacklin & Kinoshameg, 2009; Macaulay et al., 1999).

Martin-Hill (2009) speaks to the importance of using an Indigenous knowledge framework for understanding issues relating to Aboriginal health and wellness. She argues that the wellness of an Aboriginal community can only be understood from a holistic and inclusive framework that considers multiple spheres of life including the spiritual, emotional, physical and social. This sentiment is echoed by Marie Battiste (2000) in her introduction to the book, *Reclaiming Indigenous Voice and Vision*. In this book, Battiste (2000) shares a story told by Eber Hampton (1995:42) about an elder who asked him to carry a box. He shared how after agreeing to help the elder presented him with an empty box and asked him this question:

“How many sides do you see?”

“One,” I said

He pulled the box towards his chest and turned it so that one corner faced me. “Now how many do you see?”

“Now I see three sides”

He stepped back and extended the box, one corner towards him and one towards me. “You and I together can see six sides of this box,” he told me. (Hampton, 1995:42 in Battiste 2000:xvii)

This story resonated with me as it very clearly demonstrates the importance of multiple perspectives in any attempt to understand a problem. I have privileged multiple perspectives throughout the course of this research and have made an effort to include a discussion of spiritual, emotional, physical, and social realms in my analysis of aging and dementia because I believe they are crucial to understanding the true impacts of this disease. This holistic perspective is also reflective of Aboriginal peoples’ understandings of health and wellness. I am also acutely aware that dementia is understood and experienced differently by different groups of people. The design of this research project is structured to bring together these varied voices, of people with dementia, family caregivers, seniors, health care workers (Aboriginal and non-Aboriginal), and traditional healers precisely so that a holistic understanding of the full impacts of dementia can be gathered.

I have made a strong effort to understand dementia holistically and to privilege Indigenous ways of knowing. However, I am aware that as a non-Indigenous researcher

with an academic background I bring certain knowledge, understandings and prejudices to my understanding of aging and dementia that may differ from the perspectives of the people and communities I worked with. I have made an effort throughout the research process to stay constantly mindful of these possible biases and, as Kovach (2009) recommends, to be open to the Indigenous worldview and alternative ways of knowing. Although there are challenges involved in being a non-Indigenous person conducting Indigenous research, Ermine (2000:121) suggests that when Indigenous and Western worldviews are brought together there is an opportunity to create “ethical space.” Ermine’s (2000) perception is that the place where these two viewpoints intersect represents an opportunity to create shared meaning and new understandings because in this space, there are no definitive rules. Although there are inherent power differentials in the relationship between a researcher and participants, Ermine’s (2000) assertion that the voices of both parties can come together to negotiate meaning has promising implications for the possibility of developing research models centered on equality and respect.

I came to this project with knowledge of dementia and how people live with dementia that was shaped by my own experiences, experiences that are biased towards my own background and belief systems. This knowledge came from diverse places: personal experience with a grandfather experiencing memory loss, volunteer training based on biomedical knowledge, reading academic publications, attending conferences, friendly visiting experiences with people with dementia, and the mainstream media. Most of my initial knowledge came from mainstream or biomedical sources. However, I also came to this project with a desire to learn about experiences of dementia from a different perspective, the perspective of Aboriginal peoples. I was very willing to open my mind to different understandings of dementia, even if they clashed with my pre-conceived notion of what dementia is and how it is experienced. Although it was difficult at times to set aside my biomedical understandings of dementia, the process of interviewing and observing Aboriginal people who were coping with the disease allowed me to broaden my own perceptions.

I went into interviews with an open mind and the goal of just listening to what people had to say, learning from them. In some instances, my own perspective or understanding did emerge in interviews because people would have questions about dementia – how it was caused, if a certain symptom or behaviour was “normal”. On these occasions, I would use my prior knowledge to help answer these questions. This is one example of an occasion when my perspective and the perspectives of a participant might intersect. I would share information with them while they shared new information from me. This was an opportunity for both myself and the participant to create shared meaning. Although my voice is necessarily visible in this thesis, I made an effort to privilege the voices of my participants by presenting their perceptions in their own words, using quotations, as much as possible.

Phenomenology

A phenomenological data analysis approach was used in this project. This approach is focused on rich thematic descriptions that grapple with how people make meaning of their lived experience (Starks & Trinidad, 2007). Phenomenology is also concerned with embodiment, the bodily aspects of the human experience, and the lived experience of the life world (Desjarlais & Throop, 2011; van Manen, 1997). Phenomenology is understood to be compatible for research with Aboriginal peoples because it privileges narratives and storytelling and respects values such as holism, circularity, and oneness (Struthers & Peden-McAlpine, 2005). An additional benefit of a phenomenological approach is that it captures the whole picture of peoples' experiences with dementia; it preserves meaning and context (Crazy Bull, 1997; Leonard, 1994; Struthers & Peden-McAlpine, 2005).

Phenomenology has been used as both a philosophical standpoint and as a methodological approach. It can be difficult to pinpoint exactly which school of phenomenological thought one belongs to, since scholars have borrowed, recombined, and altered phenomenological frameworks for almost a century. As the oft-quoted Spiegelberg (1982:653) states, "there are as many phenomenologies as phenomenologists". With this in mind, I provide a brief discussion of the history of the phenomenological movement and the particular aspects of phenomenology that I have drawn on to conduct my analysis.

Philosophical phenomenology was first developed by Edmund Husserl in the 1930s (Dowling, 2007). Husserl was interested in reaching an understanding of true meaning. He believed it was possible to understand the essence of an object, the identifiable characteristics that made it unique from other objects (Edie, 1987; Lavery, 2003). Husserl recommended the practice of phenomenological reduction, or bracketing, in order to see a phenomena clearly free of individual biases, cultural content, and the outer world (Dowling, 2007; Lavery, 2003).

Heidegger's hermeneutic phenomenology differs from Husserl's phenomenology. Heidegger was trained by Husserl in phenomenological processes or intentionality and reduction, but later revised these ideas based on his own perceptions of the goals of phenomenology (Dowling, 2007; Lavery, 2003). Heidegger's hermeneutic phenomenology maintained the focus on the life world and human experience as it is lived (Lavery, 2003), it "illuminates what is and brings out that which is taken for granted" (Barton, 2004:521). However, Heidegger approached phenomenology somewhat differently than Husserl in that he recognized that time, culture and history were part of human understanding, and that it was not possible to "bracket" out important contextual understandings such as time, the body, space, and relationships with others (Koch, 1995; Lavery, 2003). Heidegger perceived all understanding to be

related to a person's historicity, their history or background, and that it was not possible for a person to eliminate their background from their understanding of the world (Lavery, 2003). Therefore, he suggested that a researcher, for example, needs to be explicitly aware of these influences, and account for them in their interpretations of experience. This is achieved through an interpretive process known as the hermeneutic circle (Lavery, 2003).

The hermeneutic circle of understanding refers to the analytic process of searching for meaning by considering discrete parts of experience against the experience as a whole, moving back and forth between the two (Barton, 2004). Barton (2004) suggests that there are similarities between the Heideggerian hermeneutic circle and the Aboriginal sacred circle, a significant paradigm in Aboriginal thought (Bird, 1993 cited in Barton 2004) which relates to well-being, holism and the medicine wheel. The suggestion is that the hermeneutic circle and the sacred circle are complimentary because they prioritize reflexive thinking, relationality, and cultural and historical knowledge as experience (Barton, 2004). I perceive a hermeneutic phenomenological approach to be relevant to this project in part due to Barton's (2004) assessment that hermeneutic phenomenology is compatible with Indigenous ways of making meaning.

Barton (2004:521) considers that the goal of a hermeneutic approach is to understand "how the horizon of the interpreter and the horizon of the interpreted become enmeshed and create meaning in that context". She suggests that through dialogue, the researcher and the participant co-create a new horizon, and develop a relationship which helps them to create knowledge together. This understanding is drawn from Gadamer's (1975) perspective of horizons, which he understood to include everything that could be seen from a particular vantage point (Lavery, 2003). As I read this description of hermeneutical horizons, and how they come together as part of the interpretive process, I was reminded of Ermine's (2000) concept of ethical space, and the way in which bringing together two worldviews opens up opportunities to discover new meaning. This perhaps provides another argument for the applicability of hermeneutic phenomenology to research involving Aboriginal peoples.

The concepts of hermeneutical horizons and ethical space relate to the overall methods and goals of this project. As I previously discussed, the very nature of this project involved bringing multiple horizons together. I, and the rest of the research team, came into the project bearing knowledge about certain aspects of dementia. Each of the groups of research participants (people with dementia, seniors, etc.) also came with their own knowledge and biases. The process of responding to Aboriginal communities' expressed need for research relating to dementia and listening to Aboriginal peoples' beliefs and understandings of the disease brought together multiple forms of knowledge and allowed us to create new meaning. By compiling the information gathered through interviews, focus groups, and participant observation with

the expertise and knowledge of the research team we were able to identify community needs, pinpoint shared and divergent understandings of dementia held by health care providers and service users, and look towards finding solutions. These different perspectives, when pooled, create a new, shared understanding that has the potential to be used to improve policy and health care strategies for people coping with dementia.

Of course, during this process it was still important for me to be aware of my possible biases and to address them as I engaged in data collection and analysis. As I mentioned previously, I worked hard to keep an open mind during the interview process. I approached interviews as an opportunity to learn from the participants and not to judge their understandings against my own. During the analytical process when I was working with recorded and transcribed interview data I had to make a conscious effort to recognize how my history and background might colour the way I interpreted what my participants were saying. I also had to recognize how my goals (completing a Ph.D. thesis) related to the goals of the communities I was working in (learning more about peoples experiences so that their needs might be better addressed). I found the process of the hermeneutic circle, considering data both as small, discrete pieces of the puzzle and as a larger whole, and moving back and forth between these different scales of understanding to keep me grounded in my participants' understandings.

Hermeneutic phenomenology resonated with me as an appropriate approach to studying First Nations people's experiences with aging and dementia not only because of the support for the compatibility between phenomenological approaches and research with Aboriginal peoples that I encountered in the literature, but also because hermeneutic phenomenology allows for an interpretation of experience within the context of culture, and recognizes that meaning is neither universal nor static (Caelli, 2000). The ability to incorporate culture into my analysis is important, since gaining knowledge of cultural understandings of dementia among First Nations people is central to the goals of this thesis. However, pinpointing exactly what culture is can be problematic and thousands of definitions of culture exist (M. J. Brown, 2008).

In this research, I understand culture to be a shared set of knowledge, values and a way of understanding the world held by a subset of people that encompasses traits such as language, spirituality, and ways of life. I relate to a fairly standard interpretive definition of culture that sees culture as a shared set of socially learned and transmitted ideas that motivate behaviours (M. J. Brown, 2008; Geertz, 1973). In this thesis, culture is understood to be fluid, flexible, and adaptable. I recognize that any one person may perceive themselves to belong to multiple cultures on different scales, and that they may relate more strongly to some aspects of their culture than others. For example, although all of my participants likely identify in some way with "Aboriginal culture" there is great diversity among these individuals in such areas as the languages they speak, or their identification with traditional spirituality versus Christian teachings. Other scholars

have recognized that there can be variation in the ideas held by different people in a society (Borofsky, 2008). For example, Warry (1998:35) addresses the idea that cultures change, stating that although specific practices or traditions may go out of use, culture is something larger, and more enduring, something that transforms and changes over time.

As stated previously, phenomenology has its roots in philosophy, but has been adopted and adapted by many other disciplines. Many scholars today recognized that the way phenomenology is being used in some disciplines, such as nursing, differs quite significantly from traditional philosophical phenomenology (Caelli, 2000). The phenomenological approach that I have used is reflective of the phenomenological approach that has been taken up in disciplines with an interest in studying health and caring which has been variably named “new” (Crotty, 1996), “scientific” (Giorgi, 2000), or “American” (Silverman, 1987) phenomenology. I have utilized phenomenology in a way that is generally consistent with this “new” phenomenological perspective which is centered around Heidegger’s hermeneutic approach and recognizes that health, illness and caring are products of cultural and social contexts (Benner, 2000).

Sample

Several types of people were selected to participate in this research. A total of 42 interviews were carried out with people with dementia, informal family caregivers, healthy seniors, and key informants including community health care workers, traditional healers, physicians and specialists. In addition, three focus groups were carried out with nurses and personal support workers (n=17). This sample size was adequate to provide me with rich data and theoretical saturation. Participants for this study were chosen by convenience sampling. Gathering perspectives from a wide variety of people was important to this research, as it provided for a more complete understanding of the complex experiences of dementia for individuals, families and communities. Clear guidelines were established about the type of people who were desired as participants and easily accessible participants were selected based on these criteria (Kemper, Stringfield, & Teddle, 2003; Marshall, 1996). Informants from Manitoulin UCCMM communities were identified by the researcher with assistance from the Home Care Nurse Manager (Debbie Selent) from Mnaamodzawin Health Services. Participants in Wikwemikong were identified by a local research assistant (Karen Pitawanakwat) who is also a nurse at the local health centre. These community health workers made first contact with potential participants to ask if they would be interested in being contacted by a researcher to participate in the study.

Table 4. Interview and Focus Group Participants

Research Site	Wikwemikong	UCCMM Communities
<i>Interviews</i>		
People with dementia	5	5
Caregivers	5	6
Seniors	6	4
Total	16	15
<i>Focus groups</i>	2	1
Number of focus group participants	10	7
Key informants	3	8
Total participants	29	30

People with Dementia

Ten people living with dementia were interviewed, six were female and four were male. They ranged in age from 62 to 81. All people with dementia were community-dwelling. That is, they lived in their own home or the home of a relative. The majority (7 out of 10) lived alone in their own homes or apartments. Of the remaining three, two lived with their spouse and one lived with an adult daughter. Eight of the ten people with dementia disclosed complex health issues in addition to problems with their memory. These issues included cardiovascular disease, diabetes, cholesterol, osteoporosis, arthritis, depression and cancer. Of these individuals I am only certain that four had a formal diagnosis of some form of dementia. The criteria for acceptance as a participant relied not on a formal diagnosis, but on the recognition by themselves, a family member, or a community health care worker that memory problems were an issue. The symptoms that people who were interviewed were experiencing included forgetfulness and repetition, a loss of a sense of time, suspiciousness, inability to manage activities of daily living, and unsafe behaviours including wandering or forgetting to turn off appliances or manage health issues. The only exclusion criterion was that a person not be in the late stages of dementia, when it would be too difficult for them to participate in a meaningful way.

Although there can be methodological and ethical challenges in working with people with dementia, such as concerns about the consent process (Bond & Corner, 2001; Cattarinich, Gibson, & Cave, 2001) it was very important to me to include people

experiencing memory loss in this research. The perspectives of people with cognitive impairment have traditionally been overlooked in research about dementia, because it was perceived that they could not participate in a meaningful way. However, more recently there has been a considerable effort on the part of many researchers to privilege the voices of PWD (Downs, 1997; Hubbard, et al., 2002; Wilkinson, 2002). Their contributions have proven to be meaningful both in researcher's attempts to better understand experiences of dementia, and as a tangible benefit to the people with dementia themselves. It has been recognized that participation in the research process is inherently beneficial for the patient. By fostering recognition that dementia patients have something meaningful to contribute, inclusionary dementia research recognizes dementia patients as valuable individuals. Their participation in this type of research supports the maintenance of self esteem and "a sense of personal competence, uniqueness and hence personhood" (Bartlett & O'Connor, 2010:26). Further, the inclusion of people with dementia in research can lead to the development of services that fit the actual, as opposed to perceived, needs of this population.

My interviews with people with dementia did not reveal as much as I had hoped. I believe that this is in part due to the way that the interview questions were structured. The interview schedule for people with dementia was quite focused on questions about "your memory loss" or "your memory problems". Participants were very willing to respond to these questions, however many of them did not perceive that they had any particular problems with their memory, and as a result they did not have much to say about their own experience. It may have been more productive to interview people with dementia following the interview guide that was designed for well seniors, which focused on asking more generally how a person might feel if they were experiencing memory problems. This may have encouraged people with dementia to be more vocal about their experiences or how they perceive the issue in two ways. First, because asking people about dementia more generally may be less threatening and less likely to bring up possible feelings of shame related to their symptoms than asking them directly about the problems they are experiencing. Secondly, because asking about dementia in a more general sense gets around the issue of people not being aware of their own memory problems, or not perceiving the changes to their memory as a problem.

Despite this challenge with the wording of the questions, the interviews with people with dementia were generally successful and some interviews revealed very important information which helped to give a different perspective than that of caregivers and medical professionals. Most of the participants with dementia had fairly mild symptoms and were able to understand why I was there, the purpose of the study, and the questions very well. Three interviews with people with dementia were notably short, under 30 minutes. Two of these individuals were just not talkative, and the third did not perceive that she had any issues with her memory, so it was difficult to elicit rich responses. On the whole, interviews with people with dementia that were carried out by

my research assistant, Karen Pitawanakwat, were longer and more detailed. I attribute this to the fact that these participants already had a relationship with Karen prior to the interviews through her role as a nurse in the community, and that Karen knew more about the person's experience with memory loss because she was familiar with their medical history. Due to the need to respect confidentiality, I usually had very little knowledge of the medical history or diagnostic status of the people with dementia who I interviewed.

Regardless of the inherent challenges related to interviewing people with dementia, I enjoyed meeting with people experiencing cognitive decline and hearing their voices and I believe that they contributed an important perspective of the dementia experience that helped me to have a deeper understanding of the experience of dementia. I hope that I have adequately represented the voices of people with dementia in this thesis.

Seniors

The seniors who were interviewed were diverse in their age, sex and health status. The main inclusion criterion was that they were 50 years old or older. The three males and nine females who were interviewed ranged in age from 60 to 86. Healthy senior participants differed in their living arrangements, community of residence, and marital and employment status. 6 lived alone and 4 lived with a family member (3 with spouse, 1 with adult children). Many of the informants who were chosen to represent healthy seniors were experiencing one or more health problems. These included diabetes, hypertension, arthritis, a loss of physical strength and endurance, limited eyesight, being confined to a wheelchair, and being reliant on oxygen. Some participants were healthy. Some participants expressed that they had a traditional orientation and a deep knowledge of traditional ways, but others followed Christian teachings. There were participants who spoke a Native language as their mother tongue and others who only spoke English. Individuals were selected to participate because they were perceived to exhibit traits such as resilience, continued independence, active engagement with life, and a positive attitude.

Interviews were conducted with seniors who do not have dementia to determine their explanatory frameworks for being and becoming old. Interviews with these individuals were used to develop a subjective, culturally relevant model for expectations related to age and aging in this community. This model can serve as a baseline against which to conceptualize the aspects of Alzheimer's and dementia that most significantly impact the experience of aging for Aboriginal seniors. The primary goal of interviews with this group was to identify how aging is expected to progress, what leads to health problems in old age, and how people prevent or cope with changes in their lives and their health status as they age. The seniors who were interviewed were very receptive to the topic and had many important insights into appropriate approaches to caring for a

person with dementia as well as sharing their own perspectives of the aging experience. These individuals were very engaged in the interviews and were extremely open to sharing their opinions.

Caregivers

Twelve caregivers were interviewed in eleven interviews. Caregivers were spouses, adult children, and a niece and nephew. There were nine female and three male caregivers. They ranged in age from 27 to 84. Seven caregivers lived with the person they were caring for (5 spouses, 2 adult children) and the remaining five (3 adult children, 1 niece and nephew) did not. Caregivers who were interviewed were not necessarily providing care to a person with dementia who was interviewed. The amount of care that they provided varied widely from occasional assistance with activities such as transportation and shopping to more involved, daily care relating to dressing, feeding, hygiene, and managing health issues. Caregivers were selected based on the criteria that they were providing a significant level of assistance to a senior experiencing problems with their memory. Again, a formal diagnosis was not a criterion for participation. Caregivers were interviewed because they were able to provide information about how dementia is being experienced by the person they are caring for, but also because they are in a unique position to comment on the quality and availability of services available to them and they often have a clear understanding of the needs of the person with dementia. Further, caregivers themselves face significant challenges and can be at risk for strain and burnout. Understanding the challenges that caregivers face can provide us with important information that can be used to develop supports and services to benefit people with dementia and caregivers alike as their experiences are deeply intertwined.

The caregivers who were interviewed all provided us with very rich data. Of all of the people who we interviewed, the caregivers were the most likely to become upset or emotional during their interviews. All of the caregivers who were interviewed seemed very accepting of their role as caregiver, but were clear that there were challenges involved in providing care, especially in the later stages of the disease or in the presence of other co-morbid health issues. Although many of the caregivers appeared to be coping quite well with the challenges of providing care for a person with dementia, most caregivers spoke of a need for more supportive services. Only one caregiver explicitly mentioned a negative coping mechanism – the use of alcohol – others seemed to cope in other ways such as seeking support from friends and family, and focusing on the positive gains associated with providing care.

Key Informants

Interviews were conducted with key informants including seven community health workers, two physicians, and two traditional healers. Three focus groups were

conducted with 17 home care nurses and personal support workers (PSWs). The focus groups consisted of five PSWs, six registered nurses (RNs), five registered practical nurses (RPNs), and one home care program assistant. The physicians who were interviewed included one local physician and one geriatrician from McMaster health sciences who has been making biannual visits to provide consultations on Manitoulin for 20 years. The perspectives of these individuals were gathered to provide a different perspective from seniors, people with dementia, and caregivers and helped to represent certain situations, such as cases where families were not providing care for a person with dementia, that were not documented through interviews with other participants. Key informants were also more likely to have some degree of formal education and training related to dementia, which allowed for a point of contrast to community members' perspectives of dementia.

I carried out three focus groups, one towards the beginning of my fieldwork and two close to when I was finished. The first, held with personal support workers in Wikwemikong was poorly attended ($n = 2$) and much less productive than the other two. This was in part because the PSWs expressed that they had very little knowledge about dementia or about the diagnoses of their clients. Although the data that emerged from this focus group was perhaps less rich than the subsequent focus groups it nevertheless highlighted some important issues relating to the care of people with dementia. During my time on Manitoulin, I encountered these two PSWs on several other occasions outside of the focus group and engaged in informal conversations with them. What struck me the most was that they were acutely aware that they lacked the skills necessary to cope with clients with dementia, particularly those who exhibited challenging behaviours. On a few occasions, these individuals approached me for advice about how to cope with specific behaviours.

One of the other focus groups was held with home care nurses and personal support workers from Mnaamodzawin Health Services ($n=7$) and the other was comprised of nurses who worked with Wikwemikong Long Term Care ($n=8$). The fact that the nurses and PSWs from Mnaamodzawin all came together to participate in one focus group, whereas the Wikwemikong nurses and PSWs participated in separate focus groups is, from my perspective, representative of the way that they engage with one another in the context of providing care in the community. The nurses and PSWs at Mnaamodzawin seemed to be a much more integrated group who were encouraged to communicate with one another about the care of their clientele. I got the impression from speaking with PSWs in Wikwemikong that they feel quite isolated in their jobs and separate from other care workers and physicians. The PSWs in Wikwemikong seemed less confident about how to provide care for people with dementia and lacked a sense of empowerment to affect change and improve their clients' lives.

Methodology

This research followed a participatory research design (K. Jacklin & Kinoshameg, 2009) that privileged the input of Aboriginal communities in the design, development, and implementation of the project. Myself and the other members of the research team engaged with community members at all stages of the research including the development of funding proposals, key questions, methodologies, and data analysis. Some of these components of the project development for the larger project were underway or had been completed by the Principal Investigator (PI) before I began the Ph.D. program. These included initial community consultations with key stakeholders about the research design and the ethics approval process.

However, I was an active participant in community meetings with local Elders' groups and health care workers during the development of interview scripts for the project. A consultation with elders in Wikwemikong was held at the Amikook Senior's Center, and a consultation with UCCMM seniors held at the Ojibwe Cultural Foundation in M'Chigeeng in January 2010. These meetings helped us to identify emergent themes related to seniors' perceptions of dementia and, more importantly, gave community Elders an opportunity to review our research questions and interview scripts prior to the time that we began carrying out interviews. Their input at these meetings helped us to ensure that our interview scripts addressed topics that were of concern to seniors in our target communities.

Ethical clearance was obtained from McMaster and Laurentian University and community-based ethics review boards on Manitoulin Island and all of the participating First Nations provided a band council resolution (BCR) and/or Health Council motion giving community consent and support for the project to proceed. Community health centers were also supportive in identifying potential key informants and research participants. This research adheres to the ethical guidelines outlined in *Chapter 9 of the Tri-Council Policy Statement on Ethical Conduct for Research Involving the First Nations, Inuit and Métis Peoples of Canada* (Canadian Institutes of Health Research, et al., 2010) and *Canadian Institute of Health Research (CIHR) Guidelines for Health Research Involving Aboriginal Peoples* (Canadian Institutes of Health Research, 2006) and emphasizes the National Aboriginal Health Organization principles of ownership, control, access and possession.

The project was centered on ethnographic methods. The ethnographic method is characterized by fieldwork, which involves "working with people for long periods of time in their natural setting" (Fetterman, 2010:33). Fieldwork is exploratory in nature, and can include several different methods such as interviews, focus groups and participant observation (Fetterman, 2010). I utilized each of these methods to address my research questions. A major component of this research was 11 months of ethnographic

fieldwork on Manitoulin Island, Ontario. I relocated to Manitoulin in April 2010 so that I could immerse myself in the research process and have regular interaction with the communities I was working with. While living on Manitoulin I engaged in participant observation and carried out interviews and focus groups.

A community-based researcher (CBR), Karen Pitawanakwat, was hired in Wikwemikong to assist me with interviews and data analysis for Wikwemikong. She received training in Sudbury over two days from the PI. Karen identified research participants, carried out interviews, and was encouraged to participate in data analysis by completing interview summaries and participating in team meetings. Hiring and training a CBR in each of the communities involved in the larger project that my project was a component of was intended to improve local research capacity. Karen and I communicated frequently over the course of my fieldwork. We met regularly to determine appropriate participants and to discuss emerging themes. Further, I attended some of the interviews that Karen carried out. Karen's knowledge of her community and her understanding of local language and culture benefitted this project greatly. She was able to elicit extremely rich data in the interviews she conducted and expressed valuable insights in her interview summaries and in informal conversations, which helped me to see the data from a different perspective and address possible biases in my understanding. In addition to my discussions with Karen, I also scheduled meetings with other health staff, including health directors, throughout my fieldwork to discuss the progress of the project.

Interim results were presented back to the communities and health committees at various times throughout the data collection and analysis process. In addition, a community advisory group was assembled for Manitoulin Island that included health directors and other community volunteers. The advisory group was presented with draft reports and presentations and asked to review the data analysis and ensure that local knowledge was presented accurately, appropriately reflected the community, that reports did not violate researcher-community agreements and that the knowledge was treated with respect. As I discuss further in the *Dissemination and Knowledge Translation* section of this chapter, a community report was created following data analysis and presented to the community advisory group for feedback in November 2012. In addition, copies of a completed thesis draft were sent to all community health directors so that they could have the option of reviewing it prior to submission.

Identification of Participants (Sampling)

People with dementia, family caregivers and seniors were primarily (29 of 31) identified by the CBR in Wikwemikong and the Home Care Nurse Manager from Mnaamodzawin Health Services in UCCMM communities. The remaining two participants were identified by the Manitoulin representative of the Alzheimer's Society

and by myself through interactions with community members. The CBR and Home Care Nurse Manager made initial contact with potential participants to explain the project, determine interest in participation and to schedule an interview time. An effort was made to interview diverse participants including a mix of ages, genders, diagnoses, living arrangements, and communities of residence to ensure that the full picture of experiences of dementia could be represented. Key informants were identified through snowball sampling (Vogt, 1999). As I spoke with stakeholders in the community, I asked for names of other healthcare workers who were involved in caring for people with dementia. I then approached those individuals personally to inquire about their willingness to participate in the research.

Consent

Informed consent was obtained from all participants prior to their participation. Individuals were given a written outline of the project and the researcher described the project verbally prior to the participants signing a consent form. It is recognized that there are special ethical concerns involved in establishing consent with PWD. Special care was taken to ensure consent was obtained appropriately from people with dementia. The approach I used is consistent with process consent, which involves ongoing monitoring of consent and accepts that capacity is situational (Dewing, 2002, 2007; Hubbard, et al., 2002). Process consent operates under the conditions of informed flexibility, sympathetic presence, negotiation, mutuality and transparency (Dewing, 2007). I was especially careful to pay attention to non-verbal signs when interviewing people with dementia, to ensure they were comfortable participating or continuing to participate in the research (Berghmans & Ter Meulen, 1995). I did not have any issues in obtaining consent from the participants with dementia as most were in the early stages of the condition and it was clear that they were able to understand the project and their role in it. The majority of participants with dementia signed their own consent form, but proxy consent was also obtained from some caregivers.

Interviews and Focus Groups

Interviews and focus groups were conducted with several types of people to ensure that a complete picture of the dementia experience could be reported. Face-to-face in-depth, semi-structured interviews were carried out with seniors with dementia and their primary caregivers, seniors who did not have dementia, and traditional and mainstream healers. Semi-structured interviews use an interview guide, with questions and prompts, to ensure that similar topics are explored in all participant interviews (Bernard, 1994; DeWalt & DeWalt, 2002). However, this approach still allows the participant to express themselves with a fairly high degree of freedom and flexibility, “in their own terms, and at their own pace” (Bernard, 1994:211). Interviews were performed in the location of the participant’s choice, usually their home or place of work. They lasted from 30

minutes to 2 hours. The majority of the interviews were conducted in English, but participants were welcomed to speak their language of choice and translation was available where needed. Each participant received a seventy-five dollar honorarium for their participation. Interviews and focus groups were digitally recorded and transcribed verbatim. Pseudonyms are used to protect the identity of participants.

Interview and focus group guides were developed as a collaborative process with the PI (Jacklin) and other research assistants on the project (Boesch and Kanasawe). Distinct interview guides were developed for each of the target groups in our sample (people with dementia, senior, caregiver, key informant, traditional healer, focus groups). Interview guides began with basic contextual and narrative information about the participant including their age, the community they lived in, etc. The guides then covered several key domains relevant to the interview category. The caregiver interview guide focused on explanatory models of care-giving and dementia as well as community services and supports; the interview guide for people with dementia included questions about signs, symptoms and diagnosis, treatment and care, and knowledge and understandings of dementia; seniors were asked to describe their experiences with aging, their explanatory models of healthy aging, and their perceptions and understandings of dementia. If seniors were identified as being particularly traditionally-oriented or were considered to be a traditional knowledge keeper or healer they were asked further questions relating to their traditional knowledge related to dementia. Interviews with physicians related to their understandings of their Aboriginal clients' experiences with dementia. Focus groups were asked about local perceptions and understandings of dementia, the incidence and prevalence of dementia in their case loads, health promotion and education, screening and care, as well as Indigenous explanatory models. Interview guides are appended (Appendix A through F).

Focus groups were conducted with care and support workers who worked with dementia patients and their families. Three focus groups were conducted with home care nurses and personal support workers. Focus groups typically consist of groups of 6-12 informants who are gathered to discuss a specific topic with the facilitation of a moderator (Bernard, 1994). A benefit of focus groups is the interaction between participants which helps to generate conversation and identify group norms by exploring the similarities and differences in peoples' perspectives (Kitzinger, 1994). Two focus groups had a good turnout, with seven and eight participants respectively; the other focus group was poorly attended with only two participants. Focus groups were held at the care workers' place of work and a private room in a local restaurant and lasted from 30 minutes to 2 hours. Meals were provided to all focus group participants.

Participant Observation

Participant observation involves observation and informal interactions and conversations and has the potential to shape the development of more formal interview questions and to enrich insights into the daily experiences of research participants. Participant observation can be formally defined as “a method in which a researcher takes part in the daily activities, rituals, interactions, and events of a group of people as one means of learning the explicit and tacit aspects of their life routines and their culture” (DeWalt & DeWalt, 2002:1). By carrying out participant observation, a researcher can gather data that represents aspects of a culture that people are able to articulate as well as more subtle cues and clues about the way that people carry out their day to day lives (DeWalt & DeWalt, 2002).

For this project, I carried out participant observation in family and community care settings in First Nations communities on Manitoulin Island. I spent time at seniors’ centers, attended community events for seniors, shadowed a doctor doing assessments at the nursing home, and observed care being provided in homes by formal and informal caregivers. I was also privileged to attend two powwows as well as participating in a sunrise ceremony and a sweat lodge. These observations allowed me to gather community and cultural context that aided in the interpretation of more formal interview data. Observations in these settings shed light on day to day practices of cognitively impaired and non-cognitively impaired seniors, as well as caregivers in this community.

Finding appropriate opportunities for participant observation was a challenge of this research. I did not live in any of the communities I was studying due to a lack of appropriate housing. As a result, it was difficult to stay informed of the goings-on in all seven communities. In particular, I was interested in finding opportunities to engage with seniors. I attended several seniors’ holiday parties and events organized by Mnaamodzawin or other Elder’s groups during the course of my stay including diner’s clubs, a Halloween party, a 1950s theme party, and a summer picnic. These events brought together seniors from the UCCMM communities for a meal, as well as music and organized games. The group of seniors that gathered for these events was quite vibrant and these gatherings were always a lot of fun. I could see that the seniors enjoyed the opportunity to socialize together. At these events I sat with the seniors as they ate as well as participated in the planned activities. I found this to be a good environment to engage with seniors, but did not feel that it was a particularly appropriate environment to discuss dementia. Although I did talk to some individuals about my research during these events I did not find that people at these events were particularly interested in talking about memory loss, as they were at an event intended for fun and socialization.

I was also interested in spending time at the senior's centers in various communities, hoping that there would be opportunities for informal conversations with seniors over games or other activities. Unfortunately, most of the senior's centers were not open on a regular basis for drop-in activities. And, as one of my interview participants noted, even when they were, few people came. She expressed that she sometimes went hoping to find a partner for a board game or to play cards, but often found herself to be the only one there. This is a phenomenon that I witnessed first-hand in Wikwemikong. I went to the senior's center in Wikwemikong, Amikook, every Tuesday when they were open for seniors to come in to play board games. Every week it was the same story, only one person showed up. This individual and I played Scrabble for three hours almost every week and we became close friends. Although staff members at Amikook would occasionally join us for a game no other seniors ever stopped by to play.

My observations that senior's centers are under-used conflicted with what several participants stated in their interviews relating to their values of keeping busy and engaging socially. It is very possible that people tend to socialize more often in smaller, more private settings such as their own homes. However, I also wonder about how much the low usage of these centers relates to a lack of organized activities, a lack of communication about what events or activities are available, or a lack of availability of transportation or support to help housebound seniors to participate in these activities. Upon my return to Manitoulin in June 2013 for a dissemination activity, I was pleased to observe that Amikook had been freshened up with a new coat of paint and updated décor. Contrary to my observations of Amikook as a very quiet place during my initial fieldwork, on the day of my return visit it was a hive of activity and there was evidence of increased activity planning and participation in these activities.

Outside of my observations during interviews, I felt that it would be inappropriate to attempt to carry out observations of people providing care in their homes, and that it would intrude on their privacy. Further, I did not feel that regular observation would be appropriate in a nursing home setting. However, I did spend a full day in the Wikwemikong nursing home shadowing a visiting physician as he and his medical students carried out dementia assessments, and spent another afternoon in the Gore Bay nursing home with one of my interview participants while she visited her father. The impracticality of observation in health research has been recognized in the published literature. Although observation can provide rich data, it can be intrusive and logistically difficult (Starks & Trinidad, 2007). In this project, observation proved to be most useful in learning about the experiences of seniors and the supports available to them. However, during interviews with caregivers and people with dementia I was also able to see some of the situations in which care is provided which helped me to get a clearer picture of what people were dealing with and how they were coping.

Figure 2 Amikook Senior's Centre, Wikwemikong



Analysis

Interviews and focus groups were digitally recorded and transcribed verbatim. Transcripts were then coded using the qualitative data analysis software NVivo 8. NVivo was used to store and manage data, but I personally carried out all coding and analysis of my own data. Thematic analysis, a process of using codes or themes to organize and analyze qualitative data (Boyatzis, 1998), was carried out in several stages throughout the project. I identified emergent themes myself and in collaboration with my community-based research assistant (Pitawanakwat) and with other research assistants working on the larger project (Boesch and Kanasawe). An initial coding scheme was developed based on themes that emerged from our knowledge of theory, primary research results, and the key domains of our interview guides. Brainstorming sessions with Lisa Boesch and Agnes Kanasawe, research assistants for the larger project, were beneficial for identifying the key themes that shaped the coding structure. These themes were incorporated into the coding structure and analysis so that both theoretical foundations and community-based perspectives could be used together. Further codes were developed inductively as Boesch and I coded raw interview data. These additional codes reflected themes that were not anticipated in our original coding scheme. Boesch and I communicated with each other regarding new themes that emerged from the data and to ensure consistency between data interpretation for the larger project and for my thesis. The combined use of inductively (data-driven) and deductively (theory-driven)

derived codes is recognized to be effective in promoting analytical rigor (Fereday & Muir-Cochrane, 2006).

I later worked in depth with the transcripts and coded data, engaging with the material through repeated reading, reflection, and note-taking. While working with the transcribed interview data I also referred to my field notes and the experiences and observations I had in the communities to enhance the context of the interview data. I engaged with my transcripts by de-contextualizing and re-contextualizing the data to develop themes and look for patterns and relationships (Ayers, Kavanaugh, & Knalf, 2003; Morse & Field, 2000; Starks & Trinidad, 2007). Further, I spent a great deal of time reflecting on the data, often comparing different themes and seeing how they fit together. The observations that I carried out over the course of my fieldwork also informed my analysis, as they gave me the ability not only to hear peoples' perspectives of their experiences with aging and dementia, but also to see how seniors engaged in their communities, to visualize the environments in which my participants stories took place, and to witness the challenges associated with dementia and dementia care. The writing process also helped me to get close to the data, and the process of editing and re-writing various sections and chapters of my thesis, along with conference presentations, and a detailed community report allowed me to gain increasing familiarity with the data as I attempted conceptualize the full experience of dementia in First Nations communities. The process I used, of immersing myself in the data and moving between smaller parts and the larger whole was consistent with hermeneutic phenomenology.

In the writing of this thesis I have tried to accurately represent the lived experience of my participants. This is consistent with the goals of phenomenology, which assumes that as the participant tells their story their words will "speak for themselves" (Starks & Trinidad, 2007:1365). In order to allow people's stories to be told as they intended, I have included a significant number of direct quotes in the text of this thesis, as I believe that the best way to present my participants experiences with dementia is to use their words. This also allows me to privilege their voices and their nuanced representations of the challenges of living with dementia and their strategies to cope with these challenges. The use of verbatim quotations is also consistent with a phenomenological approach.

Analytical rigor was promoted in several ways. The development and utilization of the coding scheme was a collaborative process and efforts at accurately coding the data were reinforced by regular communication with another research assistant (Boesch) on the project. Summaries written by myself and my community based research assistant (Pitawanakwat) following interviews helped to document our initial impressions of the data that emerged from each individual interview participant. I also communicated regularly with Pitawanakwat during the data collection phase to exchange ideas and evaluate if there were consistencies or inconsistencies in the way that the data was

being interpreted. My ideas were also run by my supervisor (Warry), the PI on the larger project (Jacklin) and the other members of my advisory committee (Moffatt, Ploeg) at various stages of the completion of community reports and my thesis to ensure that my analysis was consistent and well-supported.

Dissemination and Knowledge Translation

As stated previously, disseminating knowledge back to Aboriginal communities is an important part of community-based participatory research. Throughout the course of this research project, updates on the progress of the research have been communicated back to the communities at local research conferences and community meetings including the Mnaamodzawin board meeting and Wikwemikong health day. Most recently, I developed an extensive community report in conjunction with the principal investigators. The report was presented to our community advisory group on Manitoulin Island in November 2012 and they were asked to contribute their feedback.

Upon completion of a draft of my thesis, I returned to Manitoulin Island to present my findings to the communities I worked in. I organized four presentations: one with the management team at Mnaamodzawin health services, one for the Wikwemikong health committee, one intended for seniors in Wikwemikong, and one for seniors living in UCCMM communities. At the presentations for health service providers, I presented the results of my thesis and invited comments, feedback and requests from the attendees related to the results. I also took this opportunity to ask questions of the attendees to clarify anything that I felt I needed further information about to understand. There were 5 participants at the Mnaamodzawin presentation and 7 participants at the Wikwemikong health committee meeting. It emerged from the Mnaamodzawin meeting that diagnosis and training are key concerns. These areas of interest were echoed in Wikwemikong. A draft of my thesis was also forwarded to the health directors at Mnaamodzawin, Noojmowin Teg, and Wikwemikong to ensure transparency and give them an opportunity to provide me with feedback.

Only two seniors attended the presentation for seniors at Amikook in Wikwemikong. However, 6 personal support workers also attended. The two seniors who attended both had husbands with dementia and shared some of their experiences with me following the presentation. The attendance at the presentation by PSWs and PSW students indicated to me that there was a greater awareness of dementia and an increased interest in learning about how to provide care to people experiencing memory loss. Conversations with these PSWs following the presentation revealed that efforts have been made in the community to improve awareness of dementia among PSWs and to provide them with increased training since my initial fieldwork.

There were approximately 30 people in attendance at the UCCMM seniors' presentation including seniors as well as home care nurses and PSWs. Although there were few questions immediately following the presentation, a couple of individuals approached me privately during the meal that was provided afterwards. These individuals expressed concerns they had about their own memory or the risk factors that they had for dementia and were interested in clarifying some information from the presentation or identifying the steps they should take to find out if the symptoms they were experiencing might be associated with dementia.

Conclusion

This chapter outlined the ethical, methodological, and analytical approach used for this research. The ethnographic research approach that was used allowed the researcher to gather in-depth descriptions of experiences with dementia from many different types of people. Together, the rich narratives of my informants can be used to paint a vividly descriptive picture of the lived experience of age-related memory loss by First Nations people on Manitoulin Island, Ontario.

Chapter Three: What makes for a good old age? First Nations older adults' perceptions of successful aging

Introduction

Successful aging is a concept that suggests that it is possible for older people to experience well-being, functional capacity, and meaning in their lives as they age. All adults have the potential to age well and should have access to the knowledge and services that allow them to best experience a positive old age. The promotion of healthy aging practices has the potential to deliver benefits across a wide spectrum of older people. It may prevent or delay the onset of disease (including dementia), improve the ability for older adults who are ill to experience better quality of life, and may also have significant implications for care providers.

The goals of this chapter are to explore First Nations seniors' roles and experiences with aging and to describe their perceptions of what determines a positive old age. I consider personal and structural factors that impact older peoples' ability to age well. I also discuss how, by understanding local perceptions and experiences of aging, researchers create opportunities to improve the quality of life of persons with dementia and their caregivers. Learning what it means to age well from the perspective of First Nations older adults allows for a better understanding of the standard of living they hope to maintain as they age. This standard can then be used as a baseline to evaluate how well the needs of older adults, be they healthy, physically ill, or coping with dementia, are being met and what avenues need to be pursued to better improve upon the potential for all older people to have access to the resources they need to practice healthy aging.

Behaviours that support healthy aging run parallel to behaviours that are known to minimize a person's risk for developing dementia. As a result, understanding and promoting culturally-appropriate perceptions of successful aging is a critical building block in the development of dementia prevention, support, and treatment programs for First Nations older adults. Documenting perceptions and practices related to successful aging permits a better understanding of the factors that shape a person's ability to achieve a healthy old age. Recognizing the type of old age that adults in these communities wish to achieve allows for the development and distribution of culturally-appropriate interventions that have the potential to delay the onset of health problems and promote the maintenance of functionality, personhood and a high quality of life.

Context

Understanding aging

Although aging can be defined in several ways, the process of growing older is often explained in strictly biomedical terms. Within a biomedical model, aging is understood as a series of biological changes that lead to disability and dysfunction including a loss of adaptability, functional impairment, and eventually death (Rowe & Kahn, 1987; Spirduso, Francis, & MacRae, 2005). In contrast to biological processes in youth, which are perceived as development, aging, or senescence, is considered to be a process of decline. In addition, past research on aging has tended to portray aging as a time of loss of self, loneliness, and poor quality of life (Bassett, Bourbonnais, & McDowell, 2007; Fitzgerald, 1996; Rowe & Kahn, 1987; P.J. Whitehouse & Rabins, 1992). Further, a focus on health promotion has led to the potential for blaming seniors for a failure to age successfully (Jolanki, 2004). Despite the effects of the aging process and the common portrayal of aging as a time of loss and decline, many adults over sixty years old maintain active and meaningful lives that involve hobbies, employment, friendships, and involvement with family, community and cultural activities. Research among mainstream adults has also demonstrated that older people generally describe their own experiences of aging as positive and have more positive feelings about themselves than younger adults (Stone, Schwartz, Broderick, & Deaton, 2010; Tornstam, 1992).

In the past, many of the deficiencies of older people were explained as being age-determined, especially if it was not possible to identify a specific pathology as the root cause of an issue (Rowe & Kahn, 1987). However, Rowe and Kahn (1987) posited that the role of aging in these losses was often overstated and that lifestyle, habits, diet, and other psychosocial factors external to the aging process were usually more influential on a person's health status than factors intrinsic to biological aging. Other scholars have also promoted a more holistic, biopsychosocial model of aging that recognizes the impacts of biological factors in conjunction with psychological and social causes for changes related to aging (Ory, 1995). This belief, coupled with curiosity about why some older people appeared to stay healthy and engaged with life far into old age while others did not, led Rowe and Kahn (1987) to develop a theory of successful aging. In a series of papers, these researchers set out to explain the differences between normal and successful aging and to create theories to distinguish between the two (Rowe & Kahn, 1987; Rowe & Kahn, 1997; Rowe & Kahn, 1998).

Rowe and Kahn (1997) suggest that to age successfully an individual must maintain or achieve each of three components: 1) high physical and cognitive functional capacity, 2) low probability of disease and disability, and 3) an active engagement with life. Since the publication of Rowe and Kahn's papers, the concept of successful aging has been

examined at length in the literature. Despite being a significant area of research, there has been little agreement over the definition of what constitutes successful aging. Many scholars have taken issue with the definition of successful aging put forward by Rowe and Kahn (1987, 1997). Their definition has been heavily critiqued for suggesting that if there is successful aging there is also unsuccessful aging, and that this terminology infers that the blame for failing to age successfully lies with the aging person. Also, the criteria that Rowe and Kahn set forward have been recognized as unattainable for most older adults (von Faber et al., 2001). However, more recent research contrasts older definitions of successful aging by recognizing that not all healthy older adults achieve a successful old age and suggests that older adults experiencing disease and disability have the potential to age successfully regardless of their health status (Sarkisian, Hays, & Mangione, 2002)

Despite these critiques, several scholars have recognized the concept of successful aging to be useful. In recent years many scholars have come forward with descriptions of successful aging that are more inclusive, have more flexible criteria, and, importantly, recognize that the most appropriate people to define success in aging are seniors themselves (Bowling, 1993). For example, Harris and Keady (2008) suggest that we should refer to the concept as meaningful aging and that the goal should be resilience. Others recognize that well-being, adaptation, and social and psycho-cognitive functioning should be part of the definition (von Faber, et al., 2001) and that this would encompass a greater number of older adults. Yet another definition suggests that successful aging should be defined by “sufficient well-being in a number of spheres (mental, physical, social, spiritual, economic) to sustain a capacity to function successfully in the changing circumstances of one’s life” (Inui, 2003:391). Inui’s (2003) definition suggests that aging is a dynamic equilibrium that includes resilience, generativity, and feistiness. As I demonstrate throughout this chapter, this last definition is perhaps the most useful and relevant when discussing the data from this project.

The concept of control is relevant and useful in understanding successful aging. Control has been identified in psychological literature as a major determinant of cognitive, psychological and physical outcomes (Brandtstadter & Baltes-Gotz, 1990; Langer & Rodin, 1976; Rowe & Kahn, 1987) and as a key characteristic of successful aging (Ryff, 1989). Within psychology, locus control and perceived confidence are interrelated concepts that have to do with what a person believes about their control over their environment (Eizenman, Nessleroad, Featherman, & Rowe, 1997). If a person has an internal locus of control, they believe that they have the ability to effect outcomes with their own behaviours, whereas a person with an external locus of control perceives outcomes to occur based on chance, luck, or fate (Menec & Chipperfield, 1997). Understanding issues of control is an important aspect of research relating to older people. In particular, this is because older peoples’ sense of control can be threatened in later life by declining health, the loss of loved ones and financial insecurity

(Chipperfield & Greenslade, 1999). In addition, perceived control is important because it is modifiable, and interventions to increase control have been shown to have positive health-related outcomes (Menec & Chipperfield, 1997; Schulz & Heckhausen, 1999). Such positive outcomes include higher levels of happiness and a positive outlook (Flammer, 1995), an increased willingness to face challenges (Bandura, 1977; Rodin, Timko, & Harris, 1985), greater persistence in coping with stress and loss (Brandtstadter & Rothermund, 1994), and psychological adjustment to specific health issues (Affleck, Tennen, Pfeiffer, & Fifield, 1987).

Resilience is also an important trait to consider when discussing positive and successful aging. Resilience can be defined as a person's capacity to withstand and recover from stress, crises, and adversity (Walsh, 1996). The study of resilience emerged out of developmental psychology, with the observation that children living in high-risk environments who faced high levels of adversity nevertheless achieved positive outcomes (Werner & Smith, 1982). Harris (2008) suggests that resilience should be privileged in the debate about successful aging. She claims that unlike many other aspects of the successful aging paradigm, it is possible for most older people to develop resilience, regardless of culture, socioeconomic standing, or health status (Phyllis Braudy Harris, 2008). Further, Harris (2008) suggests that resilience focuses on the ongoing process of adaptability and survival in the face of adversity and not successful aging as an endpoint which a person either achieves or does not.

Finally, since successful aging paradigms have generally been developed from a Western biomedical perspective they have been critiqued for their lack of cultural appropriateness for use with non-Western minority populations (Scheidt, Humphreys, & Yorgasson, 1999). Although biomedicine considers the process of aging to be more or less universal, the way that people interpret and respond to older people, and their expectations for various aspects of aging can vary widely across cultures. Many cultures, including Aboriginal cultures, focus more on respect for elders and the importance of their roles in family and community than medicalized signs and symptoms of growing old.

Recent uses of a successful aging approach in Inuit and Alaskan Native populations have shown that, when used in conjunction with narratives from seniors, successful aging models that are relevant and useful can be developed (Collings, 2001; Lewis, 2009). Lewis (2009:iii) suggests that eliciting culturally-relevant definitions of aging well can counteract the impact of "a generic definition that portrays [Aboriginal] Elders as aging less successfully than their non-Native counterparts" and can be used to shape the design and delivery of health care programs and services. One of the few published articles that speaks to successful aging among Aboriginal people in Canada suggests that for Inuit people, successful aging is defined more by a person's willingness to adapt to their changing health status than by good health alone (Collings, 2001). Collings (2001)

suggests that an individual's attitude and their willingness to transmit their knowledge and wisdom to younger generations are key factors for success in aging (Collings, 2001). Abonyi and Favel (2012) also suggest that continued contributions to community life are an important aspect of aging well for First Nations seniors in Saskatchewan. Similar conclusions were drawn by Lewis (2009) about Alaska Natives.

By determining criteria for successful aging as perceived by First Nations seniors on Manitoulin Island, their definition of successful aging can be used to help communities recognize older peoples' needs and develop services to support their efforts to age well. In this context, the concept of successful aging will not be used as criteria for judging older people, but as a guideline for optimizing seniors' opportunities to experience a high quality of life in old age.

Aboriginal peoples' experiences with aging

Little is known about the experience of aging for Aboriginal people or the health of the older Aboriginal population. Wilson et al. (2010) carried out a thorough review of literature focusing on older Aboriginal peoples in Canada. The authors were only able to locate nine articles published between 1995 and 2009 that focused on older Aboriginal peoples' health status and utilization of health services. Gerontological literature on the subject was found to be even more lacking. Not a single articles referring to older Aboriginal peoples was published in the *Canadian Journal on Aging* between 2000 and 2009 (Kathi Wilson, et al., 2010). With the exception of the paper by Wilson et al. (2010) highlighting this issue, an article by Habjan et al. (2012) which considers barriers to care-giving for older people in First Nations communities, and a paper by Finkelstein et al. (2012) examining formal dementia care in southwestern Ontario First Nations, no further articles on the topic have been published in the *Canadian Journal on Aging* in the past three years. More information is available about older Aboriginal people in the United States, and some parallels can be drawn between Canadian and American Aboriginal peoples.

In this section I review the literature about older Aboriginal adults and consider how their aging experience may or may not differ from the experiences of the mainstream population. I explore how the unique history of Aboriginal peoples shape their perceptions of successful aging and their ability to age well. A life course approach to aging is appropriate here because it considers aging to be a process that occurs continually from birth to death, not as a discrete period in the lifecycle (Passuth & Bengston, 1988). This approach broadens the frame of reference for understanding old age and allows past biological and cultural life experiences to be considered as impacting aging (Climo, 1992). Events throughout the lifespan influence Aboriginal peoples' ability to attain a positive old age. History, politics, and culture play a significant role in shaping their lives at all stages of the life course, and these factors create unique challenges and

opportunities that can impact a person's physical, cognitive and emotional health as they age. Poor levels of education, poverty, government policies, access to health care, historical trauma, residential schools, and the impacts of changing family structure all impact the aging experience. Although it is possible that having experienced all of these things has built resilience in some older Aboriginal adults, it has set others up to be worse off than their mainstream counterparts.

Older Aboriginal adults face several challenges as they age including higher levels of poverty and lower health status than their mainstream counterparts (Cooke, et al., 2008; Kathi Wilson, et al., 2010). They experience significantly higher levels of chronic conditions, such as arthritis, hypertension, cardiovascular disease, cancer and diabetes than the older non-Aboriginal population (N. Adelson, 2005; Frohlich, Ross, & Richmond, 2006). Further, they are less likely to have good self-rated health (Blandford & Chappell, 1990) and often become functionally dependent at a younger chronological age (Reading, 1999). The challenges faced by older Aboriginal people are often a result of cumulative life experiences including socio-economic conditions, education, health, and social support (Reading, 1999). Despite these challenges, older Aboriginal people have generally positive perceptions of old age (Cooke, et al., 2008).

Social determinants of health are an important consideration in understanding Aboriginal seniors' experiences with aging. These determinants are useful in helping us to understand and contextualize some of the challenges faced by Aboriginal seniors as they attempt to age well and can also highlight the cumulative effects of these challenges over the life course. Poor health in old age is not simply something that is caused by old age, instead, as previously mentioned; a person's health status as they age is shaped by factors that have impacted them throughout their entire life span. Loppie-Reading and Wien (2009) suggest that a person's health begins during gestation and that development and health status in early childhood form the basis of vulnerabilities and resiliencies for a person's entire life. Social determinants of health are cumulative in nature, and exposures and experiences build on one another influencing health from one life stage to the next (Loppie-Reading & Wein, 2009).

Although it is improving, the average life expectancy for Aboriginal people remains below the Canadian average (Habjan, et al., 2012). Aboriginal communities, who have typically been demographically younger than the Canadian average, have long focused on the needs of younger people. As the older Aboriginal population increases, more attention will need to be paid to services and policies that support "transitions to retirement, maintenance of independence and in-home care, and provision of services related to health and disability in later life" (Cooke, et al., 2008:386). Healthy aging must be promoted earlier, especially social support networks and coping behaviours, which have the ability to mediate the impact of other variables that impact health (particularly mental health) such as physical health, income, and education (Narduzzi, 1994).

Improving the overall health and well-being of older Aboriginal adults also has the potential to reduce the impacts of other chronic illnesses. This includes dementia, since many of the positive lifestyle choices and behaviours that shape a successful old age parallel recommendations in the literature for the prevention of Alzheimer's disease and related dementias (Alzheimer Society, 2010). Further, healthy aging behaviours can increase the resilience of older family caregivers and provide some protection from the strains and stresses of providing care for a person with dementia. It has been suggested that supporting Aboriginal seniors to age in place in their own communities, and promoting informal community and kin-based care approaches would greatly benefit this population (Abonyi & Favel, 2012).

In the previous section, I discussed the idea that control is an important component of a healthy aging experience. In an Aboriginal context, the idea of control relates individuals but is also important at a higher, more collective level. Clarke (1992) considers locus of control to be central to Aboriginal peoples' conceptions of health. This is especially true when individuals and communities have been in a position where they lack control over their own social health. According to Warry (1998) control over health and well-being is directly linked to income levels and economic status. People who have higher incomes and greater economic security also have a greater sense of control over their health and the behaviours related to their well-being. Links between Aboriginal peoples' perceptions of health and the amount of control they have in their life is also recognized in the health promotion literature (Warry, 1998).

Understanding Aboriginal peoples' experiences with aging and promoting healthy aging has important implications for seniors' quality of life. Quality of life has been defined in many ways within the published literature. Often, quality of life is assessed subjectively and relates to happiness, comfort, security, well-being and life satisfaction. In an Aboriginal context, quality of life is a global and holistic concept (Salee, Newhouse, & Levesque, 2006). Salee (2006) asserts that for Aboriginal people, good quality of life is defined by balance with self, family, community, the environment, and the spiritual world. Harmony and the teachings of the medicine wheel are also perceived to inform definitions for good quality of life for Aboriginal people. Since seniors' perceptions of a "successful" old age reflect their desires for a high quality of life, this is an important concept to keep in mind.

Results

The experience of aging

Growing older can have rewards associated with changing roles and status in family and community. Seniors who were interviewed expressed that it was natural for them to take on different responsibilities as they aged, such as shifting from physical tasks to responsibilities more focused on teaching and passing on knowledge. Several participants discussed the importance of their role in their family, such as sharing knowledge and advice with their children and grandchildren. One senior expressed that this was a great responsibility.

Oh, I enjoy, like I said, my grandchildren are my part of my life today, like, you know. I think that's ways. Well, you still have to give that your children directions, too. You give them directions on the what's the, give them advice, too, and share your own experiences with them. So, it's ways you have to share your what you went through, too. It's ways so there's those, your grandchildren and your children have to, I guess, in a way balance them in a good way, you know? You have to balance them, your children and your grandchildren, too, really. (KP SE 01)

This senior expresses that he considers it to be an important responsibility to provide guidance not only to his children, but also to his grandchildren. He believed that sharing not only advice, but also stories from his own life could help them to learn how to have balance in their lives.

Many participants expressed that traditional roles such as holding a central role in family life and acting as a resource for traditional knowledge, guidance and emotional support were important to them. However, there was also a concern that some of these traditions were changing, and that it was more difficult to fulfill traditional family roles when families lived far away from each other and work, school, and technology competed for quality family time.

Yeah, there is a big change. It's that loss of respect is what I see, eh? Your traditional values are lost. Yeah, just, I don't know, sometimes the things that young people are doing just appals you. It even comes down to uh, financial abuse, emotional abuse from these uh, young people, eh? With their elderly people, that bond or that closeness is gone, the way it used to be like, I don't know, you work like a team and when people were small...I know

how, how we used to work, and it wasn't it wasn't work, we it was just like uh, play, it seemed like uh, we weren't being physically abused 'cause we uh, we planted and we um, gathered potatoes in the fall and they were being dug up and things like that. And we travelled a lot, 'cause uh, my dad was a fisherman and a hunter and he'd take us out on the boat and school didn't start that early way back then. It started, I went to school when I was 8 years old. So, nowadays they tend to put the children right into school, which is of advantage too because they can start learning soon, but I think (laughs) you learn more, I'm thinking of myself, the kids are just sitting now, watching computers and they're not, their minds are not stimulated their own thing, they're just copying that thing and in my world I had to uh, think differently, "how do I do this?" I don't know how to say it, but I see now, I tell my grandchildren "what, you never went through what I went through" (laughs) Like it was fun going hunting, we did partridge hunting. (JP TRAD 02)

This traditional Elder perceived there to be a loss of traditional values relating to the relationship between children and their grandparents. She perceived the erosion of intergenerational closeness to be caused by children starting school at a young age and spending too much of their time engaging with technology instead of engaging with older people in their families. She perceived this lack of closeness to impact the respect that seniors received from younger generations. She believed that elder abuse was a direct result of the lack of closeness between seniors and young people.

Living arrangements are another example of how the traditional roles of seniors in families have shifted. For example, despite a persistent image of Aboriginal seniors living out their old age in large, multigenerational family dwellings, the reality is that many seniors on Manitoulin Island live completely alone. Of the seniors in our sample, four out of five in UCCMM communities live alone and two of five on Wikwemikong live alone. It must be noted that some seniors live alone because they prefer to maintain their own space and their independence. Living alone is not itself a predictor of a lack of family care among the individuals we interviewed. Most of those who live on their own have support from relatives who live nearby. However, living alone and having a lack of family support can contribute to feelings of loneliness and isolation. Of the individuals who live with someone else, one lives with his wife, another lives with his wife, two adult children and some grandchildren, and one lives with her son and disabled daughter. The situation is similar with people experiencing memory loss, four out of five PWD in UCCMM communities live alone, and one lives with her husband. In Wikwemikong, three PWD live alone and, one lives with his daughter and one lives with his wife.

Our participants expressed that being treated with respect and having care provided by their families when it was needed was highly valued. However, some seniors expressed that they wanted to retain control over their lives until they felt they were ready for assistance. Others expressed a concern that they would become a burden on their families if their health failed as they grew older. As I will discuss in greater depth later in this chapter, autonomy was considered to be a very important aspect of aging well. However, autonomy was a flexible concept, the parameters of which often shifted as a person's health, abilities, and needs changed.

Several participants expressed that there were many benefits to growing older such as having more free time to participate in hobbies, spending more time with family, and taking on new roles in their community. For some individuals, the ability to spend time alone and participate in activities they enjoyed without time restraints or the demands of other people was one of the most positive aspects of growing older.

Oh yes! I love being alone and I just, you know, putter around and go and do knitting, I play my music. I just, you know, occupy my time. I can stay in my nightie, uh, all day if I want to. (JP SE 02)

For others, trying new activities and having the time to socialize was especially enjoyable. One older woman spoke about her initial reluctance to participate in a quilting group, but then expressed how she felt after joining in:

Finally I went, and I like it! Enjoy it, we laugh and it's a, you know, it's communicating with other people. (JP SE 03)

Although the majority of participants expressed that there were positive aspects of growing older, many also expressed challenges such as loneliness changes to their health and physical abilities. In the sections that follow, I describe in more depth my participants' explanatory models for successful aging and the behaviours, barriers, and enablers that they perceive to shape their aging experience.

Explanatory models of successful aging

Healthy aging...I guess the ability to, um, you know, to be able to do the things that you always have, like doing things for yourself and, um, and being healthy, like, uh, free from illness. Maybe not free from illness, but maybe not so severe. (JP SE 02)

Despite the diversity of our senior participants in age, sex, and health status, they expressed similar perceptions of a healthy old age and the factors that influenced their and others' ability to achieve successful aging. Among the most frequently mentioned

characteristics of a positive aging experience were good overall health, taking positive measures to promote and maintain health, an active social life including contact with friends and family, participation in spiritual and cultural life, a positive attitude and sense of purpose, keeping busy, and maintaining autonomy. One Traditional Elder expressed a very thorough description of what aging well means to her:

To me healthy aging is being really active and not even thinking, you know, about your age, not focusing on it, doing things to the best of your ability. And that's actually how I was brought up, is that you do things as much as possible for yourself and um, not rely on other people and you don't think about it so, and [if] your physical health is failing you still continue to trying to do as much physical activity as possible. And, um, doing a lot of, um, engaging at a social level, so you're constantly communicating and also, um, as you age you shift to a different role that where you start teaching. That's our responsibility. So that's what I-the area I'm in now is teaching. Teaching other people, teaching my family members and teaching in my work – I've shifted more to not doing the physical work, like going out doing herbal walks uh, I do a little bit of that. (JP Trad 01)

Individuals who put in an effort to continue to lead an active and engaged life are perceived to enjoy a more positive aging experience than those who withdraw from activities they used to enjoy. However, it is recognized that some modifications to roles and activities may be needed in order to accommodate changes to health and mobility that are likely to happen as a person ages. As the previous quote indicates, this senior believes that it is important to participate in physical activity even if you do not possess the same level of strength and endurance that you enjoyed when you were younger, and that social interaction is a key component of staying engaged with life. She discusses the idea that a person may need to shift roles to accommodate changes in ability as they age. The idea that a person should shift their activities or roles, or alter the things they do to reflect their changing abilities is a key theme that was repeated by many of the seniors I spoke with.

Other participants expressed similar perceptions of healthy aging. The following quote highlights the importance of health, self-sufficiency, and having a sense of purpose:

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

These quotes begin to indicate the shared perception of successful aging that is held by First Nations seniors on Manitoulin Island. In the following sections I discuss in greater depth the specific factors that impact older adults' opportunities to age well in this context. I consider elements of successful aging that are within the control of seniors themselves as well as larger socio-cultural and structural factors external to these individuals that impact their health status and quality of life. This includes barriers and enablers that impact the aging experience as well as both positive aspects and challenges associated with aging.

Factors that Influence Healthy Aging: Behaviours, Barriers, and Enablers

Older adults expressed actions that a person could take to improve or maintain their health. These healthy behaviours included eating well and avoiding alcohol, smoking and drugs. Most participants also discussed the importance of exercise and engaging in activities that kept their brains and bodies active. Other factors, such as social support, a sense of autonomy and maintaining a positive attitude were also seen to facilitate a successful old age. In contrast to the positive behaviours and enablers to successful aging discussed above, participants also referenced factors that could hold a person back from having a positive aging experience. These included actions that individuals might be able to control, such as alcohol and drug use, as well as external factors such as poverty, lack of access to services and historical trauma. In the following section I have grouped these factors together under four overarching themes: biological, psychological, sociocultural and behavioural. Within each theme I speak to the barriers and enablers that participants believe to impact their efforts to age successfully and reference relevant literature that supports or contrasts these perceptions.

Biological

Physical and cognitive health play an important role in shaping a person's aging experience. Well-being in these areas can significantly impact an individual's ability to participate in day-to-day activities. Changes in health status are frequently a part of the aging experience, especially for older First Nations people who are known to have poorer overall health than their mainstream Canadian counterparts.

Physical health

As described in Chapter Two, most of the seniors who were interviewed for this project were experiencing one or more medical concerns including diabetes, hypertension, arthritis, cancer, and respiratory illness. Several participants also referenced changes to their strength and mobility that had occurred as they got older. Changes in health status were often discussed by informants as a part of the aging

process. To some extent, both physical and cognitive decline were perceived as a natural and acceptable part of aging. While some seniors talked about how their health conditions held them back, they tended to spend more time focusing on the positive things they did and the strategies they had devised to overcome their disabilities or health challenges. The biggest concern informants expressed about physical impairments was the ways that they restricted their ability to complete tasks or participate in activities.

I just started getting a housekeep - a homemaker - there just this past week, a couple weeks ago because uh, I had problems with my, uh, a little bit of problems with my health. (JP SE 01)

Yeah, yeah sometimes I can't, I can't do a lot of things. I can't lift my vacuum, so I have a worker that comes in, she's going to be coming in this week and that's, that's another thing I've shied away from, tried to do, but finally I decided last week no, I can't do it anymore. I'd love to do it, but I just can't. It'd take me a couple hours to do this floor. (JP SE 02)

These quotes refer specifically to how these individuals' health was impacting their ability to carry out their housework. Both of these women expressed that they had recently accepted help from a homemaker with tasks such as vacuuming because their health was making it too difficult for them to do on their own. However, it was clear in the interviews that these women had tried to continue these tasks as long as they were able, and only accepted help when they became too challenging. Accepting help was not equated with dependency. These women, for example, accepted help with physically demanding chores such as cleaning the floors, but continued to do other household activities, such as cooking, independently.

Another senior expressed that the most difficult aspects of aging were changes to his physical abilities.

[The] physical part of yourself, I guess, you're, you know, the like, I've, ah, I picked up a chain saw not long ago, you know. It was right up here that I could go out, do the, but after a few minutes I had to sit down and put the chain saw down so, it's, ah, I think, ah, accepting that you can't do the physical things that you used to do. (KP SE 01)

Although it is inevitable that people will experience changes to their health and physical abilities as they grow older, it is possible for individuals to adapt to these changes and adjust their behaviours so that they are more in line with what they

continue to be able to do. From the perspective of our participants, it is this ability to accept changes to one's health and abilities and to adapt to the changes by modifying the task, altering their expectations about how long it might take to achieve, or seeking assistance for tasks that have become unachievable so that they might focus their energy on other tasks that they are still able to complete, that characterizes a person who is aging well.

Yeah, yeah, I remember when I think it was about a month, I came home from the hospital, I really wanted to go downstairs. I wanted to get something down there so I had to make three stops when I climbed back up, and that's only twelve steps. I had to make three stops, I did not have the energy. So, and I knew that I had to, ah, exercise. I knew for the oxygen to get everywhere, so when I, I kept pushing myself, I was tired, I was sore, my legs were sore, but I did it anyway and sometimes it would get frustrating. (KP SE 04)

This participant expressed some of the challenges associated with overcoming physical health problems and changes in one's physical abilities. His behaviour demonstrates his determination and perseverance to stay as active and independent as possible despite challenges related to his health. This trait was consistent among the well elders who were interviewed. In my sample, many people discussed the impact of their health on their ability to stay active and engaged, but highlighted the importance of continuing to do the things they were able to even if they had to shed some of the more demanding or difficult tasks.

Cognitive health

Memory loss and forgetting were often mentioned as part of the aging process. Occasional memory problems were referenced by almost every informant. However, most of them laughed this off as a normal part of aging and did not perceive it to be problematic or to interfere with their daily lives.

Even people younger than I am they say they seem to be quite forgetful at times, you know, you go to another room and you try, you try, you want to go in there in the other room, you think, you're thinking, but when you get there "what did I come in here for?" Eh? That happens a lot! (JP SE 01)

I am finding that I am not able to do what I used to, to be able to do, work, even my thoughts I do forget sometimes, but I do retrace my steps and I remember what I was planning to do. It's

like, I could say, I retrace my thoughts back to what I was really trying to do [laughter]. (KP SE 02)

Seniors rarely equated memory loss or forgetfulness with a disease process and often expressed that some memory loss was a normal part of aging. Participants' beliefs about memory loss will be discussed in much greater depth in the next chapter, which deals with cultural perceptions of dementia.

Psychological Health

Psychological well-being was seen to play a critical role in aging well. Perhaps the most important indicators of successful old age, however, were attitude, autonomy and control. The ability for a person to accept changes to their health and well-being and to be willing to make an effort to adapt to these changes were perceived as the strongest characteristics of a person who had aged successfully.

Attitude and Adaptability

Attitude and outlook on life emerged as key contributors to a positive aging experience. Traditional teachings related to attitude, including acceptance of the changes that come with old age, were seen to shape a person's aging experience. Having a positive attitude included willingness to adjust to changes in ability or circumstances. Most informants expressed that they accepted or made efforts to accept the changes that were happening as they aged. Many reported relying on cultural teachings or spirituality for the strength to cope with these changes and adapt to their new attitudes and abilities. The acceptance of aging is not just blind acceptance. Informants spoke of the changes and challenges they experienced as they aged and the effort it took to work to accept them. While some informants talked about aging as something that just crept up on them and had not really changed their life in many ways, other informants spoke of a fear of aging. Some discussed that it took effort to work to accept the changes associated with aging and to learn how to handle them, and were candid about how much of a struggle this could be.

One participant was focused on acceptance, and the teachings she had learned from her grandfather. This quote expresses a certain feeling of a lack of control over the length of your life, but that to enjoy a good old age an individual must learn to accept this and continue to enjoy the days you do have on earth:

Healthy aging...that, for us to accept aging, I guess. For us to accept aging, what they call circle of life. That is what some call it these days, but I learned that when I was with me, whatever, I learned like I said, I learned from my grandfather. You accept aging. The time comes for us, he used to say, the time comes for

us, come to, come to the end and when that happens he said, that is what he used to say. The ones I really accept, I believe in. He used to tell me today you are born, your days are going to be your day is already numbered, already they were placed, how many days you were going to have here on earth how many days you gonna...and when those days are over then you're you pass away then you, you finish your days here on earth. You go to another life then. I do believe in that. I think, you know, sometimes see...well, I guess, he used to say, well, I guess he/she is finished their days, you finished your days, that is what, that's what I had to learn that I could say to accept that. (KP SE 03)

The importance of acceptance was central to the discussion of aging that I engaged in with my participants. Whether acceptance related to changes to physical health and abilities, cognition, or mortality, participants clearly expressed that recognizing and adapting to changing roles and capabilities was a crucial component of aging well.

Informants expressed that balance and state of mind were more important in achieving successful aging than physical health or abilities. The most important factor expressed by informants was attitude, particularly acceptance of and adaptability to the aging process and the changes that accompany this time in a person's life. Although physical and mental health were expressed as a desired state, physical illness or disability were not seen to preclude someone from enjoying a good old age as long as they made an attempt to stay engaged in life.

Humour also emerged as a mechanism that people used to keep a positive attitude and come to terms with any difficulties they might be experiencing. Participants mentioned occasions when they used gentle teasing as a way of discussing health issues with their friends, and that this approach took the pressure off of the person who was forgetting or experiencing an illness.

Well, like I said, we joke about our, our, ah, getting old, our, and to me that is healthy. I think that we need to, ah, if I feel bad about getting old, you know, I would. I don't know where I would be, you know, but to really, then again, that harmony is a very powerful teaching in the medicine wheel, harmony is your feelings are very important. (KP SE 01)

Humour was a key component of social interaction and the enjoyment of activities, which helped to reinforce these positive behaviours and keep people involved.

I have so much fun gambling, feel young when I sit there with people laughing away if I call the wrong card. They laugh at me and I says, said don't cover that, I said the wrong number. Lot of fun. (KPSE 05)

Humour was a positive outcome of socializing with friends, which helped people to feel happy and engaged. These traits are discussed further in the context of culture later in this chapter.

Autonomy and control

Informants discussed autonomy as one of the positive aspects of growing old. Older adults often expressed that they enjoyed having more leisure time and the freedom to make their own choices about how to spend it.

Oh yeah, you can, you can do what you want, your time is yours, nobody can't come and tell you you've got to do this and you've got to be over there and stuff like that. You can take your time and just do whatever you do; you don't have to watch the clock. 'Cause I'm in my shop over there doing my crafts and sometimes it's dark when I look my head up...I don't bother with the clock. (JP SE 04)

As this woman expresses, she loves having the freedom to get engrossed in her craft projects and to spend time working on them without being interrupted. She took me out to her craft room and showed off her many projects including knit scarves, quilts, and other crafts. Not only did these activities give her something to do to fill her time, but they were also a mechanism through which she stayed connected with her family, even those who were far away, as she often made gifts for her children and grandchildren.

Many of the negatives that the informants raised about aging were in some way related to restrictions of their autonomy and control. For example, illness and mobility issues were seen as negatives because they restricted the person from participating in activities or accessing information about things that were happening in their community. Although assistance from others was appreciated and desired, there was resistance on the part of the well seniors to the idea of reliance or dependence on family members or health care workers for support.

No, we've always been, um, we've always been told to take care of each other and when I was younger we had a lot of extended family life, like cousins, um, that would actually come and come live with you, till you know, in their old age, take care of them, that's what we used to do. Now they have nursing

homes. So, I don't know. Like, with me, my kids are just ready to take me in they, they're just waiting to jump on it and I'm here and I tried to explain to them, I said, you know, I like being independent, I want to do things for myself. I said, when I do get sick, I said, I'll come to you. But I think they're slowly starting to understand that because they're just like, I was sick over the weekend and they were just "oh mom, think about it now, don't you think it's time now?" and I said no, it's not time yet, you know? Yeah. So I know they're there, they're ready. (JP SE 02)

As this woman expresses, she is grateful that her children are willing to take her in to their homes when she is in need and it gives her comfort to know that she will not need to go to a nursing home. However, she is clear that she wants to stay in her own space and maintain her independence for as long as possible. She actively resists her children's efforts to have her move in with them because she wants to remain in her own community and to enjoy the unstructured time and independence that she is afforded by living in her own home.

Seniors spoke about the importance of accepting changes to their physical activities, and of effort, perseverance, and staying involved in as many activities as they could. One key component of a person's attitude was whether they had a sense of purpose. Many seniors spoke about the types of activities they participated in that made them feel important or about making long term plans so they had something to look forward to.

Get involved in these things and then the main thing is feeling good about yourself that you can uh, apply yourself to something different, mingle with people. I used to be not like that so much. Especially here in Wiky. I said "Oh, I didn't want to go quilting, all they do is gossip down there." We'd hear stories, you know, somebody gets upset about something so I, I started to go and I liked it. (JP SE 03)

Although this person was initially resistant to joining the local quilting group, once she tried it she found that she liked it and it became a regular part of her social calendar which gave her something to look forward to each week.

Many informants were proud of their continued independence and expressed the importance of also having a sense of purpose.

Um, if you have, um, like hobbies, like if you're uh, if you have a garden and you can put your flowers out and put your vegetables out and I-I know some elders do that around here and

then in the fall they do all their pickling and their jamming and uh, you know, I think that kind of keeps you, like, a purpose to your life, you know, like you know in the spring you're going to have to get your garden and everything. I don't do it, but I see my neighbours doing it. And they really have fun, you know. I have one lady over here she has a sister that comes up and they put the garden together and then they put jam, put the jam up and preserves and stuff, you know? Yeah, so it's, and they're very healthy actually, just up and about. (JP SE 02)

A sense of purpose could be derived from many different sources. The above quote indicates that some people found a sense of purpose by having something to look forward to. Gardening and harvesting the products that came from the garden gave these women something to anticipate – planting in the spring and harvesting in the fall – and it provided them with an opportunity to stay active and engaged because the garden needed regular tending such as weeding and watering.

So, I find different things to do, I'm never bored since I retired. I thought I would be, but no way, I keep myself really busy with stuff and I make quilts for all my grandchildren, great grandchildren I each, made them each a blanket, eh? I just got another new grandson in [Brampton] and my daughter's gone down there, and I happen to have two baby quilts made, eh? So I just went and got one and sent it down over there. (JP SE 04)

If one is able, like, sewing. I am very happy that I am still able to sew and when I make a little bit of money selling what I have been able to make what I have made (KP SE 02)

The two women in these quotes both found a purpose in doing crafts. Sewing and quilting not only gave them something to do to fill their time, but also resulted in tangible products that they were able to gift to family members or sell to generate income. Our informants perceive purpose, autonomy and control to be important aspects of their aging experience, and supports that allow them to continue to pursue control over their environment and seek out a meaningful purpose in life were perceived to be beneficial.

Behavioural

Four sub-themes emerged relating to behaviours a person could engage in to improve their chances of aging well. These included regular cognitive stimulation, physical activity, and eating healthy foods. Avoiding smoking, alcohol and substance

abuse were also seen to help a person to maintain or improve their health. Living a traditional lifestyle encompasses the four behavioural traits that were emphasized and was seen to be optimal in the prevention of age-related health decline, loneliness, and isolation. The perception that a traditional lifestyle is a key factor that shapes the aging experience is discussed in more depth later in this chapter.

Cognitive stimulation

The majority of the healthy senior participants expressed actions they took to promote cognitive stimulation including reading, crosswords, puzzles, and other games. Some participants also spoke about how other activities, such as cooking, quilting, using a computer, or making crafts could help a person to keep their mind active.

I can't sit still to watch TV, you know? It's boring for me to do that. If I sit over there I do a crossword puzzle, do a lot of crossword puzzles and reading. Same with my husband, it's what he does, too. Crossword puzzles and books, books, all sorts of books. (JP SE 04)

Yeah. I like reading. I-I don't read as much as I should, really, so I'm more into puzzles, using my head or brain to figure out things and I started doing a puzzle, that's a pastime an elder could really enjoy too, eh? (JP SE 03)

I do a lot of reading. I do puzzles. I do reading. I like to read about history. They got all kinds of history. I could say I don't, I don't bother watching TV there is nothing there for me. (KP SE 03)

These quotes focus on reading and puzzles, but participants also discussed the importance of other activities that they felt kept their minds active. Cooking and food preparation in particular emerged as something that helped people to stay cognitively sharp. However, some people noted that a reliance on pre-prepared foods was detracting from the cognitive benefits of cooking. One woman indicated that she felt that people who relied on recipes to cook were losing out on cognitive stimulation. She explained that in the past people often cooked from memory or kept their recipes in their heads, and that this was no longer the norm.

Physical activity

Participants also considered physical exercise to be an important component of healthy aging. One participant used a pedometer and routinely kept track of the number of steps she took per day.

I hadn't been taking my walking, training, eh? 'Cause you had to train for that, too, so... 'cause it's a long distance walking. I've walked half that much a day actually. I haven't done it lately. Again, I've got my pedometer. Yeah, I had about 7,000 steps yesterday. (JP SE 03)

Another individual showed us a contraption she had rigged up to help her with stretching and light cardiovascular exercises, one participant discussed jogging on his treadmill, and others spoke about going for bike rides. Participants also spoke about exercise in terms of general exertion such as tending to a garden or cutting firewood.

You were surrounded by a lot of old people like that. Did they ever complain about that they were not able to perform anymore, [were] exhausted? Oh no, they never. I never heard of anyone to complain, also there was no one who ever gave up. The old men, they were the ones who baled hay, rode the wagons, cared for the gardens, preserved. The old ladies also, there were lots we would see while strawberry picking, they were picking too, the old ladies, they were warriors to look for what they were going to preserve. (KP SE 02)

It is clear that although some older people make a more conscious effort to exercise than others, that the idea of doing physical activity on a regular basis was considered to be an important way to maintain physical health.

Well, it's just like what I told you. It's, you know, exercise. Your main thing is to exercise. Exercise your body and eat, eat the right kind of food. Don't smoke, don't drink. Main thing is to exercise. Exercise those big muscles, you know? The leg, the leg muscles, walk, that's the main. (JP SE 05)

I've been doing exercises before I get up in the morning. I've made it a point about two weeks now. I do leg exercises, I go like this and then I go like this (demonstrating) with the knees flexed like that. And then one leg up. Twenty times, twenty times, twenty times. And then I do my two feet up twenty times. That's hard. Yep. And then I, on my side and then I go bicycle, and then the other one I go sideways and then I have the little bars I started to use again. (JP SE 03)

Physical activity was perceived to be a major component of an overall healthy lifestyle. Although many of the participants we spoke with mentioned efforts that they

took to be physically active, it also became clear that this was less of a possibility for some individuals with severe health issues or restricted mobility.

Healthy Eating

Many participants discussed the importance of eating well and mentioned the types of foods that one should and should not consume. Many seniors also had food guides or recommendations of what to eat posted on their fridge. One senior showed me a list of “Okay foods” and foods she should avoid that her PSW had helped her to create. Another senior pulled out an assortment of healthy recipes she had collected at health promotion workshops.

Vegetables were perceived to be the most important food to eat. Some seniors distinguished between the nutritional value of fresh or frozen vegetables versus canned vegetables.

Um, I like to eat basic foods like, the, what comes out of the garden has kind of changed like, uh, I, I eat turnips and carrots and cabbage and anything that comes out of the garden and I try to cut down a lot on canned stuff. I don't eat canned vegetables at all and I will eat frozen. (JP SE 02)

Several factors were discussed by our participants as possible barriers to eating well. Financial resources and loneliness were mentioned by seniors to be barriers to getting adequate nutrition. Transportation, family support, and the quality and type of meals offered through programs such as Meals on Wheels were also believed to impact a person's ability to eat healthily.

All I know how I feel about living alone, it is difficult to get someone to come over. Sometimes I need something, like bread, I have difficulty getting someone to bring this over, but I receive mercy from my relative and my niece, they help me they bring me something to eat. Even neighbours, I have them they bring me something to eat sometimes, but it is difficult to ask to go to the store to get something. I feel like a person bothering someone else, not in a good way, too, they may say, oh jeeze, this person, what now? (KP SE 02)

Finally, several individuals spoke of how growing, preserving and preparing food might contribute to a healthy lifestyle. Usually this related to the physical or cognitive exercise a person might benefit from while undertaking activities related to food procurement or preparation.

Alcohol and Smoking

Two behaviors that were perceived to counteract healthy aging were smoking and the use of alcohol. Many participants discussed their alcohol consumption patterns in their younger years and how they have since quit drinking. At least one person mentioned her enjoyment of beer but later stressed that moderation was important.

We used to drink but we don't do that anymore, my husband used to smoke, he doesn't smoke anymore, so we just try and keep ourselves as healthy as we can. (JP SE 04)

Just, you gotta watch what you eat, one thing, watch what you drink, too, also. Like, never too much, eh? (JP SE 01)

One older man associated drinking specifically with arthritis. He explained that his arthritis flared up when he consumed alcohol, but that it cleared up when he quit drinking. He also perceived alcohol to cause gout.

'Cause that time I was still drinking a little bit and that's what causes that arthritis. Drinking, you know, and not taking care of yourself, you know? I'm, I'm never sore, I, like here, see this (shows me his finger) that's the arthritis there that – I seen that thing, I was like this one time, you know? I seen that thing puffin' out like that, man, with my eyes and then I, holy smokes. And that's where I was sore all the time, that arthritis, but after I could quit drinking completely that arthritis went away. (JP SE 05)

The same participant continued on to explain that people who drink often withdraw from life and do not exercise or engage in other activities.

Well they, well they drink a lot, shouldn't be doing that. And when you drink you don't do nothing. You just get lazy. You don't exercise and you got nothing else, you got no time for nothing else when you start drinking. But when you're, when you're not, you do it all; you do things with your life when you're not drinking. (JP SE 05)

In more than one interview alcohol consumption was directly linked to altered or reduced cognitive capacity. Participants recognized that it was best to minimize or avoid alcohol consumption if they wished to have a healthy aging experience.

Socio-cultural

Social and cultural factors also emerged as key factors that shape the aging experience. Social contact with friends and family was perceived to be important in maintaining a positive attitude and active engagement in life. Meanwhile, social support such as assistance with groceries and transportation was seen to greatly improve a person's ability to manage their activities of daily living and remain independent in their homes. Cultural activities, language, and spirituality were also seen to improve life for older people. By contrast, poverty emerged as a significant barrier to many of the positive aging behaviours that have been discussed so far.

Poverty

Many factors play in to an older adults' ability to access the goods, services and information they require to engage in health behaviours and participate fully in life. Poverty is a major factor that can impede seniors' access to the goods they need to live comfortably, eat well and maintain their health. It may also impact their ability to access transportation to doctor's appointments or social events. Poverty impacted the ability for some older people in our sample to access basic needs that are necessary for daily living including food, clothing, heating oil, and hygienic products such as pads for incontinence.

I always try to encourage her, you know to eat, and then she'll say "well, I don't get enough money to buy the food I'm supposed to have" she'll say, you know, like, uh, "I can't buy no fruits and vegetables, they're too expensive." Especially the fruit, you know it's such a high price and they're always yakking about how you have to eat all this stuff, she said, you know, and, but, uh, I don't know, I think if you budget properly they get it, yeah. All this stuff. (JP SE 02)

I could say we don't get enough. Everything is getting expensive we are told how to eat and we can't eat that way. It is so expensive to eat that way everything that is we are told not to eat sugar. I don't eat sugar. When I go to the store to look for the sugar I need. It's so [much more] expensive than the regular sugar. (KP SE 02)

The ability to access these types of products was strongly influenced by several factors including finances, transportation and social support. Financial stability impacted not only an individual's ability to buy products such as food, but also impacted their ability to get access to the store because of the cost of transportation by taxi. Only one participant expressed that he was financially comfortable.

Well, with me I don't, you know, some people might have a hard time, but I don't because I got money. You know, I went out and worked, so I get a pension. (JP SE 05)

He perceived that his financial situation allowed him to age well because it gave him the freedom to pursue his interests and did not cause him worry or anxiety. This gentleman represents a minority, as many other participants expressed concerns about the cost of living.

Transportation

Transportation is another social issue that shapes the aging experience because it is shaped both by the availability of social support and adequate financial resources. Transportation was a barrier for many of our participants either because of the cost of taxis, the lack of public transit, not having family members who could drive them somewhere, or the limitations of community-run transportation services. The lack of public transit was felt especially acutely by individuals who had lived in bigger cities at other times during their lives.

But I get so frustrated about not having, like now; again, I'm going to be paying to go to Little Current for the bank. Transportation is the hardest thing even for some people too, you know, shopping. (JP SE 03)

I guess it's different, different, different, they ask me they come and check me anyway or sometimes they call me tell me to call an ambulance, but if you call the ambulance they just take one ride over to the hospital and your there to see the doctor, wait for the doctor to see you, and after he sees you he says you're, you're okay you could go home, you'll be alright and there's no ride there. (KP SE 05)

Transportation can have a significant impact on a person's ability to age well in many ways since transportation can be a crucial link between older people and social support, community activities, health care, food and other goods. Individuals who lack access to reliable transportation may have a more difficult time engaging in positive aging behaviours and be at risk for higher levels of isolation and loneliness.

Housing and home maintenance

Most of the older adults in our sample lived in their own homes or apartments, either with a spouse or by themselves. Seniors living in apartments generally lived in buildings designated for independent seniors. However, one participant lived in the

assisted living apartments at the Wikwemikong long term care centre. Our participants were proud of their ability to continue living independently and shaped their space to suit their own interests and taste. I observed that seniors often asserted their identity by displaying things that were important to them such as pictures of family and friends, craft projects, collections, or cards and letters. It was important to these individuals that they had space to engage in their hobbies and interests.

For some people, tasks around the home such as making the bed, gardening, doing the laundry, or cleaning the house gave them something to do and helped them to maintain a purpose. However, many informants spoke of the challenges of living alone including home and yard maintenance such as clearing fallen leaves or snow, mowing lawns, and daily upkeep such as changing light bulbs and air filters.

'Cause, us here, my husband is, well he'll be 80 next year. You have to look after him and so we don't really need no outside help because I can do most of the things, but we have to get our wood cut for us and stuff in the past couple of years because my husband had heart bypass and valve changed this past Christmas, so we have a guy come in and mow the lawn and stuff like that. (JP SE 04)

The only thing I notice is in the winter time that's when I feel it, when I have to shovel the snow and I can't shovel the snow. (JP Trad 01)

Two individuals expressed that they had recently accepted help from a home maker for tasks such as vacuuming and washing the floors, but that they had tried to do these tasks as long as they were able. Some participants perceived their ability to manage their own home maintenance tasks to reflect their autonomy. Some participants sought help for home maintenance tasks from family and others from formal services, but there are very few options available to older people on Manitoulin that fall between independent living and nursing home care, particularly for individuals who have no family support.

Safety and security

Safety and security were a significant concern to the informants I spoke with, especially for individuals who lived alone. Several participants brought up experiences they had had with vandalism or theft in their communities.

One time Wiky was a safe place. In the 40's you could leave your pail outside, you could leave your axe outside, you could leave your stuff outside. Nobody did come along and pick them

up. Now you can't leave anything out there. Vandalism, too much vandalism. Too much vandalism in the [community]. (KP SE 03)

These experiences caused worry and a reluctance to venture outside alone. On several occasions I heard seniors discussing concerns that their communities were not as safe as they once were they perceived that young people had less respect for elders than they had in the past. They perceived that some youth lacked a good upbringing which led them to engage in drug and alcohol abuse. They also felt that too many young people were left unsupervised, which led to them getting into trouble. It was these youth who were perceived to be responsible for acts of theft and vandalism that made some seniors feel unsafe.

Security was also discussed in relation to a fear of falling or overexerting oneself while attempting to complete home maintenance activities or cleaning. For some seniors these activities were challenging and caused their health issues to flare up.

Most challenging, I wonder what I could say, to wash my floors I can't, my back is sore, even just sweeping my back aches I can't even lift the broom or mop. Laundry, I can't, my pressure jumped sky high so they told me not to bother with my laundry anymore, that is why I bought these, the washer. (KP SE 05)

One participant, who attributed her memory problems to be the result of falling and hitting her head expressed that she was very cautious not to fall, especially on stairs. She was waiting for railings to be installed in her home, so she would take one step at a time, holding on to the wall to try and protect herself.

Social support and stimulation

Seniors expressed the importance of family support in many areas of their lives including emotional support and physical assistance with shopping, home maintenance, transportation, and activities of daily living. Assistance in these areas often helped elders to continue living independently in their own homes.

My sister-in-law usually and my daughter, when I want to go grocery shopping I just call either one of them, whoever is home that day and they'll come pick me up and pick up groceries. (JP SE 01)

I observed that seniors who had this type of support generally expressed less stress about things like transportation and home maintenance, and were more confident that they would receive care from their families if they required it.

Respondents also spoke about the benefits of social interaction. Meeting with others, laughing, sharing stories, learning, and participating in activities with others were all seen as contributing to a healthy old age. The psychological benefits of social interactions were especially noted. Participants expressed that sitting alone and dwelling on the negatives only made aging worse. Some respondents expressed the changes and challenges involved in socializing as you grow older including the loss of a peer group, difficulty with mobility or transportation, and feeling criticized if they did not meet the expected social norms.

But people, there's, a lot of them are critical, you know? They look at somebody because they're doing that, what's she trying to prove? It's true, you know, it's very bad in a small community, you know. Or you're trying to do things if you're at this age, "What is wrong with her?" You know? (JP SE 03)

On several occasions I was able to attend events organized for seniors including seasonal parties, diner's clubs, and educational events. These events gave seniors the ability to visit and catch up with friends. Seniors who attended these events would share a meal and other activities with their peer group. The mood at these events was happy and social.

Contact with grandchildren or other children also was seen as a particularly important source of social contact. When asked what she enjoyed about aging one senior replied:

When I see children, when they are brought to me. Babies. I have a lot of pictures of babies that are brought to me, I carry them. I never have any babies and this makes me very happy when the young men bring their babies. (KP SE 02)

Senior participants enjoyed contact with children, and being able to interact with children also allowed them an important opportunity to pass on knowledge and teachings. It was also apparent that many people took a great deal of pride in their children and grandchildren as family pictures were often prominently displayed in participants' homes. Many older people expressed that they did not get enough opportunities to interact with young people in their community and that they would be interested in more opportunities to visit with children.

Mm hmm, mm hmm, yeah. They should be uh, taken oh, or they should be made useful in sharing their knowledge of, uh, make them feeling uh, useful, eh? (pause) But it doesn't happen. They'd be very proud to think that they are useful. I thought of

doing that when I was doing um, I used to um, start the long term care program and I left because the I had to leave, and I left anyways, and that's what I was thinking about doing, bringing in the elders and the kindergarten kids together so they can uh, exchange or talk to each other or visit the nursing home, those young kids from the kindergarten. (JP Trad 02)

One traditional elder who was interviewed recognized the importance of bringing elders and children together. She believed that it would be beneficial to have an organized program to bring older people and young children together to talk and share with each other. One event that I did observe which brought seniors and children together was an annual Grandparents' day celebration at Amikook in Wikwemikong. This afternoon event allowed Grandparents to spend time with their grandchildren in a social setting which included games, prizes, and photo opportunities.

Not all seniors have adequate social support or the ability to pursue socially stimulating activities. Loneliness and isolation can be a major challenge for individuals who lack social support and can have negative impacts on their health. Loneliness and isolation were perceived by our participants to be a major challenge associated with aging. One informant with severely restricted mobility indicated that she desired to be more active and involved in community social activities, but was unable to access information about upcoming events, which made her feel isolated and lonely. She expressed her frustration with being stuck in her house and having no knowledge of the goings-on in the community or ability to get transportation to attend them. She lamented:

I don't know, but the programs I see they have they are for the ones that are capable of going there, that's the way I see it I am not capable of going there seniors gathering...it is written over there, I didn't know anything about seniors gathering, nobody came to see me...nobody asked me if I wanted to join, nobody came over, I just seen that in the expositor, seniors gathering I guess they had, Amikook. I didn't hear anything about that its only the ones that are capable of walking over there, going over there, that that do get something out of it I guess, but not the but not seniors like me, housebound, I could say...what could you say? What do you call it? I'm housebound and the doors are locked. (KP SE 03)

Social stimulation was seen to be generally within the control of individuals, although participants who were housebound or lacked transportation discussed how difficult it might be for them to gain access to social stimulation unless they had good

support from family and friends who would come to visit them or take them out for outings and to events. The previous quote demonstrates how challenging it can be for a person with limited mobility to participate in many of the behaviours associated with positive aging, and is a special concern for individuals with poor health, limited mobility, and limited social and familial support. Social support is a key factor in enabling people who face major obstacles (poor health, restricted mobility, etc.) to achieving successful aging, and can allow people who are not able to participate independently in activities such as physical exercise to become engaged in them. Social stimulation was also seen as important in keeping the brain active and staying happy since visiting allowed opportunities for conversing, laughing and learning.

Culture

Seniors often spoke about the positive effects of culture and spirituality which provide them with a sense of strength, balance, acceptance and guidance. The medicine wheel or the circle of life were often referred to when seniors spoke about aging. Maintaining balance between mind, body and spirit was seen to contribute to a healthy old age.

I guess, ah, spirituality I guess, ah, something we need to look at, you know, spirituality is, ah, then again spirituality is, ah, simply means that I need to balance, ah, my weaknesses and my strengths, you know. To me that is what spirituality is, you know, so in order to, so, so, I feel that we need to, ah, continue to balance our life in a good way, ah, and being responsible for our actions you know and so it's and try to be an example to the younger generation you know to you know to focus on. (KP SE 01)

Well, we have sweat lodges. We go in a sweat lodge and purify your, try and purify yourself and you can talk with whatever is troubling you while you're in there, and it stays in there, you don't bring anything out what's said in the sweat lodge...Mm hmm, and when you go in the sweat lodge, when you cleanse yourself your mind comes clear, eh? You can cry, whatever you want to do. When you come out of there you've got a clear, clearer head and know what you should be trying to do with yourself to get rid of whatever problem is you have, problems you have is supposed to be taken away when you are in the sweat lodge. (JP SE 04)

For some individuals, working towards managing mental health problems was an important part of achieving a positive old age. Other seniors referenced the importance of balance in the areas of the medicine wheel and the importance of finding harmony in

one's life and making an effort to heal emotional traumas. Some participants referenced cognitive and emotional health in terms of a broader understanding of health relating to the medicine wheel and the idea of balance between physical, spiritual, mental and emotional realms. Taking the time to work through emotional issues such as trauma and grief were considered to positively contribute to achieving balance, which was understood to be an important part of overall well-being in old age.

Powwows and ceremonies were also seen as opportunities for social and cognitive stimulation.

It's healing and it's uh, um, it's the idea of being all together and then, um, um, yeah, I think it's being together that's a big thing. Coming together with different people, you get to know different people and they come from other reserves and they come up from the states and you know you meet all these interesting people. (JP SE 02)

The previous quote referred to one female elder's perception that having the opportunity to get together with friends and family at powwows was healing, and allowed her to actively engage with other people.

Language was also perceived as important, because it was seen to keep people connected to their spirituality and because of the way that the Ojibwe language encourages humour, which was seen to help individuals to maintain a positive attitude.

It's just the, just the understanding of, 'cause a lot of that traditional cultural stuff is all in the native language, so you've got to understand the language in order to understand what this is, the sweat lodge and stuff and traditional lifestyles is all about. If you understand your language then it is easier to understand. (JP SE 04)

Although there were several participants who did not speak a Native language, the ability to have access to services and supports in Ojibwe was important for those that did speak the language. In addition, day-to-day use of the language in social situations was seen to be beneficial to maintaining a healthy mind.

Well, because our language is such a fun language, we're always laughing, eh? So, it's good when you speak the language, when we visit, when we have people in here you hear a lot of laughter. It's probably the – in terms of the, of all the mental health therapists down this way we are the, everybody is laughing when they come in this room, 'cause we speak the

language and we're laughing, we say something and it means something else and it's so, it's a fun language, there's a lot of humour attached to it so it's good for the brain because of that, that humour to it so,...you say something in English people usually don't unless they mispronounce the word and then you'll be laughing. (both laugh) We joke a lot you know, it's uh we uh, and it also, it's part of our culture, and even if you're forgetting stuff we joke about that too, eh? So it's part of you know, you joke with somebody, you tease them, eh "you forgot this," or "put on the wrong boots" something like that and we laugh about things like that so people remember when you joke and say "I'm not doing that again, eh?" so it's a reminder versus you know, "somebody's ridiculing me" and feeling bad about it, it's you can take the joke and it's it also helps you to remember that you're not going to repeat that. (JP Trad 01)

It is clear from this quote that the Ojibwe language is perceived to be beneficial for the maintenance of cognitive and emotional health. This quote also highlights the importance of language and humour in First Nations peoples' reaction to aging and age-related memory loss. First, it is seen that using the language and engaging in humorous discourse can serve as a preventive measure and second, that humour can be used as a device to signal to someone that others are noticing that they are having problems with their memory without judgment or disrespect.

Culture and cultural practices can have significant impacts on the aging experience. For First Nations people, cultural teachings impact attitude and outlook, social and familial support, coping strategies, and health practices. Changes in family structures and disruptions in cultural practices such as those caused by the residential school legacy have had a significant impact on experiences of aging and the roles of older people in families.

Being around the kids is actually healing for the elderly too because you have the kids and they're engaging in new things with you all the time, so that's good for the memory so in, and because of a lot of the um, residential school incidences too, that has also affected the family dynamic so you find a lot of grandparents that are, just isolate themselves so families are not there doing their role as a grandparent's role, eh? Which is what actually keeps you young, when you play that role as a grandparent, or as an uncle if you don't have any kids, then you still engage with your family members to teach them and do things with them, eh? Like you know, everybody has a favourite

auntie or favourite uncle, so they all have a role to play in that family dynamics, eh? So those are some of the things that are missing in our in-in our communities now, so the elders are lonesome and they're not engaging with their younger when they should be because of those family issues, eh? (JP Trad 01)

The residential school system has had far-reaching impacts on First Nations people and families. In many cases, it has had the effect of disrupting traditional family structures. As the previous quote demonstrates, the disruption of traditional family roles, especially the grandparent role, can have an adverse effect on the health of older people.

Interpretation

Aboriginal seniors were traditionally considered to be a central part of family life and a significant resource for traditional knowledge, spiritual guidance, and emotional support (Reading, 1999). Alongside of this special role in their families and communities, there was traditionally an expectation among Aboriginal people that seniors would be treated with respect and that their families would provide care for them when required (Yee, 1990). Although these values remain in many instances, contemporary aging experiences among First Nations seniors on Manitoulin Island are complex. First Nations seniors are a heterogeneous group with a wide variety of interests, needs, abilities, and health statuses. This chapter made an attempt to move beyond dominant portrayals of Aboriginal seniors to show how they perceive their own aging experience and to explore the factors that characterize aging well.

Participants in this study described aging as a time of shifting roles that was accompanied by both challenges and benefits. Loneliness and changes to health and abilities were described as the most difficult things about aging. The perspective that poor health and physical problems are a disadvantage of growing old is consistent with mainstream literature (M. B. Harris, Begay, & Page, 1989). In particular, the idea that poor health can cause limitations to a person's ability to participate, and may lead to loneliness, isolation, and dependency has been documented as a shared concern of older people (M. B. Harris, et al., 1989). Despite these challenges, most participants described aging as a positive time in their lives. They perceived leisure time and independence to be one of the most enjoyable aspects of growing older. Again, there are similarities here to mainstream research which shows that improved relationships with family, more free time and relaxation, increased freedom, self-acceptance and self-respect are beneficial to older people (M. B. Harris, et al., 1989).

A strong definition of successful aging, or aging well, emerged from my interviews with seniors. Participants perceived successful aging to be characterized by several interrelated factors. These factors included physical and mental health, an active social life, participation in spiritual and cultural life, a positive attitude and a sense of purpose, keeping busy, and maintaining an appropriate level of autonomy. Having a positive attitude and being able to adapt to changes in health and ability were perceived to be the most important characteristics of a person who was aging well. Good health, although desired, was not perceived to be essential in determining whether a person was having a successful aging experience.

Seniors also clearly expressed behaviours, barriers, and enablers that had an influence on peoples' aging experiences. Making healthy lifestyle choices, such as exercising their brain and body, having a healthy diet, and avoiding harmful habits such as smoking and alcohol abuse were behaviours shared by individuals who were perceived to have aged well. Having good physical and emotional health and engaging in spiritual and cultural life were seen to enable a person to age healthfully. Meanwhile, socio-cultural factors including poverty, poor access to transportation, not feeling safe and secure, or lacking social support were seen to negatively impact peoples' aging experiences.

The various factors that impact the day to day lives of older adults are inextricably intertwined and attempting to separate them into distinct categories is challenging. The aging experience is dependent on the interaction of a multitude of different factors. For example, something as seemingly simple as maintaining physical health can be impacted by factors as diverse as finances, social support, nutrition, community services, transportation, attitude, and access to information. At the same time, a person's physical health may impact their ability to engage socially, eat well, stay active, and maintain a positive attitude. As a result, the design of services and supports to assist older people in maintaining or striving for a successful old age requires foresight and sensitivity to ensure that the diverse needs of a wide variety of seniors, with different levels of health and support, can be met.

Cognitive stimulation, physical activity and healthy eating were all factors that seniors perceived to be a less integral part of their daily lives than they had been for seniors of earlier generations. Although the individuals we interviewed valued these healthy lifestyle behaviours, and made conscious efforts to be engage in them, they recognized that changes to ways of life had made it more difficult for some people to participate in healthy behaviours. Many participants indicated to me that traditionally, people had regular access to fresh foods, and that harvesting these foods, preparing them, chopping wood for fuel, and engaging in caring for grandchildren all contributed to using your brain and body in healthy ways. These activities were not perceived to be

as naturally ingrained in peoples' lives today, but were seen more as things that a person had to actively seek out.

Many of the issues raised by older adults in this sample are expected and are congruent with the results of studies of perceptions of successful aging that have been conducted with other Aboriginal groups as well as mainstream Canadians. Data from the *Canadian Study of Health and Aging*, a multi-sited, longitudinal study of Canadians over age 65, yielded results that suggest that French and English Canadians recognize similar factors to play a role in their health and well-being. Elements that overlapped with the results from my project include beliefs that success in aging is shaped by a positive attitude, autonomy and independence, healthy lifestyle choices, keeping active, and having regular social interactions (Bassett, et al., 2007). A healthy lifestyle, optimism, and autonomy are also demonstrated to be predictors of a successful old age in other published literature (Franklin & Tate, 2009; Hartman-Stein & Potkanowicz, 2003; Steptoe, Wright, Kunz-Ebrecht, & Iliffe, 2006). As mentioned previously, the perceptions of healthy aging by Manitoulin Island First Nations seniors are also consistent with the findings of Collings (2001) and Lewis (2009) regarding Inuit and Alaskan Natives. Similar to these populations, First Nations seniors emphasize attitude and adaptability rather than focusing on challenges associated with declining health and abilities. These understandings of aging relate to cultural and spiritual belief systems within which aging is considered to be a natural process, health is understood from a holistic perspective, and there are strong values relating to the acceptance of adversity and family support for seniors. The importance of continued involvement in life and engagement with community is also supported in the literature (Abonyi & Favel, 2012).

Earlier in this chapter I referenced Inui's (2003) description of aging as a dynamic equilibrium that includes resilience, generativity, and feistiness. Inui (2003:391) also suggested that successful aging should be defined by "sufficient well-being in a number of spheres (mental, physical, social, spiritual, economic) to sustain a capacity to function successfully in the changing circumstances of one's life." The descriptions of successful aging by Inui (2003) and First Nations seniors on Manitoulin Island are compatible. Both represent a holistic understanding of health that encapsulates multiple aspects of a person's lived experience. These definitions of successful aging allow for flexible and fluid perceptions of health and success. Illness and disability are not perceived to discount someone from having aged successfully. Instead, success in aging is characterized by a person's ability to respond and adapt to their changing physical and cognitive health status and life circumstances. These definitions, therefore, do not exclude older people who rely on others for assistance in some areas of their life or who have to make changes to their usual activities, from "achieving" a successful old age. Instead, they recognize that resilience and adaptive behaviours can allow even those seniors with significant health challenges to achieve a positive aging experience. This is important in a context where many seniors are ill and have co-morbid health issues.

As previously highlighted, supports that assist relatively healthy seniors in achieving a successful aging experience can be applied to all seniors, including individuals with cognitive decline and other health and mobility impairments, with similar benefits. Facilitating access to these enablers and attempting to minimize the effects of barriers can improve quality of life for seniors across the board. Looking to the healthiest seniors in a given community can give us a point to strive to achieve. By discussing successful aging with these individuals we have seen that successful aging is possible, and can infer that the hopes and desires that they express for their aging experiences run parallel to the wants and needs of most seniors in their communities.

Seniors who participated in this research expressed a great deal of knowledge about how a person might age well. However, they also discussed barriers that they perceived to impede them from having a healthy old age. The barriers that they expressed align with social determinants of health that are known to influence well-being across the life course (Loppie-Reading & Wein, 2009). In the literature review at the beginning of this chapter I explained how some of these determinants, at the proximal, intermediate, and distal levels, are known to impact health. Seniors in our sample spoke of several of these determinants in terms of barriers to their own health and well-being. Food security, poverty, and housing were all factors discussed by participants. Ensuring that older people have access to appropriate and adequate food choices should be a goal of services for elders. Poverty also significantly impacts Aboriginal seniors. Poverty is known to be highly prevalent among First Nations seniors and is a predictor of poor health (Loppie-Reading & Wein, 2009; Kathi Wilson, et al., 2010). For the seniors I spoke with, a lack of financial security was a source of stress and impeded them from accessing healthy food, heating oil, and hygiene products. Further, participants in this research clearly indicated that not having access to transportation services or a family member who was willing to drive them places made it more challenging to participate in healthy aging practices. These inequalities in access to services, social supports, and other resources made it more difficult for them to manage their health and cope with illness.

More than half of the seniors in our sample were living alone, indicating that there may be a need for non-traditional housing supports. Seniors are resistant to the idea of nursing homes. However, intermediate supportive housing options that foster continued independence while providing support when needed could be a positive contributor to successful aging. This is especially likely for people who do not have access to family support or social capital to allow them to continue to live independently in their own homes as their abilities change as they grow older. Supportive housing may also help seniors to feel safer and have a stronger sense of security.

Although safety and security are not commonly discussed in the literature as contributors to successful aging, I believe that they are important. Fear about personal safety and well-being can cause older people to withdraw from activities and to isolate

themselves in an attempt to avoid dangerous situations. This can have impacts on their health and well-being. A sense of safety and security can also play into a person's feelings of control. As I have previously discussed, the literature clearly demonstrates that perceived control can have a significant positive impact on the aging experience and that it is a relatively easy factor to influence through interventions (Menec & Chipperfield, 1997). For many seniors in my sample, an eroded sense of security related directly to concerns about youth in the community who were engaged in alcohol and drug abuse and diminished feelings of closeness and respect for elders from younger generations. Implementing programs to facilitate intergenerational contact and foster good relationships between seniors and youth would likely have positive effects and benefit both groups.

Although I do not want to jump too far ahead into the description of dementia, its impacts, and the needs of older adults experiencing cognitive decline, it is important to take a moment in this section to explain why it is so important to understand what First Nations older adults perceive to be a positive old age and to indicate the factors that help or hinder them in achieving successful aging. There are four key reasons that it is so important to understand and promote successful aging in the context of dementia. First, behaviours that influence successful aging run parallel to recommended practices for the prevention of dementia and the maintenance of a healthy mind (Alzheimer Society, 2010). Second, understanding how seniors perceive success in aging highlights their beliefs and values related to growing older. That is, by knowing older peoples' perceptions of an ideal aging experience we can better understand how they wish to be treated as they age and what type of values to promote when developing care programs and services to improve the quality of life of older people (healthy or ill). This enables the design of programs and services for First Nations people with dementia that reflect their beliefs about personhood and meaning in old age. Third, well elders have some insight into the things that are holding back other seniors in their communities who are not aging as well as they might be. In several cases they suggested opportunities for improving upon this situation. If we can recognize some of the hurdles that healthy older people have overcome and the things that they find to be a continuous struggle we can identify areas where education and support are effective and other areas that need improvement. Finally, the promotion of healthy aging and resilience in old age is beneficial to family caregivers of people with dementia, many of whom are themselves seniors. Good health and well-being can serve as a protective agent for caregivers that can increase their ability to cope and prevent burnout.

The understanding of successful aging that emerged from interviews with seniors can be used to make inferences about personhood in old age. It can also provide insights into how people would like to be treated as they age. In the past, successful aging and dementia have been portrayed as incompatible since people with dementia were not perceived to have the capacity to age well. However, researchers are

increasingly advocating that people with cognitive decline still have the capacity to experience successful aging and that resilience may be an important concept in assessing how well a person with dementia is aging (Phyllis Braudy Harris, 2008; Phyllis Braudy Harris & Keady, 2008). Further, participants' descriptions of aging well also help us to understand what they understand to constitute a good quality of life.

The Alzheimer Society of Canada (2010) recommends healthy lifestyle choices as a means of reducing the risk of developing dementia. A healthy diet, aerobic exercise, cognitive stimulation, and an active social life are all considered to be beneficial in preventing the onset of cognitive decline. In addition, they recommend that people take precautions to avoid head injury and that they seek appropriate treatment for medical conditions such as diabetes, high cholesterol and high blood pressure (Alzheimer Society, 2010). These suggestions for the maintenance of brain health echo the perceptions that First Nations older adults have of the behaviours that signify successful aging. As I discuss in a later chapter, our participants' understanding of successful aging mirrors their beliefs about preventive measures for dementia. As a result, the promotion of healthy aging can be a useful and culturally relevant tool that also acts to encourage behaviours that may lead to the prevention of cognitive decline. In fact, I believed that the promotion of healthy aging has the potential to be used as a proxy for dementia-specific health promotion campaigns. The recognition by First Nations seniors that activities like cooking, reading, and doing puzzles can keep a person's brain active, and the evidence that many seniors are consciously engaging in activities to keep their minds working is promising in relation to the prevention of dementia.

Earlier in this chapter I referenced a quote by Lewis (2009:iii) who suggested that eliciting the perceptions of older Aboriginal people about aging well could counteract the impact of "a generic definition that portrays [Aboriginal] Elders as aging less successfully than their non-Native counterparts". Statistics that show that First Nations older adults experience lower health status and higher functional dependence than their mainstream counterparts suggest that older Aboriginal people do not know how to age as well as non-Aboriginal people or perhaps do not care enough to try. However, it becomes clear from reading the quotes presented above that not only do older Aboriginal people have a great deal of knowledge about how to pursue a healthy old age, but that many also take action to attain a successful old age. The individuals I spoke with demonstrated a great desire to stay active, engaged and healthy as they grow older. So, we need to be careful about using definitions that paint Aboriginal elders as unaware of how to age healthfully or suggest that they are not interested in an active and engaged old age because this may act as a further barrier to them achieving a successful aging experience. Instead, we need to recognize that many First Nations adults face significant challenges in achieving a positive aging experience because of their life histories, socioeconomic conditions, and structural barriers. As a result,

supports are needed to ensure that older people are able to carry out the actions they need to contribute to a healthy old age.

In light of what is known about the barriers and enablers to positive aging in general, and as they relate to First Nations elders in particular, we can begin to understand some of the factors that might be beneficial to consider as a part of policy and programming related to the promotion of successful aging in this community. One aspect of this is changes to traditional lifestyles. Participants related many of the positive lifestyle behaviours they discussed to a traditional way of life and lamented that changes to this way of life had eroded many opportunities for older people to engage fully in behaviours related to successful aging. In particular, exercise, healthy eating, cognitive stimulation, social stimulation, and social support emerged as key lifestyle traits that had been eroded by changing family structures and ways of life. Although we cannot bring back the traditional way or life or change family structures, community-level supports that encourage these healthy behaviours and allow older people to access and develop social capital would be beneficial in many ways.

There are many possible programs and activities that may be effective in promoting healthy aging. One example is community gardens or cooking classes for seniors which would encourage exercise, socialization, cognitive stimulation, and give older people access to fresh produce and healthy foods. Intergenerational programming that brings together elders with children of different ages has the potential to reinforce traditional elder's roles related to teaching and passing on knowledge and would likely have added benefits for younger generations. Even something as simple as a friendly visiting program that matched up healthy elders with other older adults with less social support might be beneficial in preventing isolation and loneliness. Community-based exercise programs with modified activities for people of different fitness levels and physical abilities might also be beneficial. Some kind of modified fitness program available in the home, at a community center, or as part of a seniors' program might assist seniors with less support and mobility in accessing some kind of physical exercise (i.e. VON Seniors Maintaining Active Roles Together (SMART) program)(Connelly & Mersich, 1997). Much as with cognitive stimulation, physical exercise also has far-reaching benefits for the aging person. Research has demonstrated that engaging in healthy lifestyle behaviours such as physical activity and cognitive stimulation can increase longevity, health, and positive state of mind (Glass, de Leon, Marttoli, & Berkman, 1999).

The importance of social stimulation and enjoying the company of children are referenced in the literature. Polacca (2001) discusses that socializing, laughter, family, community, spirituality, and traditional lifestyle are all factors that can help older Aboriginal people to cope with changes associated with aging. Further, social capital, the resources that are available to an individual through their social connections, has been demonstrated to increase seniors' ability to maintain independent, productive, and

meaningful lives (Cannuscio, Block, & Kawachi, 2003). Facilitating social gatherings for seniors with other seniors, but also with youth would help to encourage social stimulation. I observed that activities that involved socialization were popular, especially those at which a meal was served. Debbie Selent, who frequently organized events for individuals in the UCCMM communities, expressed that *Lunch and Learns* were an ideal way to convey health information to seniors. Quilting and crafting activities were also very popular among women, and seniors' outings such as bus trips and boat trips were popular and well-attended. All of these things contributed to social stimulation and some also incorporated cognitive stimulation or physical activity.

Ceremony and other traditional activities may also be important for some seniors, especially those with a more traditional orientation. Ensuring that seniors who desire to use traditional medicines and traditional healing, and participate in cultural and spiritual activities such as powwows and ceremonies, have access to these resources is crucial. As mentioned earlier in this chapter, several seniors in our sample expressed that sweat lodges, powwows, and spirituality enabled them to engage more fully with their families and communities, and that teachings such as the medicine wheel and the seven grandfather teachings helped them to accept the changes associated with aging. Like attitude more generally, humour related closely to culture and language, and has been linked to healing and resilience (Garrett, Garrett, Torres-Rivera, Wilbur, & Roberts-Wilbur, 2005). For Aboriginal people, humour is a spiritual tradition and a powerful healing force that helps to bolster resilience (Garrett, et al., 2005). Since language is inherently intertwined with culture (Riley, 2007), it is also important that the option for traditional language use be built in to health promotion services and supports for seniors related to aging well.

Of course, for any programming for seniors to be useful, certain barriers must be addressed. In particular, the availability of these programs would need to be clearly communicated to all seniors, and reliable transportation that is accessible and affordable would need to be arranged. These two things may appear to be minor hurdles, but they can be a significant challenge, especially for older people who do not have support from family and are not under the wing of the home care system where support workers might inform them that these things are happening and help them plan to attend. There have been efforts by some community health workers to implement these types of interventions, but in some instances these efforts have been thwarted because of a lack of resources, and the more pressing demands of administrative duties.

I have separated out culture as a distinct theme in this chapter, but in reality, culture and cultural change touch almost all of the themes that have been discussed throughout. As I suggested at the end of the section about behavioural aspects of aging well, changes to traditional ways of life have impacted peoples' ability to engage in behaviours associated with healthy aging. The same can be said about many of the

socio-cultural themes I have discussed in this section. For instance, safety and security are perceived to be linked to changes in the ways children are being raised and a general lack of respect for seniors. Likewise, housing issues are directly related to seniors more frequently living alone and traditional social support structures are easily disrupted when adult children move away from their communities in search of employment.

Despite the fact that older First Nations people face higher levels of poverty, lower health status, and lower life expectancy than their non-Aboriginal counterparts, much can be done to improve their aging experience. Cultural beliefs about the acceptance of aging and adaptability in the face of adversity provide a strong starting point from which to begin to build the capacity for First Nations elders to experience a positive and successful aging experience. The First Nations population is aging rapidly and more attention needs to be placed on services and strategies to assist older people to stay active and engaged, and to maintain a high quality of life. These programs need to begin to target younger adults, and possibly even youth, since many of the practices that support health in old age are beneficial to people at any age, and preventing the onset of health issues in a younger person has cumulative effects across the lifecycle.

Conclusions

This chapter set out to understand successful aging based on the perspectives of First Nations seniors, and to determine why understanding perceptions of successful aging was beneficial to health promotion as well as the development of prevention, support and treatment programs for dementia in these communities. This chapter demonstrated that First Nations seniors on Manitoulin Island perceive aging as a natural process and have a holistic perspective of the factors that impact a healthy and positive old age. For these seniors, a successful old age is characterized by acceptance, good overall health, making an effort to maintain health through behaviours such as exercise, eating well and avoiding alcohol and tobacco, staying engaged in social activities, participating in spiritual and cultural activities, having a positive attitude and a sense of purpose and maintaining autonomy. These factors all run parallel to recommendations in the literature for the maintenance of function, engagement, and longevity in old age.

Further, this chapter identified four key reasons why understanding successful aging is relevant to a study about dementia. First, behaviours that support healthy aging in general are effective in promoting sustained cognitive health. Second, older peoples' values and desires about an ideal aging experience can be integrated into dementia care practices, which can improve the ability of caregivers to support personhood and meaning. Third, identifying the challenges faced by individuals who are aging successfully can assist communities in designing programs that help older people to overcome these barriers; and, finally, promoting health and resilience in old age can be

protective to family caregivers who often face significant stressors that can erode their ability to age well.

Successful and healthy old age is desirable to the participants in this study. They have insightful perceptions about how a person might go about maintaining good health and engagement with life as they grow older. However, these desires for a healthy old age, the knowledge of how one might achieve success in old age, and the efforts that our participants are taking to age well stand in stark contrast to the reality faced by Aboriginal seniors that is represented by statistics about poor health and longevity in the literature. How might these two contrasting realities be reconciled? How might policy, education, programming, and other supports be designed that can reflect the needs and desires of Aboriginal seniors to age well and assist them in overcoming the significant barriers that they face, such as poverty, access to resources, co-morbid health problems, and the effects of historical trauma and colonialism?

It became clear throughout the analysis of this data that changes to culture and ways of life are perceived to be the most significant impact on my participants' efforts to age successfully. Changes to traditional life ways cross-cut many of the themes I discuss above. Taking a holistic perspective that considers the effects of many factors across the life course is crucial to understanding First Nations seniors' experiences with aging. A shift to a more sedentary lifestyle, reliance on store-bought foods, the disruption of traditional family structures due to the residential school legacy and the migration of people off-reserve to seek employment have all eroded peoples' ability to participate in behaviours that they perceive to lead to successful aging and to access the supports that they need to sustain their health and continued engagement with life as they age.

Chapter Four: Understanding dementia: First Nations peoples' explanatory models of forgetfulness in old age

Introduction

Cultural constructs of disease and explanatory models are important concepts for understanding how people within a cultural group conceptualize and respond to illness and disease. This chapter explores Manitoulin Island First Nations peoples' explanatory models for Alzheimer's disease, dementia, and age-related memory loss, that is, how ADRD are identified and explained. In order to determine how First Nations people understand dementia I draw on data that reflects their beliefs about the potential causes of dementia, perceptions about the changing prevalence of the condition, and the way that people talk about memory loss in old age. I then examine these perceptions in the context of other literature about Indigenous peoples' cultural perceptions of memory loss and dementia. This chapter demonstrates that memory loss in old age is primarily accepted as a natural occurrence among Manitoulin Island First Nations. However, the data also reveals that there is a secondary perspective associated with dementia symptoms which includes fear and anxiety about the course of the illness and how care and support will be provided.

Context

Although there remains very limited knowledge about the experience of dementia for Canadian Aboriginal peoples (Lanting, et al., 2011) there is a small, but growing, literature concerning the experience of Alzheimer's disease and other dementias among Aboriginal peoples in North America. The first reference to dementia in Aboriginal peoples in the literature was the mention of a single case of dementia in a comparative study of psychiatric care in Winnipeg, Manitoba in 1972 (H. C. Hendrie & Hanson). The issue next emerged in the 1990s in both Canadian and American literature (Hall, et al., 1993; H. C. Hendrie, et al., 1993; Kaufert & Shapiro, 1996; Rosenberg, et al., 1996). At that time, the interest in dementia among Aboriginal peoples was focused on prevalence (H. C. Hendrie, et al., 1993; Richter, Weiner, & Rosenberg, 1994), the development of appropriate cognitive screening tools (Hall, et al., 1993; Kaufert & Shapiro, 1996), care-giving (Hennessey & John, 1995; Hennessey & John, 1996) and the impact of genetic factors on the development of dementia in this population (Rosenberg, et al., 1996). Interest in better understanding Aboriginal peoples' cultural understandings and

experiences of dementia has continued to increase slowly but steadily. Here, I review the existing literature that examines dementia in Aboriginal peoples in North America. There is a need to understand Aboriginal perceptions of aging and dementia so that appropriate assessment, treatment, and care tools can be developed (Lanting, et al., 2011)

Prevalence

Although several researchers have attempted to gauge the prevalence of dementia among Aboriginal peoples, accurately determining the frequency with which dementia appears in this population has proven to be difficult. However, it is generally accepted that the prevalence of all dementias in Aboriginal peoples is similar to their mainstream counterparts, with Alzheimer's disease making up a smaller proportion of overall dementia cases and vascular dementias being more common (Henderson & Henderson, 2002; H. C. Hendrie, et al., 1993; Rosenberg, et al., 1996). This has been suggested because of various risk factors for vascular dementias that are more prevalent among Aboriginal peoples including alcohol and substance abuse, diabetes, cardiovascular disease, traumatic brain injury and obesity (Henderson & Henderson, 2002; L. L. Jervis, Cullum, & Manson, 2006; L. L. Jervis & Manson, 2002). Although there is a perception of higher rates of non-AD dementia and lower rates of AD in this population, Jervis et al. (2006) warn that it may be premature to make such estimates since so little research has been conducted on the subject.

Some research has attempted to determine the prevalence of dementia in Aboriginal peoples, especially in contrast to their mainstream counterparts. Results published in 1993 (H. C. Hendrie, et al.) demonstrated a similar prevalence (4.2%) of dementia between a small sample of Cree ($n=192$) living on two reserves in Northern Manitoba and a comparative non-Aboriginal sample from Winnipeg ($n=241$). In this same sample, the prevalence of Alzheimer's disease, specifically, was considerably lower among Cree (0.5%) than the non-Aboriginal sample (3.5%). Other researchers have attempted to understand the prevalence of dementia in Aboriginal peoples by considering factors that may increase or decrease their risk of developing the disease. For example, Rosenberg et al. (1996) assessed the prevalence of the apo E allele among Cherokee Indians in northeastern Oklahoma. He used the results to compare the degree of genetic Cherokee ancestry against the results of cognitive screening test results and concluded that higher levels of Indian ancestry were protective against the development of AD. Other research has suggested that the age of onset for dementia may be greater for American Indians than Caucasians (Weiner et al., 2003). However, that finding may be a result of American Indians' acceptance of memory loss as a normal part of aging, which could lead to them holding off seeking cognitive assessments until dementia has progressed further (Weiner, et al., 2003).

Recently, a publication by Jacklin, Walker and Shawande (2013) has demonstrated that the age-standardized prevalence of dementia among Alberta First Nations is 7.5 per 1000, which is higher than the rate of 5.6 per 1000 in the non-First Nation population. This information, derived from population-level data on dementia, also indicated that the prevalence of dementia between 1998 and 2009 increased more rapidly among First Nations people than their mainstream counterparts and that dementia in First Nations populations affected males and younger age groups more than was expected (K. Jacklin, et al., 2013). This is some of the first evidence that suggests that the prevalence of dementia may be higher in Aboriginal populations than non-Aboriginal populations.

The perception that there is a lower prevalence of dementia among Aboriginal peoples may also be shaped by Aboriginal peoples having a lower life expectancy. This may cause Alzheimer's disease and dementia, which are age-related, to appear to be occurring less frequently because fewer people are living to an age where we would expect them to begin to exhibit symptoms (L. L. Jervis, et al., 2006). Research on the prevalence of dementia in this population is generally focused on AD or on dementia as a more general concept. Little research had focused on the prevalence of other types of dementia such as fronto-temporal dementia, Korsakoff's syndrome, or vascular dementia. However, a 2004 study (Sabbagh et al., 2004) did indicate the existence of dementia with Lewy bodies in two Navajo elders and concluded that these cases could indicate that Native Americans were susceptible to a similar range of dementias and symptomology as Caucasians (Sabbagh, et al., 2004).

Despite attempts to understand the prevalence of dementia in Aboriginal populations, both incidence and prevalence of these conditions remains poorly documented today. Several factors have impeded researchers' ability to make more concrete estimates about the prevalence of dementia in Aboriginal peoples. These factors include a lack of access to diagnostic services, difficulty in appropriately assessing dementia in this population (Kaufert & Shapiro, 1996), and the fact that dementia is a relatively new problem for Aboriginal peoples and may not be recognized or reported as frequently as in mainstream populations (H. C. Hendrie, et al., 1993). Further, the incidence of dementia may vary between Aboriginal cultural groups.

The ability to accurately determine the prevalence of dementia in this population is also hindered by a lack of valid and culturally relevant screening tools (Griffin-Pierce, et al., 2008; L. L. Jervis, et al., 2006; Kaufert & Shapiro, 1996; Whyte, et al., 2005). Screening tools and the screening process are often culturally inappropriate and are biased against traditional knowledge, people with lower levels of education, and people who do not speak English. Further, the Western biomedical system often does not allow for time to build trust with clients in a cognitive testing environment, which is a vital step in health care for Aboriginal peoples (Hendrix & Swift Cloud-Lebeau, 2006). Issues

surrounding cognitive testing are complex and will be further examined in the next chapter.

Cultural Constructs and Explanatory Models

Extant work that examines cultural perceptions of normal aging, dementia and dementia care-giving in Canada is largely exploratory (Lanting, et al., 2011). Research focusing on the cultural construction of Alzheimer's disease and dementia in Aboriginal peoples began to emerge in 2002 (Henderson & Henderson, 2002; Henderson & Traphagan, 2005; L. L. Jervis & Manson, 2002). This research focused on better understanding the mechanisms through which Aboriginal people understand and cope with dementia (L. L. Jervis & Manson, 2002) and how they were responding to dementia as a "new" sickness (Henderson & Henderson, 2002:198-199). Although memory loss and cognitive decline are not completely new phenomena in Aboriginal populations, the prevalence of these conditions is increasing, making it a problem of new magnitude (Henderson & Henderson, 2002).

Among the first research to consider Aboriginal cultural perceptions of dementia was a study by Henderson and Henderson (2002) which explored the response to dementia in a single American Indian family. In this example, 84 year old Mrs. Maytubby experienced symptoms including memory loss, confusion, hallucinations and difficulty recognizing her surroundings. She also exhibited hostile and agitated behaviour that included emotional outbursts, verbal abuse and throwing things (Henderson & Henderson, 2002). Although Mrs. Maytubby's family had difficulty in coping with some of these behaviours, they perceived her hallucinations as communications with the supernatural world. She was able to communicate with dead family members and her granddaughter reported that, "She sees people we don't see." She did not have the ability to do these things prior to the onset of other dementia symptoms (Henderson & Henderson, 2002:207). Mrs. Maytubby's hallucinations and ability to communicate with "the other side" were interpreted by her family as being special and positive (Henderson & Henderson, 2002:207; Henderson & Traphagan, 2005:273). Among the Choctaw, this perception of dementia as an indicator of a person's transition to the next world is one of three main perceptions of dementia. Other perceptions include a belief that memory loss is a natural part of aging, or an understanding of dementia that combines lay and biomedical knowledge (Henderson & Henderson, 2002).

Research conducted with Aboriginal people in Saskatchewan demonstrated a perception that changes in culture and life ways is having a profound effect on normal aging and care-giving roles (Lanting, et al., 2011). These changes away from a traditional lifestyle were considered by older adults to have a negative impact on older peoples' health and wellness (Lanting, et al., 2011). This is similar to perceptions held by Elders in British Columbia First Nations, who also understand dementia to be a result of changing

diets and a transition away from living off the land (Hulko, et al., 2010). The results of my research are consistent with this other research that suggests that Aboriginal people perceive changes in traditional lifeways to be a contributing factor in the higher prevalence of dementia that is being observed in contemporary Aboriginal communities (Hulko, et al., 2010; Lanting, et al., 2011). A connection to the land and traditional ways of life is believed to be an important component of health and well being (Richmond, Elliott, Matthews, & Elliott, 2005; Kathleen Wilson, 2003). Changing lifeways are believed to impact health and have been associated with other illnesses including cancer and diabetes (Hart-Wasekeesikaw, 1996).

Hulko et al. (2010) determined two main perceptions of forgetfulness and memory loss among British Columbia First Nations. The first of these represents a more traditional view of memory loss. Under this model, memory loss is understood to be a normal and expected part of the aging process that comes as you travel around the circle of life, “from childhood to childhood” (Hulko, et al., 2010; Neihardt, 1972:150-151). Although the portrayal of a person with dementia as childlike can be perceived as negative and infantilizing in Western culture, First Nations cultures perceive children and babies as special and closer to the creator and thus, as possibly having more contact with the spiritual world (Hulko, et al., 2010). This perception may have similar impacts as the case study described above which shows that a person with dementia may be highly valued for their ability to communicate with the spirit world (Henderson & Henderson, 2002). The perception that cognitive and behavioural changes are a natural part of the aging process and a circular view of the life course that culminates in a person returning to a childlike state as they age was also found among Saskatchewan First Nations (Lanting, et al., 2011). The very old and very young are perceived to be closest to the point where the spirit sense is most active (Best Start Resource Centre, 2010). Below, I examine this idea more closely in relation to peoples’ understanding of the Medicine Wheel.

Preliminary results that emerged from a 2007 roundtable about dementia among Aboriginal people on Manitoulin Island also suggested that Aboriginal people perceive memory loss as a natural part of aging and consider childlike traits and the return of old memories to be an expected part of growing older (Sutherland, 2007). Despite the high levels of acceptance of memory loss among older people, stigma, embarrassment and denial do occur, especially in the later stages of the disease (Sutherland, 2007).

Hulko et al. (2010) suggest that First Nations perceptions of dementia and their responses to it have changed over the past century. Despite the presence of a traditional perception of dementia among British Columbia First Nations, there was also another dominant perception of dementia that was strongly influenced by Western conceptions of the disease (Hulko, et al., 2010). This explanation of dementia differed significantly from the more traditional views, and portrayed memory loss in later life as problematic

and a “terrible disease” (Hulko, et al., 2010:328). Participants in this research indicated that age-related memory loss was rare in their communities and a new occurrence. They discussed the importance of having trained medical staff available to help them learn how to cope with someone experiencing dementia symptoms (Hulko, et al., 2010). These contrasting views of memory loss indicate that First Nations perceptions of memory loss in old age are complex and nuanced. Although forgetfulness is accepted, memory loss is not considered to be normal or welcome (Hulko, et al., 2010). This distinction is important, and figuring out where Indigenous people draw the line between normal, accepted forgetfulness and pathological memory loss may have important implications for detection, diagnosis and care in this population.

The patterns that emerged from my research on Manitoulin Island mirror the perceptions of Saskatchewan and British Columbia First Nations people who perceive memory loss to be a normal part of the aging process (Lanting, et al., 2011), but who also recognize that dementia and its associated symptoms can be a greater problem than simple forgetfulness (Hulko, et al., 2010). Manitoulin First Nations also share the perspective that the increasing occurrence of dementia can be linked to changes in lifestyle that have led seniors to be more sedentary, less socially engaged, and eat poorer quality foods. My research contributes to our understanding of Aboriginal peoples’ perceptions of dementia and adds a greater level of depth to this understanding by considering the diverse perspectives of seniors, people with dementia, family caregivers, and community health care workers.

Results

Two main perceptions of dementia emerged from the interview data. The first is the traditional perspective that sees memory loss as a normal and natural part of the aging process. The second is a medicalized understanding in which dementia is seen as pathological, unwanted and something that is cause for concern. In this section I describe the various factors that shape these understandings of forgetfulness in old age. To do so, I examine our participants’ beliefs about the causes of dementia, the language they use to speak about memory loss, and their perceptions about the prevalence of the condition. I conclude this section with a description of our participants’ responses to dementia, including acceptance, respect, and fear.

Prevalence and Rates

As mentioned in the introduction to this chapter, it is difficult to get a true sense of the prevalence of dementia among First Nations people on Manitoulin Island. Our participants had diverse perceptions of whether dementia is a problem, how many people in their communities are affected, and if dementia has always been a problem or

is something totally new. More than once in my field notes I reflected that there was an inconsistency between how people answered me when I asked them about the number of people they knew of that had experienced dementia and how they would talk amongst themselves about people in their communities with memory problems. For example, in one conversation with a health care worker, she mentioned to me that she only knew of three people with dementia, but later when she began to talk about people in the community with memory loss with a colleague, they easily named over ten people with memory problems. To me this signaled that there may be a significant difference between how people perceive age related memory loss and how they perceive diagnosed dementia. It indicates that Aboriginal people in these communities perhaps associate normal, age-related forgetfulness with one set of characteristics and medically diagnosed, problematic memory loss stemming from dementia with another.

Health care workers found it difficult to pinpoint the number of clients in their case load that had dementia. This stemmed in part from a lack of clarity of what “counted” as dementia. Difficulty in identifying the number of clients with dementia was partially caused by a lack of diagnosis - care workers were not sure who to count as having dementia and who not to - and partially because of the etiology of the dementia – it was difficult for them to know whether they should be including people with all types of dementia, and if acquired brain injuries, individuals experiencing cognitive changes following a stroke, and people with organic brain syndromes caused by alcohol should be counted together. This indicates that nurses, at least, recognize a difference in Alzheimer’s disease/age-related dementia and memory loss stemming from other medical issues. However, community members did not appear to have the same knowledge and had more of a tendency to lump different types of dementia together.

Most of the community members who we interviewed were able to name at least one person they knew who had dementia currently or in their past. Despite this, dementia was still perceived to be quite rare. My efforts to locate people with dementia to interview also confirmed that dementia, at least dementia with a formal diagnosis, is uncommon in most communities. This is especially true of Alzheimer’s disease. Many of the participants in our study had undiagnosed memory problems or memory problems that were caused by another health issue and not necessarily Alzheimer’s disease.

Emergence of a New Disease

Although our informants did not know of many people in their communities with dementia, there is recognition that dementia is happening. Most people perceive that is a fairly new phenomenon.

I see it coming now, they didn't have it, they didn't have it 20 years ago. Mmm, it's just lately. (KP SE 03)

However, others remember older people with memory problems living in their communities when they were children. When asked if dementia had always been around in her community, one senior replied:

I think so, because long time before that I used to hear my mother talk about some guy that. They used to have the village down by the lake, I guess, when they first settled here – one guy got lost and they found him way back in the bush, they found his bones. There was a tree, like, and his leg was stuck in there, that's where he must have died. I don't know whether it was from Alzheimer's or he was just lost or disoriented somehow, couldn't find his way back out. (JP SE 04)

On the whole, the perception seemed to be that if there was dementia in the past there was either less of it or the symptoms were less pronounced. Many people expressed that dementia has emerged because older people are not as engaged as they used to be. In the past they kept busy and had more defined roles, which may have helped to prevent memory loss and other symptoms of cognitive decline.

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

But I never knew the old people a long time ago, they were the caretakers, the old people, in my time. Like, my grandfather used to stay and kept the fire going [laughter], kept the wood stove going, and the grandmothers stayed home and looked after the baby [laughter] while the mother went out and worked, that's what they used to do. I never heard, I don't remember anybody ever having it, eh? (KP SE 03)

These two quotes in particular highlight the perception that there are deep connections between seniors' roles in their families and communities, their lifestyle, and their cognitive health. This relates closely to the discussion of successful aging in the previous chapter, where participants repeatedly indicated that social stimulation, having a purpose, and having a positive outlook were key factors in maintaining health into old age.

One of our traditional participants mentioned that AD had always been around, but that the difference was that people were getting it younger today than they used to. Another senior mentioned that in the past people talked about forgetfulness in terms of normal aging, but that now people use the word Alzheimer's. Her remark highlights that perhaps people talk about dementia now because there is a word for the symptoms, or perhaps norms around respect and labeling have changed and people are more willing to identify someone as having the condition. Finally, another traditional Elder spoke about how she could identify that dementia has existed in the past because there is an old Ojibwe word that describes the symptoms.

*Yeah, ossogedebeh, ossogedebeh would mean that the brain's not functioning it's getting no activity, it's...(laughing). So, there are words for it, it's something that's not new, so that means it has been there. It's not new, 'cause I can tell when it's a new word there's something...when it has been a new word, when you look at the linguistics, eh? There's new words that have emerged, that we have created because the new things that are happening now, but ossogedebeh has been there, I remember that word when I was growing up and so that's... it's been there.
(JP Trad 01)*

As this Elder describes, there is an old Ojibwe word that references a loss or absence of brain functioning, which she equates with dementia. It is unlikely that there would be a word to describe dementia if there was no one with symptoms of cognitive decline to apply it to.

Causes of Memory Loss

Individuals in our sample expressed many different factors that they perceived to influence the development of memory loss. These include biological, psychosocial and spiritual determinants. In this section I primarily consider the perspectives of older adults, caregivers, people with dementia, and traditional healers, since the perspectives of health care workers are shaped by biomedical knowledge and training. However, I do draw on health care professionals' perspectives of their clients' beliefs when it is useful

in illustrating how dementia is understood or highlighting a perspective that they observe but that others did not speak about in their interviews.

Physiological Factors Influencing Memory Loss

Physiological factors relate to things that happen to or within a person's physical body. Within this category people referenced aging as a predominant factor. Head injury, prescription medications, and other illnesses such as stroke, diabetes, or heart disease were seen to play a role in causing symptoms of dementia. In addition, family history and genetics were seen to be indicators that a person might develop dementia.

Age/Natural

Age is perceived to be the primary cause of changes to memory. Our participants believed that forgetfulness is a natural part of aging and not something to be alarmed about.

So that is how everyone understood it, because he was getting old, so it was a normal thing. It was a normal thing to happen to him. (KP PWD 01)

Just, it's just part of aging, you know? That's the understanding I have. (JP CG 02)

Yeah, it's, I don't know, I think everybody, I don't care who it is, everybody has trouble remembering and they blame it, they put it on us because we're getting older. Yeah, I mean...there's some older people out there who can remember things that happened back when they were kids and, 'course, some of them are going to forget. I mean, I think it's just natural. I think it's normal. I mean, I even think there's doctors and lawyers and that out there that forget. (JP PWD 03)

Many seniors casually referenced changes they had noticed to their own memory as they had gotten older, referencing occasions where they had misplaced their keys or forgotten to turn off the coffee maker. Although forgetfulness was considered to be a normal part of aging, there was the recognition that the onset of memory changes could occur at different ages. Most people associated memory loss with advanced age.

Well um, you know, your memory changes anyway, like, uh, it comes with age, I think, some of it, some, it has some, some of it happens to some people earlier or later on. (JP SE 03)

I think it's old age, you know, he's 83. (JP CG 04)

Umm it might have been his age it didn't happen until later in his life 70 or 75, around 75. (KP PWD 01)

The type of age-related memory changes that most informants associated with old age were repeating or forgetfulness. Only one participant mentioned old age as a cause for dementia specifically.

Yes, early, um, early spring of last year he was repeating himself a lot and forgetting things but, like, most of us we were thinking it was just part of aging. (KP CG 04)

Um, oh, I guess maybe just getting old would give you dementia. (JP SE 02)

Although memory loss was seen to be normal, some older participants still considered it to be frustrating, though not something to be alarmed by. Aging was the most natural cause for memory loss that was discussed by our participants; it was also the most frequently mentioned. Below I discuss other factors relating to lifestyle and biology that were perceived to influence memory loss.

Head Injury

Head injuries were seen as a significant cause of memory loss in our sample. Four individuals directly addressed head trauma as the cause of their symptoms and others referenced people they had known who had lost their memory after an accident or incident involving an injury to the head.

It's caused by your accident, eh [Ron]? So, um, because that's what I know, is he had a lot of trauma to his head, and so, um, uh, they weren't very nice people that did it. (PSW in interview with Person with Dementia, JP PWD 02)

I recognize that it's also a lot of um, environmental factors like in terms of not just the pollution, but also the traumas people have experienced, like even a car accident if there's head injuries that will end up with dementia and, um, Alzheimer's because the brain has, has been jarred, so it leads to that. (JP Trad 01)

In some cases, the effects of the trauma to the head were immediate and people noted a specific incident that caused the problems with their memory.

He'd lost his, uh, memory that old guy, partly from alcoholism and partly from injury, eh? A young man shoved him off his stairs and he fell all the way down. He was never the same after that. (JP CG 01)

Mm hmm. Well, that's the only time I lost a little bit of my memory was when I fell down there and slipped on the floor. And banged my head on the cement floor and that was very hard. (JP PWD 04)

However, some people referenced childhood head trauma and linked head injuries they sustained when they were very young to memory problems in their old age.

I'm really forgetful anyway because of my fall over at uh, residential school. When I fell on my head I-I, uh, I haven't got no long term memory, I-I-I-I, uh, forget only, only one thing, I only remember one thing at a time. You know, and if it's real important I'll never forget it, but if it's not...(JP SE 05)

Well, one time he was telling me when they were young boys, you know, they used to play out hockey, you know, or ball and one of his friends throw a rock way up and then it landed on his head he said so this was long time so there's a lump there. So they checked on that too but there was nothing. But you wonder about an old head injury like that, eh, if that makes it more prone? (KP CG 05)

Whether the effects of head injury were immediate or delayed, people strongly associated head trauma with memory loss and cognitive changes.

Medications

Western prescription medications were referenced as a potential cause of cognitive decline. Participants believed that medications had the ability to cause both short and long term disorientation or memory loss. These medicines include pain medication, antibiotics, anesthetics, or chemotherapy drugs.

Um, I, I've been told that she, it, it's probably since it's getting worse it's due to a chemo fog is what they call it, so it's um, I

guess it's not real bad, not to where I'm real concerned that she's going to get lost or end up going somewhere she's not. (JP CG 05)

No one drug was indicated as predominant in leading to memory symptoms. Rather, it was thought that too many medicines were prescribed and that all of these drugs were too much for people's bodies to process and could cause these symptoms.

So we had to get back to the doctor's after because she wasn't, you know, in her right mind most of the time there, just too many meds. So, kind of gradually got her weaned off and she's fairly normal now as far as memory and knowing what's going on around her. (JP CG 01)

But I know it's not Alzheimer's. It's those dam pills. (KP CG 03)

No, no that's all I was thinking. I was thinking that I was taking too many pills. I was thinking maybe this is why this is happening to me. (KP PWD 03)

Individuals in our sample strongly believed that medications were overprescribed and were wary of Western medications, their side effects and their potential interaction with traditional medicines.

Heredity

A few participants recognized that Alzheimer's disease and memory loss can be hereditary. This perception generally emerged from personal experiences whereby an individual had witnessed one or more parent, grandparent or extended family member struggle with their memory as they grew older.

I believe it's hereditary. Um, her mom had it she said that she fell one winter going outside to check, um, the oil tank. She said she fell and hit her head, and the same thing happened to her mom. She fell and hit her head she was outside and they found her outside there, her mom out in South Bay, so I don't know if that was it or I was thinking, ah, her mom had Alzheimer's and then I am just assuming its hereditary that my mom got it. (KP CG 02)

Well, I'm glad you brought that up because my grandmother she had that, too, eh, and my mother she, she had the same symptoms. My dad he is dead from something else. Especially with me anyways, that's my line of thinking, of that 'cause I get

that I have to fall in line with the rest of the people [laughter]. (KP PWD 04)

Yeah. I don't even know if it's handed down from his parents or grandparents. (JP CG 02)

So that will be, could be an early cause which could be identified as, um, which would that be? I think that's dementia, eh? One of those is like, could be genetic. I already talked about that dementia now Alzheimer's, they're actually two different things. Basically the same, but it's how they're caused. (JP SE 03)

For some individuals this realization caused a great deal of fear. One caregiver broke down in tears as she told us about her experiences providing care for both of her parents when they developed dementia. She looked to the future and wondered if she might face the same symptoms one day. Others did not express significant concern about the pattern.

They wanted to know if it was Alzheimer's because they were afraid of having the same thing, you know, they're concerned about the fa-familial tendency. (JP CW 04)

Although some people explicitly mentioned heredity or genetics, others did not clearly define the connection, even when they spoke of other people in the family who may have exhibited symptoms.

Biomedical Risk Factors

Many informants expressed that other health issues were contributors to dementia symptoms. The main type of health issues referenced were vascular problems including stroke, mini-strokes, heart disease, blood clots and heart attacks.

Could have been this, the stroke he had or the heart attack he had. He had one in 1975, his first one. The second one was, uh, maybe 15 years ago. Then he had the stroke, 10 years I guess. That might have, you know, that might have been the cause if it, I don't know. I don't know that much. (JP CG 02)

Sometimes it's, uh, I know I think my brother got it from, uh, heart disease because, uh, um, he started having these little mini strokes and then uh, and then he started this wandering business and my sister in law was so scared. (JP SE 02)

I thought it was because due to her stroke and as time went on you're supposed to recover from that stroke. She didn't. (KP CG 01)

One informant also expressed that blockages in the arteries or the brain might contribute to forgetfulness.

They use NAME PIN here too, ah ,but what [Ben] said that NAME PIN he works with the heart, your heart and blood that is what this works on, so when you put NAME PIN and then you add NAADAWE ANAK, NAADAWE ANAK works with the oxygen so here's this vein, okay, here's this vein here, NAME PIN works with the blood so here's NAADAWE ANAK coming along and he pushes that if there's a blockage in the arteries like diabetic when you take these two medicines it will open up that artery 'cause he, he dissolves that and he pushes oxygen and, and this NAADAWE ANAK he pushes oxygen to the brain so what if there's blockages in the brain like that causes dementia after a while this medicine will be able to open it and he puts oxygen into the brain. It may not, may not, ah, revive all the dead cells but he makes it workable. (KP SE 04)

It was also recognized that a person's overall health might contribute to memory loss symptoms and that disease or overall physical condition might play a role.

Um, probably a long time, but most recently since she's had cancer, um, her memory has gotten worse. So I would say in the past, mostly in the past 7 months. (JP CG 05)

I think it's caused by his nerves. Of course, I'm not a doctor, but...you don't live with somebody for 60 years and then not notice there's something wrong. (JP CG 06)

A wide variety of health and illness factors contribute to the development of dementia, and people recognized the impact of co-morbidities and overall health on the development of symptoms of cognitive decline. Much like head injuries, people were aware that a person's health over the course of their life could contribute to their cognitive health in old age.

Often it is not clear exactly what caused a person to develop cognitive decline and memory loss.

My mom went through a depression when she was a teenager when she was married and um she went into a depression so much that she was hospitalized and they did shock treatment back then it was shock treatment and they said that shock treatment down the road can cause Alzheimer's so that is what I am thinking how it affected her that was through the shock treatment. I guess the scarring of the tissues in the brain cause the can cause it I guess affecting her memory. (KP CG 01)

This individual noted several possible causes for her mother's memory loss, including heredity, shock treatment, emotional trauma, and head injury, which indicates that she either is not sure about what caused it or believes it to be a combination of multiple factors. Stories told by other informants also referenced many possible influences that may have contributed to a person's memory loss. Although these ideas were sometimes simplified, it was apparent that people had questions about how dementia really came to happen – was it one event or the confluence of several life experiences and other factors?

Along with overall health, particularly relating to vascular causes, some people perceived the cause of dementia to be directly related to the functioning of the brain. Improper brain functioning including a chemical imbalance in the brain, blockages in the brain or general brain dysfunction were perceived as a cause of dementia.

I have no idea. No idea. It just comes and whenever the person is, you know, they're usually, you know, not sick or anything, they're well, it's just their brain is not working right, that's the only way I can explain it. (JP SE 01)

Um, oh, I guess maybe just getting old would give you dementia. Maybe some kind of a chemical imbalance in your brain as you get older? I don't know. (JP SE 02)

Although some of the people we interviewed seemed to have very little understanding of the mechanism of Alzheimer's disease or other dementias, there were definitely individuals who strongly made the link between vascular health and brain function to symptoms of memory loss. As discussed in the previous chapter, participants understood health holistically and perceived many different factors to contribute to their health as they aged including cognitive stimulation, physical activity, attitude, and food and nutrition. Similarly, these same factors were perceived to specifically impact cognitive health, and will be discussed in more detail in the next two sections.

Psychosocial Factors Influencing Memory Loss

Two key psychosocial factors emerged from the interview data. First, participants recognized the role that alcohol consumption and alcohol abuse might have on a person's cognitive function. Second, participants described the impacts of trauma, stress, and grief. Stress and grief at the individual level, such as the loss of a loved one or at a more global level, such as historical trauma were both seen to have potential impacts.

Alcohol

Participants expressed that alcohol was a factor that might influence memory loss. In the context of short term effects, people referenced occasions where they or someone they knew temporarily became forgetful while drinking.

I don't know, my wife was like that. She was drinking though. She'd drink and she'd, she'd forget, or she'd see something, you know? She'd see like she's in a, another mind, you know? My wife drank and she said that, uh, lady come up to me over there and said I ran into her, I backed into her. She come right in the house, she said. All that didn't happen, you know? But since she quit, she ain't been drinking and now that don't happen to her. (JP SE 05)

Long-term effects of prolonged heavy drinking and alcohol abuse are also seen to have potentially detrimental effects on memory, leading to the deterioration in a person's ability to remember and recall. Smoking and substance abuse were mentioned less frequently.

Well, some of it is caused by something like, uh, drinking alcohol will do that, will probably just, uh, speed it up maybe to, you know, be afflicted with it. Uh, alcohol and there's even the way we eat, too, that's been mentioned too. Smoking, people that smoke. 'Cause you know, when you drink you're actually kind of um, uh, taking something from your, you know, your, you forget and you forget and you kind of well, especially if you get drunk so, in the long run you're actually doing something to your health, your brain. If you're in the habit of drinking or something. So that will be, could be an early cause which could be identified as um, which would that be? I think that's dementia, eh? (JP SE 03)

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

Individuals were able to recognize that alcohol abuse could have both short and long term consequences on cognition. At least one healthy senior even blamed small lapses in his memory on drinking he had engaged in when he was younger and expressed that he was glad he had given up alcohol.

Trauma, Stress and Grief

Emotional, physical, and spiritual trauma and imbalance in the areas of the medicine wheel are all believed to have the potential to impact a person's cognitive health. Although some informants spoke of this explicitly in terms of traditional beliefs, others mentioned grief from a death in the family, depression, stress, worrying, and other forms of emotional distress as things that could impact mental health and cognition. The idea that you can have too many personal problems, financial stresses and a heavy load in life are all factors that people thought could potentially lead to problems with memory.

I think, I think some of it is stress. (JP PWD 03)

The heavy load nowadays, I mean, you know, there's people that have problems with children and you name it. You know what I mean, here and there, there's also the thing that we know now, there's the alcohol and drugs and so on that we deal with today, eh? I think that that's a lot to do with it, that's like every day. I don't know, if somebody asked me, you know, I'd say well, gee whiz...and there's the money problems too, eh? Financials on your mind, and uh, so forth. (JP PWD 01)

Grief stemming from the death of a loved one was also perceived to play a role in triggering symptoms of dementia.

Well, we lost our son real suddenly, uh, before it was, it was four years and, uh, or three years in November and I noticed [my husband] going downhill after that. 'Cause it was too sudden. We're having supper the night before at the hunt camp and the next morning my son wakes me up and says he's gone. (JP CG 06)

Boy, ah, when my mom passed away that is when my father started to fall apart mentally and also loneliness, eh? I think financial has a lot to do with it, stormy thoughts, thoughts of hardship, thoughts of sadness, breakdown of thoughts causing emotional disrupt and after a while it kinda gets you into a place your stuck or you feel there is no way of getting out. (KP SE 04)

Taking the time to solve emotional problems, heal and get yourself back in balance were all considered to be ways that a person could prevent or lessen the possibility of experiencing memory loss. Healing was perceived to be very important, not only in the context of personal challenges such as stress and grief, but also in relation to the effects of historical trauma which were also perceived to play a role in causing memory problems.

One of the traditional elders that I spoke with explained the potential effects of trauma and the importance of working to remedy any mental, emotional, physical, or spiritual imbalances to preserve cognitive function.

Well, um, one of the things that we have seen and, or I've heard about also is that uh, any trauma, any type of trauma can, effects the holism of the individual, so which is, the brain is related to that part, eh, you know, the brain, the emotions, the physical and the spiritual, eh? So when somebody is traumatized, you know, it is all those areas that are affected, so if you don't get that healing for those areas that is one of the first areas you'll see is the brain, the effect on the brain. People will, uh, disassociate themselves, so that in its, that imbalance also affects the brain, because of the trauma, you know, that...they're never the same again, so unless you do the healing for that, because a lot of our people have shifted away from traditional healing and mainstream therapy has a different approach, you know, a lot of times for uh, um, any kind of trauma you are medicated so, and then the medication (laughs) actually affects the brain too, so, uh, the person can be heavily medicated and they won't be moving around or they won't be doing anything because they're depressed so they, uh, but it's actually the um, the chances of healing from that trauma um, is um, questionable. (JP Trad 01)

This elder is particularly articulate about some of the issues that relate to trauma. The majority of our other participants did not speak as explicitly about the effects of trauma in a cultural or traditional context. However, at least one participant did express that the residential school experience and re-living past sexual abuse during the

residential school survivor settlement process may have triggered some of her mother's memory problems.

I would think I would have to say that it's the trauma. She was a residential school survivor there was a lot of things that she blocked out and, ah, I don't know if its re-traumatisation that's going through that settlement that really might have triggered something with her that she had to...I heard that she had to go and talk about...ah, she had to prove that it was, she was, sexually abused. Um, the lawyer [Carly Williams] told me that, "do you want the word from word that she went through?" I said, "it would help us, it would make us better understand what she went through" and she said, "it is really, really, really bad," she said, and I said, "oh," so I am thinking because of residential school it might have really done an impact and I think I think from that point on, ah, it may have brought triggers back, you know? I don't know, but I do know that when a person is traumatized they do block out certain things and maybe it's just, maybe it could be for native people anyways...'cause they kinda lose reality after a while, eh? (KP CG 01)

Historical trauma may act as a factor that increases risk for the conditions that cause cognitive decline. Although few participants in this study spoke explicitly about the effects of historical trauma, their references to changing life ways indicate just how significantly changes to family structure, diet, use of native languages, and elders' roles in their community have impacted physical and cognitive health. I discuss the perception that the environment, eating habits, cognitive stimulation, and physical activity impact cognitive health in the following section. Although I discuss these individually as discrete themes, it is important to keep in mind that the overall message that emerged from my interviews was that it was an overall change in the way in life that impacted each of these factors and that together these factors impact the development of dementia.

Indigenous Interpretations

Indigenous interpretations relate largely to changes in lifestyle and reflect a shift away from traditional subsistence patterns. Participants expressed concern that this shift had impacted not only the way that people procured and prepared food, but also the roles of seniors in their communities. Changing roles and activities were perceived to make people more sedentary and less socially engaged. Environmental contamination and supernatural causes are also discussed here.

Environmental and Food Contamination

Food additives and environmental contamination were frequently mentioned as a concern relating to health. This included growth hormones and antibiotics in meat, food additives and environmental pollutants that contaminated water sources and wild foods.

No, because, uh, even, even, it's funny how we're, actually it's funny how we're living because this, this whole, this whole earth is contaminated. Everything you eat now is no good. That's why a lot of people are, are sick. This whole earth is contaminated. (JP SE 05)

I guess they say fish, people eat a lot of fish (laughs). Now it's, it's, uh, I don't know, it's probably, uh, for me 60 years ago when the water was clean and now I'm thinking to myself, uh, the water is probably so polluted that I don't feel like eating that much fish although I like to have fish every day, but then I'm thinking about what does it carry, what is it getting from these waters and they're polluted. And people didn't get sick so much and I think it was from the fresh stuff they always had, eh? (JP Trad 02)

There was also a concern that contaminated water and chemicals and sprays used in farming might impact memory and brain health.

I think its maybe the food we eat, the food we eat. And another thing, the food now, everything is sprayed. Everything is sprayed. I know that I've seen it. Everything. Even the apples, oranges, everything is sprayed even before, and the gardens, all the vegetables, they are all sprayed even when you have them at the groceries they are absolutely beautiful all the vegetables, you know, they spray those, they spray those. I don't know what they use to spray them. (KP SE 03)

Although people believed that you could try to avoid these contaminants, they were perceived to be such a widespread problem that they were beyond an individual's control. By contrast, a person's eating habits and food preparation activities were seen to be something that a person could take charge of to help prevent the onset of memory loss.

Eating Habits and Food Preparation

Individual eating habits were considered to influence brain health including eating too much salt, too few vegetables, and too many store-bought foods.

I don't know, I guess that would be it, if you eat too much salt, I guess, eh? Salt or lack of vegetation, maybe? Or a human should not be eating too much salt. If you eat salt it goes up here to your head and you start feeling the effects and then your pressure comes up then and you don't really remember. (KP SE 05)

Using the microwave was also considered by one informant to have potentially harmful effects.

I don't know if it has something to do with the water we drink and the food we eat, like can foods, I think that's where most of it comes from and microwave. No one is able to wait for they take it right away and eat it right away so there is radiation in there so, I don't know if that could be one of them but over there, say 20 years ago, it wasn't that apparent like just the odd one, eh? (KP SE 04)

A shift away from traditional foods and food preparation practices was also linked to memory loss. Our informants recognized that there has been a significant change in the way that people procure, prepare and eat their food as they have moved away from more traditional ways of living.

I don't know, not my grandmother or grandfather didn't get to have it, but they were very old and I don't know why they didn't get it but maybe it is the way we eat, too. I'll talk about it again here, they always planted food, had gardens, and preserved what was full grown. They got everything they needed to live, they had farm animals, chickens, everything was there. You didn't go anywhere to buy anything you had, so this might be where it comes from because now everything is sold, what people are selling. Companies...no one knows what is done to the food that is cooked. Vegetables, everything, there is too much of what is going to ruin you as a living person. (KP SE 02)

Foods...I...it does in a way, because uh, they're not preparing the stuff that used to be prepared by the people way back, eh? Now they just, they buy it so there's no brain stimulation in, uh, knowing how to prepare these foods and in those days they didn't

use recipes, they just had to think and process the foods to uh, preserve them. (JP TRAD 02)

Those ones we don't see are the ones that are actually more into being diagnosed with Alzheimer's because they're not engaging in that. They're eating stuff that's bought in the store and with all the additives in it and the people we see that are in the traditional healing program are the ones that are engaging in those things. They go hunting, they, they, um, go fishing and they have little gardens, so they're growing their own food and cooking for themselves and doing all those activities part of their self care so those are the ones we see, we're not seeing the other ones because they're not interested in that, so when I say that people just like to move on, away from that victimization, eh? Those are the ones that are end[ing] up in the nursing homes. (JP Trad 01)

Participants observed that growing, harvesting and preparing your own food benefits brain health because wild and homegrown foods are healthier and of higher quality. Learning how to grow vegetables, tracking their progress as they grow, harvesting vegetables and cooking foods all involve physical and cognitive stimulation that can stave off cognitive decline.

Lack of Cognitive and Social Stimulation

Another factor that was frequently attributed to causing memory loss was a lack of cognitive and social stimulation. Many people mentioned that people who sit alone all day and do not engage in activities or have company are at a higher risk for losing their memory.

I sometimes wonder if it's just from sitting around and maybe not reading you know 'cause he sleeps a lot, eh, during the day. (KP CG 02)

Isolation and lack of engagement was perceived by some to stem from the shift away from a traditional lifestyle.

Oh! Isolation. You have to have your mind, uh, you have to be, there's always, there should be some stimulation and uh, (laughs). Ok, way back then too, eh, people were quite busy the elderly people were always busy at, in uh, later years now there is so much, uh, just sitting around, so that kept their minds active.

Mobility, now they tend to sit there and they're not doing anything. (JP Trad 02)

And I, I kinda think sometimes those old people in the nursing home it becomes rapid when they are in there, so when it becomes rapid. They have no one to visit, eh? And, ah, they see the others in there they don't even talk to them, they just quietly sit there until you say something to them and then they'll look at you and there comes to a point they'll want to say it and then it doesn't come out and they just look at you then sometimes it does come out when they speak, eh? (KP SE 04)

Some isolation was seen to be out of a person's control, such as if they were severely limited by other health issues and had to depend on others to visit in order to have access to social contact.

I would say it's more forgetfulness, um, and like I have to think and you know, kind of put myself in my mom's situation as well, um, like I know myself, if I was stuck in a room, you know, for hours on end, you know, hooked up to dialysis or just being home and not well, I'm sure I would probably lose some sense of time there as well, um, and that's what she says, like I, she lost a lot of her independence, so she's not able to do the things that she wishes she could do, um, so, you know, a lot of her life consists of sitting in front of the window, you know, looking out the window seeing what's going by, or in bed. So, I think that's kind of where a lot if it is coming from is she's just, as far as like the sense of time um, like she's just there. She says, like sometimes I just exist. (JP CG 03)

However, it was also perceived that a person could remedy boredom and isolation by reaching out to others, even if they had limited mobility or visitors.

I don't know what the causes would be (pause), that's the only thing I can think of. Loneliness and stuff like that, and the way to get out of being lonely is there's telephones, you can even just talk to somebody on the telephone, have a visit that way if you don't want to go out. Everybody knows how to dial a phone. (JP SE 04)

Another cause of loneliness was the fact that traditional extended family structures have been disrupted and that many families no longer live together and care for each other, which has led to less support and social stimulation for older people.

I think it's something that, ah, gets to be the way it is because of, say, family loss, stress, depression, financial. I guess the other thing is all your children are living in their own homes, there is no one left to visit with you. Loneliness, I think. It's not like that anymore, the so called extended family, now it's just linear families. That was what was really admired, extended family, like, our, like, our children, us, our parents, and our grandparents we all lived together or, like, say if our grandparents lived here this was where family would build to live and they cared for each other, that's how it used to be. (KP SE 04)

Isolation and a lack of cognitive stimulation can be a major problem for seniors with significant health issues and low levels of family support. However, participants perceived that these two problems could easily be remedied through community support such as senior's programs or friendly visiting.

Loneliness is seen as a growing problem, relating in part to changing family structures and a shift in the roles of seniors. For example, the shift from extended to nuclear family units means that many seniors are now living alone. It also means that individuals are less likely to have an active role in day-to-day activities involving other family members. People referred to changes that have occurred over the last couple of generations that have left more seniors sitting at home with little to do. Seniors in our sample referenced the role their own grandparents had in caring for their grandchildren, tending to the garden, gathering firewood, and other such tasks. These responsibilities have in many cases been lost, which means that older peoples' roles are less defined and they may not have responsibilities that keep them active or opportunities to interact with others on a regular and meaningful basis. These are seen as factors that are contributing to increased rates of dementia and memory loss in seniors today.

Supernatural Causes

One informant mentioned that bear walking could lead to poor health including memory loss. This is notable, but did not emerge as a major perception shared by the sample.

Because Anishnaabek used to know how to do that, but they got turned around too, that's how they, they uh, they, they, they do bear walking, you know? And bear walking is a, is, uh, no good. Make you sick, those guys could kill you if they want to, or

they could make you sick for a long time....It's uh, it's evil, being evil. You wanna, you want to kill people. It's, it's just being greedy and you know, just thinking about yourself and thinking that uh, you're better than other people. (JP SE 05)

Although many informants referenced changes to various aspects of traditional life as contributing to cognitive decline, very few mentioned supernatural causes for dementia or memory loss. Instead, the traditional view of forgetfulness more often related to the natural process of aging and coming around the medicine wheel to complete the full circle of life and not to bear walkers or other evil spirits.

Describing Dementia

The words that people use to describe a condition can shed light on their thoughts about what causes it, if it is normal, or if it is frightening or unknown. In the last section, I mentioned that one Traditional Elder had mentioned that there was an old Ojibwe word that described dementia. In this section I look more closely at the words and phrases that our participants used to talk about memory loss and dementia in order to get a better sense of what they believe dementia is and how they perceive and respond to a person who is experiencing memory symptoms. Here, I consider both Ojibwe and English words that informants used to describe memory loss.

English Words and Phrases for Dementia

When our participants referenced memory loss in English they usually spoke of forgetfulness or being forgetful. Many participants also referred to memory problems, memory loss, having a bad memory, or not being able to remember anything. Only a few individuals used the words Alzheimer's disease or dementia. However, some health care providers mentioned that this term was sometimes used. They mentioned that some individuals or families jumped to the conclusion that memory loss automatically meant Alzheimer's disease, suggesting that they might not understand other mechanisms by which symptoms of memory loss can be triggered. Another prominent description of memory loss was an association with old age. Some people would just say getting old, while others would talk about having a senior's moment or would joke about "Oldtimer's" disease. Other words and phrases that were used less frequently included senile, confusion, losing it, not all there, or going crazy.

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

Some of these words have connotations that are quite negative, especially the word crazy, and at least one informant expressed that you should not say that about someone because it was not nice. The terminology used to speak about dementia was quite broad and mostly neutral although some words such as crazy, senile, or “not all there” do have potentially negative connotations. Although shame and stigma were only mentioned infrequently by interview participants, some of the words use to describe dementia suggest that there is some level of discomfort with certain types of memory loss and the other symptoms that can be associated with dementia.

Ojibwe Words and Phrases for Dementia

The Ojibwe words and phrases that were used to talk about dementia were also quite varied. Although several people in our sample did not speak Ojibwe or did not know any words in Ojibwe that were equivalent to forgetfulness or memory loss, many other people were able to come up with words to represent memory loss and confusion.

Well, I guess there's not a word....nendamowin, that's uh, forgetfulness, nendamowin, nendamowzeh. Like, you'll say somebody is, so that's the adjective, nendamowzeh, yeah. It's uh, forgetful. Or like uh, they'll say gawanamendah geeahsee, like she's not here. Not here, or there, whatever. Nor here nor there, like uh, not, not insane, but uh, you know what I mean. (JP SE 03)

Oh, there is the...in our, in our native tongue. Oh, there is... KEW NAA DIS, KEW NAA DIS NA that is the, that is the, I guess that is what the...that's like saying you're losing it, you know? (KP SE 01)

One senior had a lot to say about Ojibwe words for dementia and memory loss and his explanation of the words for memory loss, confusion and dementia were quite nuanced. First, he used the word *NEN DUM-GEWNENDAAMAASAA* to refer to memory loss, then he elaborated by explaining that you could also say *GEEWNGOSHKAAAGWAN WE EKENDANG*, which suggests that the knowledge a person had “*is buried within, his knowledge of what he knows, it got buried inside, like to bury someone, buried.*” (KP SE 04) When he was asked if there was a difference between Alzheimer’s and dementia and being confused he replied:

It would be GAAGEWTAAWAAJIMAA, telling stories in circles. ‘Cause that’s what that is, it’s, ah, you are talking about one thing and then another. ‘Cause my dad would sit there sometimes and he’d catch himself, “oh boy, I am telling stories in

circles, aren't I?" (laughter) I'd say, "yah, you were just hunting and then all of a sudden you were sliding." (laughter) (KP SE 04)

Finally, he concluded that:

Maybe 30 years ago maybe 40 years ago it was a big thing to hear talk about someone and they used to say well they have MAAJII GOOGPIDIZID but that doesn't mean stupid. That means ah in the state of where they can't help themselves GOOGPIDIZID and that's another form of saying Alzheimer's. But we kinda change that word into saying ah EH GOOGPIDIZID is somebody that can't even that is plain dumb stupid or dumb. But it isn't. Totally helpless is what that means. (KP SE 04)

The responses of this one participant demonstrate that dementia can be conceptualized in several different ways. Yet another perspective came from a female senior from Wikwemikong who equated a person with dementia to a developmentally delayed child, saying that they need help to do everything and they forget easily and do not retain information. Another participant, a woman with dementia, also shared this perspective.

No, not really. I know that I will get care, because I've seen it. Yeah, I've seen it with children. There is now a question for you: with children with memory problems, uh, as we get older we think it's normal for us to develop that, right? But, as for younger children...how come? I remember a child, you know, one of the patients, and sometimes she couldn't respond or something like that she used to go in the cupboard. What do you think of that? I bet you people haven't even thought of that, the children and also the adults on the level of it. Well as you get older, you probably deal it that way, but have you dealt it with children? You haven't heard that, eh? I've seen that you know, would it be brain damaged, or, for a child doing with, for a child's condition. But also with the, uh, with the spina bifida...would that affect them? Yeah, they can live with that, you know, eh? (JP PWD 01)

Two individuals with dementia described their symptoms as frustrating. One described what was happening to his memory as "miserable," and he continued by explaining some Ojibwe words he might use to describe the problems with his memory.

I don't even know how to say that in Anishinaabe. I'm not Anishinaabe [laughter]. MISQUIIGDEHENDUM - brain full of blood in frustration. (KP PWD 02)

Another informant with dementia also mentioned the same phrase, “brain full of blood in frustration.”

That's when anything happens, when you are being babysat, something happens that never usually happens I don't think anything of it. I am not MISQUIIGDEHENDEHENZI, brain full of blood in frustration, nothing like this at all, just as you see me now. (KP PWD 05)

And he continues, in conversation with his wife,

Wife: GDONENDAMAAWIS, you are forgetful.

PWD: I don't really bother with my symptoms of forgetfulness. I, I don't feel sad about it.

Wife: NENDAMAAWIS, to feel sorrow is what you just said, it's not what was asked.

PWD: Oh yah, well that's just it, I would feel sorrow if I thought about it [laughter].

Wife: When you're forgetting.

PWD: Yah.

Wife: You forget things.

PWD: My brain is not full of blood in frustrating emotions.

Wife: No, you forget things, not frustration, you forget. (KP PWD 05)

Based on the context of what he says about this in the conversation with his wife I wonder if he is referring more to how a person might feel if they had dementia, rather than speaking about what dementia actually is.

Although many people told us about Ojibwe words for dementia, a few informants suggested to us that it was disrespectful to discuss dementia or that it was not really talked about.

It is quietly referred to as NENDAMAA, forgetful...NENDAMAA, they don't know anything anymore they said, like, they are no longer able to use knowledge processes to function. This is how they could see it. (KP SE 02)

One informant made it clear that it is not something people talk about and that it was disrespectful to label someone with any word that referred to their memory loss.

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

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

The above quotes demonstrate the way that people talk about dementia in more abstract terms. When we asked seniors what they thought of when they heard the words Alzheimer's disease and dementia, they indicated symptoms that they perceived to be characteristic of the condition. A few individuals indicated that they were not familiar with these words. Others said that these words brought to mind forgetfulness, loss or slowing of the mind, getting lost, wandering, not recognizing people or things, losing awareness of your surroundings and sense of time, and living in the past. One informant who had experience working in a nursing home expressed that the disease progresses and that people in the latest stages may forget what to do with food and how to eat it which may lead to starvation. These symptoms, combined with perceptions of causes of memory loss, language used to speak about forgetfulness, and beliefs about dementia begin to paint a picture that can help us to understand just what dementia means to First Nations people and how it impacts their day to day lives.

Dementia as a Natural Part of Aging

The majority of people in our sample described memory loss as a natural and expected part of aging.

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

This perception led people to be very accepting of memory loss and dementia symptoms. Care workers were especially likely to comment on how much their clients accepted memory loss as natural.

I think that it's often um, misinterpreted maybe um, so rather than saying it's Alzheimer's disease they would just explain it as "oh, he's just getting older, he's forgetful" so, it's...so I don't know whether it's that memory problems later in life are more accepted on the reserve or they just don't have the awareness about a disease that causes those symptoms and medications that could possibly benefit but uh yeah, I'm not sure about that one. (JP CW 05)

A lot of people just say "well, all my friends are the same as me, so I'm not too worried about it". You know, they just think it's normal to get forgetful as you get older. And, I mean...to some extent it is, but sometimes it's more than that and I think they just, a lot of times just write it off to getting old and think that there's nothing they can do about it. It's the same with depression, it's just part of being old..."I'm supposed to be lonely and I'm supposed to be....whatever" and I don't think they can really see that people can help them. Some do, but a lot don't. (JP CW 03)

The barrier there though, like, is right away there's uh, the sense that either it's themselves or their families who are saying there's not a problem, 'cause I'm sure that there's times, too, where a family member has said I feel like I'm forgetting "oh Mom, that's the, that's just the way things are as you get older" (JP FG 02)

Care workers often saw this as a concern, since people accepted memory loss as normal to such a strong degree that they did not perceive it as a reason to seek diagnosis or treatment.

But is that cultural though? It could be, because I know there is a strong emphasis on respect in Aboriginal culture. I mean, that goes without saying. I mean, I like to think the rest of us respect our elders as well, but you know, I don't think to the same...but then...the, the question becomes with respect, does that mean avoidance as well, like does that mean you avoid those things because of, out of, out of respect? Like I'm not sure if that's...so,

like, like you were saying it is a fine line trying to just figure out, you know, how far you can go. And sometimes you can't at all, and, but then the responsibility factor is my concern, when it's like...but then it comes back to being somehow our [community health workers'] responsibility as the people going in that this thing didn't happen, or that she didn't follow through with whatever was supposed to have been done in that day, or, pills weren't taken, whatever and then it's like why didn't you guys make sure her pills were. (JP FG 02)

Care providers worried that this response, especially on the part of families, was a barrier to people seeking care for symptoms even if the situation was becoming unsafe.

Dementia as a Second Childhood

A major theme that arose when people described memory loss was the idea that people return to child or infant-like traits as they age. Part of the reason that memory loss is considered to be a normal part of aging is because of cultural beliefs about the life cycle. In the First Nations worldview, life begins in infancy and moves around the circle of life through childhood and adulthood before a person becomes an elder. As the person moves around the circle of life, and through elderhood they are perceived to return again to infancy, where life began. The very old and very young are perceived to experience the supernatural much more strongly than older youth and mature adults.

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

One senior described in detail the progression of the lifecycle:

This is how I was taught. There's 7 stages of life, eh, the first stage from childhood to 7 years, from 7 years to 14, and then from 14 to 21, 21 to 28, 28-35, 35-42, and then 42 to 49, and after that this is the beginning of the recognition of aging, so and then it kinda comes to a stage where he goes back from 7 year old to 1 year old. This person would be travelling back, leaving that way, so like that 7 year old is maybe when he becomes in that state of dementia, so by the time he becomes 2 years old 3 years old this is where it's already Alzheimer's. That's why, ah,

when those, the doctors, say he's got about another 2 years, that is when he'll be at that point where, where he'll be like a baby in every sense, you could say. Or he'll just sit, you have to feed them or you have to tell them to eat. Yah, some of them, there, is this kinda like a vegetable. (KP SE 01)

Through this mechanism, it is considered normal when older adults begin to lose the capacity to carry out some adult tasks and need to be cared for the way a child needs to be cared for or lose skills such as memory or the ability to feed themselves. That they may also need assistance with basic daily tasks such as dressing and toileting is also considered to be normal.

Like your client says, you go back to your baby years and you're forgetting, you're depending on everybody else to feed you, change you, you know? To, you know, take care of you totally after, so maybe that's part of it. (JP FG 03)

The perceptions of dementia as a second childhood is widespread and many people spoke not only of people requiring care that a young child would need, but also suggested that people with dementia can take on the traits of their younger selves, such as giggling like a teenager or becoming possessive of their belongings.

Dementia as Frightening

Although there is such a strong tendency towards the acceptance of dementia as natural by people in our study population, some people also described dementia as worrisome and frightening. This perspective came mostly from people with dementia and their family caregivers. To these people, memory loss had ceased to be a normal and accepted part of aging and had progressed to something that caused worry and anxiety. Fear and worry about dementia most often related to a lack of knowledge of how the disease would progress and what would happen in the future and did not reflect a fear of the disease itself

Caregivers expressed fear about what would come next in their care-giving and how the symptoms would progress.

At times I sit by myself and think, you know, what's in store, you know? How bad is it gonna get? What are going to be the symptoms to look for, how am I going to handle it 'cause I'm living here by myself with him and, I mean, the doctor did tell us when he was first diagnosed that it will probably progress fast cause he got it at such a young age. (KP CG 04)

Sometimes they also reflected on the fears of the person they were caring for:

Um, and I think somewhat it is a fear for her because she had mentioned to me that my grandfather ended up with Alzheimer's towards the end, before he passed and she said the hardest thing was going in and him not knowing who she was at that point, um, and she talks about doing puzzles or some kind of memory games, even if she is playing with her grandchildren to try and keep her memory, that's a, it is a fear for her to not know who her children are. Um, I think that's part of the reason she goes back and tells the stories about her childhood and stuff, so that we have something, um, to hang on to if she doesn't remember herself. (JP CG 03)

People with dementia also expressed fear about what might happen to them as their disease progressed.

But this, I have no idea what someone would do, Alzheimer's, like, I just get afraid at times. My dad used to, when he had it, he used to just leave, "oh I'm going home myself," he would announce. They visited me once in North Bay, "I am going home," and he started walking, we didn't know. Later we were losing him, eh, I was scared. I hope that this doesn't happen to me. (KP PWD 01)

That's what I was thinking, I guess, it's part of getting old, old age, but I get worried too. I said, "what's going to happen to me later on, when my mind goes on me? Would they just going to be shoving me around?" [laughter] I get worried too, eh, what going to happen, what's going to happen to me? (KP PWD 03)

Some healthy seniors also expressed fear about what would happen if they developed dementia.

Yeah. I don't want to be uh, I don't want to put anybody in uh, you know, to have to look after me. That's another thing. And I'm afraid of this uh, if I start to lose it like you know, that's one thing I'm afraid of – Alzheimer's 'cause of my dad is uh, is uh, has a symptom of that, that's what they said and that's, that's what that is too eh, uh, your short term memory goes too, eh? And you're disoriented about your whole life. You don't but then, I

don't think you have the capacity to think about it though, eh? (JP SE 03)

Feelings of fear associated with dementia were usually associated with not knowing what to anticipate in the future. For caregivers, this involved worry about how they would cope if things got worse. Seniors and people with dementia worried about who would care for them, if they would be a burden on their families, and how they would be treated if they lost their memory. For some people these fears stemmed from things they had heard or seen about nursing home care.

Few people expressed that they were afraid of the disease itself, especially when symptoms were not present. However, some people who were beginning to notice symptoms did appear fearful about their health and their future. When I presented results to the communities as part of my dissemination process, at least two seniors spoke to me privately after my presentation about concerns they have about the condition. One had recently been told by her daughter and her niece that they were concerned that she was forgetting, and she herself had noticed that she was doing things that she would never have done normally, such as leaving dinner in the oven too long twice on the same day. Another participant pulled me aside and expressed concerns about many factors in her personal history that she perceived to put her at risk for dementia. Although she was not experiencing any symptoms, she nonetheless had several concerns.

Living with Dementia

Living with memory loss can cause many challenges, and our participants with dementia expressed several things that they are aware of relating to the challenges with their memory. By far the most common issue was forgetfulness, although there were several manifestations of not being able to remember. Participants most often indicated that they realized that they forgot what they were looking for, where things were, and people's names. A common complaint was going into a room to get something and then forgetting why they were there.

Mmm, yeah, I do, and then I turn around and I say, "what did I come here for?" and then I have to go back [laughs] to get you...my...memory back again. (JP PWD 01)

They also reported losing things or not being able to locate things they had put away.

I had no bank card I lost all of those recently. I put them all away for a short time. I don't know why I did that. I wanted to go somewhere and I forgot where I had set them. I didn't know

where I put them. I looked all over the place for them in that area. I sat down for a while and wondered where could I find them. I sat and thought of my drawers. I always looked in them. I couldn't see them and that's where they were (KP PWD 01)

Yes and then I put the stuff away and then after like ah my cheque book eh I know they were all over the place. I said I'll put them all in one place. I could never find them eh that's the problem. I always looking around and I'm here by myself. I have nobody to blame. I put things away but I can't find them and that gives me a headache when I go through with the papers, eh. Can't find nothing. it's the same thing when I go out eh I have to make sure the coffee pot is off the stove I off. I keep checking again and again make sure everything is off (KP PWD 03)

Well, at the beginning like, um, um, I would forget, um, uh, like say, where did I put my uh, my cleaning stuff, you know? I'd be running around down in the basement, you know, and um, be checking where did I put it, you know? And it's always there I guess where I did put it and here I was looking around all around here. (JP PWD 04)

Names also caused difficulty. Several participants expressed that they recognized people, but did not know how to address them.

I don't know. I just see a face and I know it, but I just don't know, remember the names. That happens to me quite often. (JP PWD 05)

Sometimes and sometimes I don't know what to call someone when you get here I know you but I can't say your name until way later I do when I name someone I just forget it right there)[laughter] (KP PWD 01)

Names. You think I remember your name? I don't. (KP PWD 03)

Yes you sit in front of me I don't know your name I think its Karen [laughter], eh, yah I forget as well Karen you said I think that's what you said I see lots of people women they send me greetings they say greetings Theodore and I just say greetings back and wonder what their name is (KP PWD 05)

Several individuals also expressed that they had trouble with communication, either not remembering what they said, repeating themselves, or not knowing if they were saying things that might be hurtful.

At times she says, "that's what you said," but I didn't know I said that (laughter). "I didn't say that," I say back to her or maybe she is just saying that I don't know (laughter), ah, she almost makes me angry at times (laughter) I say, "I didn't say that". (KP PWD 01)

Yah, especially with the the kinda disease that I have, that's the worse part, eh, see you forget, eh, and later on you thought about that, that's what I should have answered. But not right away, you don't know how to answer right off the bat, eh, you gotta think (KP PWD 02)

Well, I don't realize it, but [Laura] said like I've been visiting her and I've been talking about the same thing [laughter]and she said to me, "you told me that already" [laughter]. "Oh," I says, "I don't remember[laughter]". I don't realize it myself. And I keep repeating the same thing. (KP PWD 03)

My friends, they said to me, "you keep repeating," "oh," I said, "oh, I don't know," and then I told them if I say something to you just ignore me 'cause I don't know sometimes what I'm saying or maybe I'm hurting people but I don't mean to do that. (KP PWD 03)

Participants also reported several other impacts of forgetfulness including not remembering what to buy at the store, forgetting appointments, having difficulty recognizing places, getting disoriented, losing track of the storyline of their book, putting their clothes on incorrectly, and confusing everyday objects.

I bent over to tie my shoes and the other. When I looked back up she wasn't there, she already turned the corner where the door was. I tried to follow but I couldn't see her and the door, there was no one there. I was lost, no one would be able to get lost there [laughter] this is what always happens to me even today. (KP PWD 05)

One woman explained her difficulty in differentiating between the portable phone handset and the remote control.

He comes over here one time and he says, “[Mary] I have to borrow your phone, I have to call Amikook.” I came up and give it to her and it was the remote control for the TV. He said to me, “this is not a phone, this is a remote control.” I say, “oh,” I said, “I’m sorry [laughter].” And that happens to me, too, sometimes I take my phone in there, the living room, and the remote control is there and they are both the same color, then I go and pick up that remote control, I said, “hello [laughter].” Well, the things I do here when I’m alone I can’t even think, but I could do some stupid things but I realize that though after what am I doing, what am I doing this for? I got this in my hand. (KP PWD 03)

From this quote, you get a sense of how frustrating it can be to live with a changing memory, to know that you are mixing things up but not being able to do much to fix it. Although our participants expressed that memory loss was considered to be a natural part of the aging process, they still recounted occasions when they were frustrated with their changing abilities or embarrassed by things they had done that they had not intended to do.

Finally, a few participants expressed that they were able to recall names and events that happened much earlier in their lives, but had trouble with more recent occurrences.

I can remember stuff if I heard some jokes there 60 years ago when I work in the bush [in the] 70’s they come, come back to me just like that but, but from here I get up from the table and pick up something in the kitchen, I forget what I went in there for. (KP PWD 04)

No, it’s funny, I say it, yeah. I notice. And, or, I’ll stop and I’ll say “oh dear, I went over there,” you know, “and what is it I went for?” and then I come back again and I seem to get it back... but my memory is....I can think of things way back, you know, years ago. (JP PWD 01)

The olden days, I remember them all. But the new ones, there, I’m having a hard time trying to remember them. (JP PWD 05)

As they told their stories, many people laughed at the troubles they had with their memory. However, their feelings about what was happening to them and what might happen in the future were not all so lighthearted. Some participants reported that memory problems were “miserable” (KP PWD 02) and made them feel sad. They also expressed that they felt frustrated and angry at times.

Well I get so frustrated, I get so mad that I can't find anything. I don't know what I am looking for. (KP PWD 03)

That's about, about it. Can remember faces, sometimes I don't remember the person that comes and talks to me. I know them, but I-I just can't seem to know their names. That bugs me. (JP PWD 05)

These feelings are not unexpected. I also asked people with dementia if they worried about their memory problems or if they would get worse. Their responses were often contradictory, half of our respondents indicated both that they did and did not worry about it. For example, one woman said, “Yeah, I do. I always think, oh geez, I won't remember, maybe I'll even forget, you know what I mean, as you go along,” (JP PWD 01) when asked if she worried about her memory but later expressed that she wasn't really worried because she knew she would get care when she needed it. How they would be cared for as their memory declined was the main cause of anxiety related to memory loss. Two participants spoke about this.

Other informants suggested that they did not worry about their memory loss getting worse, but that they worried about the fact that they had it at all. One older gentleman expressed that at his age, he did not worry about his memory getting worse, he just accepted what came his way, “No, not really, no, no, I'm 81 years old just take it as it comes now I guess. (KP PWD 04)” However, he also expressed that it bothered him a little bit that his memory was no longer reliable.

Not really getting worse, it's just the, the idea that it's there I kinda worry about it, I guess, other than that I try not to think about it too much, I guess. (KP PWD 04)

Much as with other health concerns, First Nations seniors spoke about accepting memory loss and taking it in stride. Although when questioned, some people expressed that they worried about it, it more often happened that people tried not to dwell on the problem and accepted it as part of their aging process.

Don't think about it. That's the best medicine, don't think about it. Even what's wrong, when something is wrong with you, don't think about that. That's the best medicine there is. If you keep thinking it, you're getting worse. (KP PWD 02)

Many participants described strategies that they employed to compensate for the changes to their memory. Some of these included keeping their keys in a designated place, writing lists and reminders, and displaying important information somewhere easily visible. For example, one woman had a clear plastic table cover that she would put

important papers under, like instructions for medical appointments and the date she was going. Another woman noted that she left things out so that they would act as reminders.

There's always a reason, if I have something in front of my it's always to remind me. You know, they're all around me. I used to be really punctual and really neat, but not anymore, 'cause I have to have stuff to remind me. And usually [Liane] says something like, oh, you've got an empty box there and I say, I say I'm reminding myself because I need to tell the druggist that I need it. (JP PWD 01)

Other participants used calendars to mark off visits, appointments, days that they needed to shower or simply to help them keep track of the date, “so I know what...what day it is for sure.” (JP PWD 03)

Interpretation

By looking at the various perspectives presented above, we can begin to get a sense of what people believe dementia to be, how it impacts people who are experiencing it, and what people feel about dementia. By looking at the perceived prevalence of the disease and peoples' perception that dementia is a growing problem, we can attempt to grapple with whether dementia is a new phenomenon or whether changing life ways, social norms, and health beliefs are putting pressure on people to think about dementia in different ways. A simple quote from one of my focus groups highlights one of the biggest challenges of this chapter. When I asked the group to give me a sense of the prevalence of dementia in the communities they worked in, a registered nurse responded, “Well, we see it, like, it's hard to until it's diagnosed, when do you, when do you start counting it?” (JP FG 02). While working with the diverse data we gathered from our participants regarding age-related memory loss and dementia, I often found myself asking the same question, when do you start counting it?

Our interviews revealed a primary perception that memory loss is a normal and accepted part of the aging process for First Nations people. Based on this perception, people often responded to mild memory loss by using humour to diffuse tension or embarrassment caused by forgetfulness and family members provided extra support for the person with memory loss when needed. However, it is also clear from the data that some people have had distinctly different and more troublesome experiences with memory loss that starkly contrast the idea that memory loss is a natural part of growing older. For these individuals, memory loss is frightening and may be associated with other symptoms, such as wandering, burning things on the stove and losing the ability to

recognize family members. Despite strong cultural beliefs about memory loss being a natural part of the aging process, some First Nations people have clearly noticed a difference between mild forgetfulness and something else, a kind of memory loss that is neither normal nor expected.

This divergent view of memory loss in old age has also been documented by Hulko et al. (2010). Their research with Elders from First Nations communities in British Columbia revealed that Elders held both a traditional view of memory loss as a natural part of going through the full circle of life as well as the perception that ‘your dementia’ was a terrible disease (Hulko, et al., 2010). The latter view was held primarily by people experiencing memory loss or providing memory care. These findings parallel the patterns that emerged in my research. I noticed these contradictory perceptions early in my fieldwork and began to wonder about the point at which memory loss ceases to be normal and begins to be worrisome. When asked, some participants were able to describe differences between normal memory loss and Alzheimer’s disease or dementia. However, no one was able to give me a clear answer about when normal memory loss became abnormal. So, in trying to understand peoples’ perceptions of dementia and memory loss I again find myself drawn to the question posed to me during the focus group, “when do you start counting it?” Knowing what to count as problematic memory loss and when to start counting has implications for my attempt to understand experiences of dementia among Manitoulin Island First Nations and for future attempts to develop and deliver education and support services to this population.

Understanding what dementia is and what “counts” as Alzheimer’s disease is not a problem unique to First Nations’ people. Western biomedicine has also struggled to pinpoint exactly what Alzheimer’s disease is and how to differentiate it from other dementias and the normal changes in memory associated with aging. Diagnosing Alzheimer’s disease with certainty remains a challenge to physicians and researchers to this day. This is in part due to the historical events that led to the biomedical construction of Alzheimer’s disease as a disease entity (P.J. Whitehouse & Gaines, 2006). Whitehouse and Gaines (2006) argue that if any of these historical moments in the construction of Alzheimer’s disease had not converged, we may not be discussing a disease called Alzheimer’s at all and that scientific advances in the study of AD may actually be making us less certain about exactly what AD is.

The traits that “count” as dementia and those that are considered to be normal or natural shape peoples’ health behaviours. For instance, if seniors believe that memory loss is a natural part of the aging process and expect it to happen, then they will be less likely to seek help for memory loss if symptoms do occur (Sarkisian, et al., 2002). However, there is a general agreement amongst clinicians and researchers that the optimal course of treatment for dementia is to identify it early and begin treatment right away in an attempt to slow or arrest the progression of cognitive decline (Alzheimer

Society, 2010). This may be an important factor in planning interventions for First Nations people and may highlight a potential barrier to care. By this I mean that we want to develop culturally safe interventions that reflect First Nations peoples' needs and beliefs about dementia, but we also want to ensure that they have access to optimal care options. We do not want to discourage the belief that memory loss in aging is natural, because there are many positive outcomes that can stem from that belief including a higher level of acceptance of the person with dementia and a lower potential for stigma and shame. However, the perception that memory loss is natural may also hold people back from getting the care that is needed when it is most effective, or may cause people to normalize symptoms and behaviours beyond a point which they are safe. Determining how to best approach dementia education and interventions will require a great deal of sensitivity to the nuanced beliefs and behaviours of First Nations people to memory loss and dementia in old age.

Dementia happens at the intersection of many different factors and it is difficult to extricate these different understandings and impacts of the condition from one another. As I have tried to do so, even just considering the causes that people have experienced or perceived I see patterns that intersect and cross-cut one another. The shift from traditional to modern life ways is a major point of analysis where many other aspects of dementia and the dementia experience come together. Lifestyle changes have had significant effects on the lives of older adults and on their roles within their families and communities. Although many seniors still carry out very active and meaningful lives, changes in family structures have shifted some fundamental roles relating to elderhood. For seniors this impacts their ability to have meaningful responsibilities in the day to day life of their families and can also diminish the amount of social contact that they have access to.

As I discuss throughout this chapter, participants perceive that there are many factors that might contribute to the development of dementia. These causes include physiological risks such as age, prescription medicines, head injury, heredity and other biomedical risk factors such as past and current health. They also include psychosocial aspects such as trauma, stress and grief or alcohol use. Other factors such as environment and food contamination, eating habits and food preparation, supernatural causes and a lack of social stimulation and physical activity were also perceived to be related to dementia. I broke these ideas down into smaller sub-themes in an effort to represent the nuanced understanding that my participants had of the things that influence cognitive health. However, it is important to mention that none of my participants referenced any of these individual causes as discrete from all of the other factors. Most often, participants referenced many possible factors that might lead to cognitive decline in old age. When considered together, most of these factors relate directly to lifestyle and the cumulative effects of a life lived. As I mentioned in the previous chapter, many of these factors fit together like pieces of a puzzle.

A shift away from a more traditional lifestyle has impacted peoples' ability to access healthy foods, decreased the amount of physical activity in their daily lives, and increased the likelihood that older people will experience loneliness and isolation. Changes to diet and activity patterns have likewise influenced peoples' overall health leading to a higher incidence of chronic disease and the need for more prescription medicines. Changes to lifestyle have been caused by several factors, including the residential school system and other effects of colonialism such as the dispossession of land and sedentarization which have disrupted cultural continuity and access to traditional economies (Czyzewski, 2011). These factors have influenced not only the emergence of dementia, but also the ability for First Nations people to cope with the condition. Healing from the effects of trauma is seen to be important in the prevention of dementia.

First Nations peoples' understandings of dementia are strongly shaped by cultural beliefs about the life cycle, acceptance of challenges and health problems, and respect for elders. These beliefs intersect to influence peoples' response to dementia, including when they identify symptoms as a problem and if, when and where they seek help. Although the impact of these beliefs may have positive effects on the way people with dementia are treated and can minimize (to some extent) the burden experienced by caregivers, there are also problems that these same beliefs can bring. The main concern here is the fine line between acceptance and denial and respect and avoidance, as was demonstrated in a quote earlier chapter where a staff member expressed her concern that in some cases family members' tendency to be accepting of dementia may actually be causing problems and delaying care.

Although it is positive that First Nations seniors with dementia may be more likely to be treated with respect and to maintain their status as a "person" and not a body with a condition, there is also the risk that families will not recognize the threat to safety that dementia can bring and may not seek help that is available. It is important to make sure that people have access to culturally appropriate care that respects their values, but also that they know about and have access to supports that exist to help with or remedy a problem that is being caused by dementia. So, although we want to be careful not to push too hard against these cultural values and the positives they can bring to the dementia experience, we also want to ensure that people are receiving the care that they need. In this way people with dementia and their caregivers can receive the support they need to continue to live happy and fulfilling lives.

This chapter presents many different facets of First Nations peoples' understandings of age-related memory loss and dementia. The data demonstrates that there are strong tendencies towards the acceptance of age-related forgetfulness as a normal and natural part of aging. This is consistent with the findings of other research. Seniors anticipate that they will lose some of their memory as they age and are able to take this in stride.

Often they will use humour to make light of minor lapses in memory. As a result, memory loss in old age is often normalized and considered to be of little concern. However, the acceptance of memory loss in old age and the belief that it is natural starkly contrasts another response to dementia, that being fear, concern and a recognition that beyond a certain point memory loss and associated behaviours are far from normal.

Further, a strong perception exists that dementia is a new phenomenon. Some evidence exists which suggests that dementia has existed in Aboriginal communities for at least several decades. A few participants remembered people or incidents from their childhood that were consistent with the existence of dementia. Further, a traditional knowledge keeper expressed that there are words in the old language that represent something akin to dementia. It is unlikely that these words would exist if dementia was not present in at least some individuals. Indeed, the First Nations worldview that childlike or infant-like traits are normal as older people progress through the lifecycle and around the medicine wheel suggests something similar to dementia. However, it is likely that dementia is more common in contemporary communities since life expectancies have increased. It is also possible that changes to extended family structures and the role of seniors in their communities have made dementia more noticeable. Since more seniors live alone, more women (who were traditionally caregivers) are working outside of the home, and there are larger geographic distances between families dementia may be more noticeable since traditional coping methods and care strategies have been eroded.

I consider the dual perception of memory loss in old age of memory loss as natural but also as worrisome to be interesting, especially since the two exist alongside one another, with people believing both that memory loss is normal and that it can be pathological. How and why would such a perception evolve and how does this dual perception speak to changes in the prevalence, severity and impact of dementia in these communities? Where do people draw the line between normal memory loss and dementia as an illness?

This question is being grappled with even outside of Aboriginal communities. There is a great deal of research that demonstrates that dementia is perceived very differently in different cultures and that, accordingly, people cope with it in very different ways. As I mentioned earlier, even western biomedicine has trouble clearly determining what dementia is and when symptoms of memory loss “become” dementia (i.e. Mild Cognitive Impairment (MCI)) (P.J. Whitehouse & Gaines, 2006). Millions of dollars are spent every year trying to determine what dementia is, when it counts, how to diagnose it, how to slow it down, how to reverse it, and how to prevent it and yet, a multitude of questions still remain about what dementia is and how to provide optimal care.

Dementia is a problem that at first glance appears to impact only the elderly. It is they, after all, who experience the symptoms of the disease. However, I suggest that the effects of dementia are actually much more widespread and have significant implications for families and communities. In turn, I suggest that dementia must be considered through a wide lens, a lens that considers the roles of seniors in their families and their communities and how these roles might be disrupted if aging does not go according to plan. From a different angle we must also consider that changes to culture, demography, community and family structures are impacting peoples' ability to age well and the support systems and care networks that have traditionally acted to assist and protect people as they age. These pressures are continuously in flux and we must be cognizant that policy and planning for seniors must recognize that family structures and strategies for elder care will not remain static, but will change with the needs of each individual senior and the resources available to them through their families and communities.

Conclusions

In this chapter I have explored First Nations peoples' understandings of age related memory loss. Throughout the chapter I have identified two key understandings of age-related memory loss; first, that it is a natural part of the aging process and second, that dementia is pathological and a cause for worry. The discourse surrounding dementia contains an unresolved tension between these two perceptions that shapes the way people talk about and respond to the condition and people experiencing it. How people interpret memory loss and when they identify that it has become a problem has significant implications for diagnosis, treatment and care.

It seems that in a First Nations context dementia is emerging as a growing problem, and that there are complex and multi-faceted factors influencing its emergence. This may be because more people are reaching an older age and more older people correlates with more cases of dementia. Alternatively, it may be that cultural change has altered lifestyles and people no longer practice activities and ways of life that naturally prevent the onset of cognitive decline. It is also possible that changes to family structures have altered natural coping mechanisms that once counteracted the impacts of dementia causing families to feel the effects of dementia more strongly than in the past. Whatever the cause, it is clear that Aboriginal people are negotiating new understandings of cognitive decline and how to cope with it.

Chapter Five: Coping with age-related memory loss: care seeking, diagnosis and treatment

Introduction

In the previous two chapters I examined First Nations cultural perceptions of successful aging and memory loss. Here, I consider what happens when someone, be it an individual, a family member, or a health care provider, recognizes that memory loss has become a problem. I have already presented some of the characteristics of age related memory loss as perceived by First Nations people on Manitoulin Island and identified that one of the challenges of developing appropriate interventions for cognitive decline in this population is understanding where people draw the line between normal memory loss and dementia as an illness. In this chapter I address how people identify that memory loss has become problematic and the actions they take in response to this problem. I also consider the value of formal diagnosis, and whether it alters the course of dementia treatment in this population.

The consensus among clinicians and researchers is that the best treatment strategy for dementia is early detection, so that precautions can be taken to prevent or slow further decline (Alzheimer Society, 2010; Rogers & Friedhoff, 1996; Small, Rabins, & Barry, 1997). Consulting with First Nations people about how they identify and manage dementia provides insight into how diagnosis and treatment procedures might be improved so that they are relevant and effective. Culturally appropriate educational materials and services related to dementia can improve the ability of First Nations people to make informed decisions about their diagnostic and treatment options and to access the services they need to cope with dementia. No matter how Aboriginal people perceive dementia, they should have the opportunity to receive appropriate treatment and care for the condition when it arises. They should also have access to the same level of care as mainstream Canadians. The difficulty comes from the question of how we can assure that Aboriginal people get early and optimal care for dementia if they do not perceive the early symptoms to warrant medical diagnosis, intervention, or treatment.

Context

Factors that affect help seeking and diagnosis

Researchers have identified several factors that influence help-seeking for dementia in Aboriginal settings including history, geography, culture, socioeconomic status, and other psychosocial factors. Availability of services, access, cultural safety and structural barriers also play a role in Aboriginal peoples' experiences with health care (Habjan, et al., 2012). These factors have broad impacts for a large spectrum of health issues and health care. In this section, I focus on factors that relate directly to help-seeking, diagnosis and treatment of Alzheimer's disease and related dementias.

Several specific factors influence the availability and provision of health services on Manitoulin Island. Each of the seven First Nations on Manitoulin Island has engaged in a Health Transfer Agreement with the First Nations and Inuit Health Branch of Health Canada under three separate agreements. Each of the two larger communities, Wikwemikong and M'Chigeeng, transferred individually and the five smaller communities transferred under one shared agreement (K. Jacklin, 2007; Maar, 2004). Health Transfer Policy is intended to allow Aboriginal peoples to design and establish health services in their communities based on needs at the local level (Health Canada, 2004). Although this program was initially developed with a goal of enabling self-determination in health, the process has been critiqued as frustrating, stressful and disempowering (K. Jacklin & Warry, 2004). Moreover, under this policy, communities' efforts to design and deliver programming are restricted by rigid parameters set by government funding agencies (Maar, 2004).

Maar (2004) also documents other unique factors that affect the provision of health care to First Nations people on Manitoulin Island. These include a high staff turnover rate, a lack of Aboriginal health professionals (particularly male health care providers), challenges in balancing the proportion of Aboriginal staff with staff that have the appropriate training, and policy development around the provision of traditional healing. Further, health programming and funding are multi-layered and it can be challenging to organize multiple disparate services into a seamless whole (Maar, 2004). However, Maar (2004) also indicates that there have been many successes related to care provision for Aboriginal communities on Manitoulin including specialized outreach services from psychologists, traditional healers and dieticians at the community level and with follow up available at community clinics. In addition to these barriers and enablers to health care provision, concerns about client confidentiality – especially in the provision of mental health services (Maar, 2004) – and the large geographical distances between Manitoulin communities and health services also shape the accessibility of health services by First Nations clients.

Knowledge of Alzheimer's disease and dementia is low in many Aboriginal communities and memory loss may not be recognized as a disease requiring treatment (Hendrix & Swift Cloud-Lebeau, 2006; Sutherland, 2007). In some communities, the term dementia may not be known or used, or the term may be associated with mental illness and may carry a stigma (Hendrix & Swift Cloud-Lebeau, 2006). I have previously demonstrated that memory loss is often perceived as a normal part of the aging process (Hulko, et al., 2010; Lanting, et al., 2011; Sutherland, 2007). Explanatory models may vary within and between Aboriginal groups, and several interpretations have been reported in the literature including naturalization, imbalance in the areas of the medicine wheel, crossing over into the spiritual world, and the disruption of traditional life ways (Henderson & Henderson, 2002; Hulko, et al., 2010; Lanting, et al., 2011; Sutherland, 2007). How people perceive dementia influences how they manage the condition, if they seek help, and what type of help they seek (i.e. traditional healing, biomedical care). Distrust of the western medical system or fear of being placed in a nursing home may also impact peoples' choices about help-seeking for symptoms of memory loss.

The availability of dementia treatment and care services can vary greatly between Aboriginal communities. A lack of access to health care, including physicians and specialists is a concern that is especially common in rural and remote communities (Griffin-Pierce, et al., 2008; L. L. Jervis & Manson, 2002). Urban areas often have a greater number of available services. The ability to travel to access services may also be difficult with long distances and prohibitive costs reducing care options (Newbold, 1997; Polacca, 2001). Specialized services for Alzheimer's disease and dementia may be especially hard to come by in small or remote communities, especially supports such as the Alzheimer's society, support groups, and adult day care centres. In addition, establishing these kinds of services may be a low priority in Aboriginal communities because memory loss may not be perceived as a medical problem, let alone a crisis (Griffin-Pierce, et al., 2008).

Even if access to health care and dementia services is good, Aboriginal communities often face many larger crises relating to health and wellness such as drug and alcohol abuse, inadequate housing, unsafe drinking water, crime, and poverty that are more urgent and of higher priority (Newbold, 1997). Issues relating to historical trauma and the residential school legacy may further impact the ways in which older people are treated, how health care issues are prioritized, and how care and support are provided for people in these communities.

Finally, because family care is the norm for Aboriginal seniors, dementia symptoms and the need for care may be expected and families may take on care-giving duties without question. As a result, they may feel that there is no need to seek formal assistance (Griffin-Pierce, et al., 2008). However, family and community dynamics are

changing and it is more difficult for many families to take on eldercare today than it was in the past. Coupled with a greater number of elders living longer than ever before, changing demographics and family structures could put additional strain on family caregivers and increase the risks for burden and elder abuse (Hennessey & John, 1995; Hennessey & John, 1996; Polacca, 2001).

There is very little literature that examines approaches to dementia treatment in Aboriginal communities. The majority of the literature focuses on diagnosis (Griffin-Pierce, et al., 2008; Hall, et al., 1993; H. C. Hendrie & Hanson, 1972; Whyte, et al., 2005), with additional literature considering dementia care practices (Buchignani & Armstrong-Esther, 1999; Finkelstein, et al., 2012; Hennessey & John, 1996). Although care and treatment can be closely connected, I separate them in my analysis because the majority of participants in our study did not actively seek treatment for dementia. As a result, I feel that these two factors are distinct issues in an Aboriginal context. I was unable to locate any sources that specifically referenced dementia treatment approaches or experiences specifically for Aboriginal people using either traditional or western medicine. Published research about the treatment of other diseases, however, demonstrated that there is often resistance toward western medications by Aboriginal people and that there may be distrust of the western biomedical approach to health care (Hurst & Nader, 2006). I discuss diagnosis and treatment in this chapter. Care-giving is addressed separately in chapter six.

Diagnosis and Testing

Although the majority of participants in my research expressed little knowledge or interest in diagnostic procedures, issues surrounding diagnostic tools for accurately assessing dementia in Aboriginal peoples have been a significant focus of the literature about dementia in Aboriginal populations. Several published papers document attempts to develop cognitive screening tools for Aboriginal people and express a continuing need to develop assessment tools that are appropriate for use in this population (Griffin-Pierce, et al., 2008; Hall, et al., 1993; H. C. Hendrie & Hanson, 1972; Whyte, et al., 2005). Despite the persistent interest in modifying cognitive screening tools, there are significant reasons why biomedical approaches to diagnosing dementia may never be appropriate for use with Aboriginal people. Key problems with dementia screening include test content, testing methods and procedures, language, and translation (Brant, 1990; Cattarinich, et al., 2001; Griffin-Pierce, et al., 2008; H. C. Hendrie, et al., 1993; Kaufert & Shapiro, 1996; Polacca, 2001).

The content of cognitive screening tests often includes concepts that depend on knowledge of mainstream Canadian culture (e.g. Do you know who the Prime Minister is?) as well as tasks that assume that the patient has had a formal education (counting backwards by sevens, drawing a pentagon). Many elderly Aboriginal people may not

have had access to these, especially if they live in a remote location or maintain a highly traditional lifestyle (Cattarinich, et al., 2001). In addition, clinical assessment tools are usually designed in English and many of the biomedical concepts and English words used to describe them have no equivalent in Aboriginal languages (Kaufert & Shapiro, 1996). Although translation is a possibility and some assessment tools have been translated into Aboriginal languages, there are problems associated with translation and the presence of interpreters. Trained interpreters are not always available and family members and friends are often used as a stand-in. The presence of an interpreter can influence test results in many ways including the way they translate the question, verbal cues, sensory information, and moral support (Griffin-Pierce, et al., 2008).

Finally, the method used to test cognitive ability often clashes with Aboriginal values and communication styles. Older Aboriginal people are generally private people and are reluctant to share information about themselves (Polacca, 2001). The western clinical experience may violate Aboriginal peoples' expectations for social encounters which may lead to them failing to engage with the material or the person doing the testing (Griffin-Pierce, et al., 2008). Time for developing rapport and trust is rarely built in to the testing procedure and reciprocity, cooperation and humour, which are valued by Aboriginal people and used as a mechanism for communication and relationship building are usually absent from the testing environment (Hendrix & Swift Cloud-Lebeau, 2006; Polacca, 2001). In addition, the direct question-answer format used by mainstream practitioners conflicts with communication styles favoured by Aboriginal people including non-verbal communication, avoidance of direct eye contact, moderation in speech and indirect communication such as the use of metaphors and stories (Cattarinich, et al., 2001). All of these factors can inadvertently impact a person's test scores and could potentially lead to a dementia diagnosis when no dementia is present.

Despite the challenges inherent in effectively using extant screening tools in Aboriginal populations, there are benefits to being screened and getting a diagnosis. For instance, individuals with a diagnosis may have better access to treatment and care options, and may have the opportunity to better plan for their future needs (Brodaty et al., 1998; Overman & Stoudemire, 1988). For these reasons it is important that efforts continue to modify or redesign screening tools that are appropriate for use with Aboriginal peoples. However, these approaches to evaluating cognitive decline in Aboriginal people may need to diverge from traditional approaches, focusing more on communication and evaluation of observed behaviours than test-oriented approaches. If a more appropriate tool was designed, we might improve diagnosis in this population.

Results

Health care professionals' perceptions of diagnosis

Although much of the published literature focuses on the effectiveness of specific cognitive tests and which components are appropriate for use in an Aboriginal context, many of our respondents had little to say about the cognitive screening process. Even participants who were aware that cognitive screening had been conducted had little to say about the procedure or how they felt about it. Health care workers were more likely to describe cognitive assessment procedures and tools and to comment on their effectiveness or relevance to First Nations people.

*Yeah, yeah, I think dementia in general is, is, tends to be recognized very, very late, you know? People make up a lot of excuses, especially themselves. There is a lot of denial and, ah, and difficulty recognizing it in yourself, but are you asking if that is more of a problem in First Nations as it is in many other chronic illnesses, ah, I'd say so, I think it would probably be true to say.
(KJ PHYS 01)*

The above quote represents one Manitoulin physician's perspectives about the recognition of dementia symptoms among First Nations seniors. He expresses that most people, mainstream or Aboriginal, face some sort of difficulty in recognizing dementia symptoms or denial that dementia is occurring. People who do not recognize or acknowledge their dementia symptoms seek treatment later than people who do notice and acknowledge the signs. He states that First Nations people often recognize dementia later than mainstream Canadians.

Although many of the caregivers and people with dementia were unfamiliar with or unaware of assessment procedures, interviews with health care providers, clinicians and specialists who practice on Manitoulin revealed that cognitive assessments have been conducted with many First Nations seniors. Care providers affirmed that they use several different tools to assess for dementia. Among these are the Mini Mental Status Exam (MMSE), the Montreal Cognitive Assessment (MOCA), Kingston Standardized Cognitive Assessment (KSCA), the Resident Assessment Instrument for Home Care (RAI-HC), and the interRAI community health assessment (interRAI-CHA).

The two physicians we interviewed discussed that they considered several aspects of these tools to be inappropriate for use with First Nations people and reported that they sometimes relied more on their gut impression or the impressions of spouses, adult

children, or other care providers who were related to the person experiencing symptoms.

I find that it is sometimes helpful, um, again, I mean, it is pretty useless actually the testing (MMSE, MOCA) so I end up often times find, using my own gut impression and thinking about their other aspects of functioning other than dementia, other than memory loss and which is really what the MMSE is all about and, um, ah, maybe going a bit more on the children's impression or the spouse's impression. (KP PHYS 01)

They're [screening tools] usually quite irrelevant. They don't work. In fact, when we first went up [to Manitoulin] we realized that the traditional screening tools were useless. And we, um, we tried to use tools that were trans-cultural and were not very successful, so for the most part we're relying on the staff of the nursing home to interpret the behaviours and inform us about the uh, the, uh cognitive deficit. (WW Phys 02)

Other care workers expressed that they found certain assessment tools to be adequate or that they made minor adjustments as needed.

It's pretty good. I've got no problem with it. Like, I change some of the questions, some of the words and some of the phrases like for example the three objects, I might change the three objects to something that's more familiar with them. (JP CW 06)

Interestingly, for example, the naming of the animals. Um, they always, it's a very common mistake that a rhinoceros is misinterpreted as a hippopotamus and that's on reserve and off reserve, so I haven't really noticed any, um, constant, um, discrepancies I guess you would say, between the testing I have done on reserve and off reserve. (JP CW 05)

The dominant perception, however, was that several aspects of the tests were inappropriate, especially for older people. For example, nurses in one focus group noted that some elders had a difficult time understanding some of the questions.

Yeah, especially with the elders, they're not going to be familiar with some of these, you know, animals like tigers and hippopotamus, and you know in that screening tool that you have...And they ask, like, who is the prime minister and whatever

and then I said what about the chief, like, do you know who the chief is and they were able to get that but they didn't understand who the prime minister was. (JP FG 03)

Although some health care staff reported altering the diagnostic tools in an attempt to make them more appropriate for their clientele, there is currently no validated dementia assessment tool designed for this population.

Community awareness of diagnostic procedures and results

It is difficult to establish a good understanding of the number of our participants who had received a diagnosis or gone through testing related to dementia. Many people with dementia and their family members were not aware of whether testing had taken place or what the results of the test had been. This is not entirely unexpected, especially among people experiencing cognitive decline, since they may not remember that they were assessed. In addition, family members may not be involved with a person with dementia's medical care, especially in the early stages and therefore, might not know if a cognitive assessment was carried out or what the results were.

Three caregivers in Wikwemikong had a better sense of the diagnostic process that their loved one had experienced than other caregivers in our sample. These caregivers were knowledgeable about the testing procedure and the results of the tests. They also spoke about experiences they had with follow-up appointments related to the diagnosis. Understandings of the diagnostic process seemed to be less clear among caregivers and people with dementia living in UCCMM communities. In this context, few people were aware of the assessment process or the results. This may be a result of less actual diagnoses in these communities or smaller populations which result in less people actually having dementia.

Although few caregivers or people with dementia had an opinion about the tests, one person indicated that she would not know the answers to some of the questions. She expressed, *"I don't even know who the prime minister of Canada (laughter). I don't bother with that (laughter)" (KP PWD 01)*. Another person with dementia also mentioned a challenge with the test

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

Although coming up with many words that begin with a certain letter may be challenging for anyone with dementia, the situation here was compounded by the fact, as noted by the interviewer, that there is no letter “F” in the Ojibwe language.

Regardless of peoples’ perceptions or experiences with the testing procedure, part of the problem is that dementia is simply not being recognized or identified and when it is, there is a lack of communication or follow-up related to the results of cognitive assessments.

Reasons people seek diagnosis and care

Despite the strong focus on assessment tools in the literature, very few of our informants expressed much knowledge or interest in the cognitive screening process. In light of this, I focus on when and why First Nations people seek diagnosis and treatment for dementia, and barriers and enablers to diagnosis and care, rather than an assessment of diagnostic tools. As I have discussed in previous sections, memory loss is generally perceived as a natural and accepted part of the aging process by First Nations people. However, there is also a point at which the person with dementia can deteriorate to such a degree that people feel the need to ask for help and desire a more concrete explanation of what might be happening to cause the symptoms and behaviours. In this section I discuss the factors that led our participants to seek assistance for symptoms of memory loss.

Safety

The primary reason that people and families dealing with dementia symptoms seek diagnosis is concern about the person with dementia’s safety. Participants discussed safety issues that were related to several activities.

Number one...they want to keep the person safe. Ummm, so, like, if they’re...like, I think, uh, yeah...if they’re starting to do things that are unsafe, like burning things in their house...so...people get concerned and they want to keep them safe. (JP CW 01)

Cooking was a significant concern because it could lead to leaving the stove on, burning pots and pans, or the person scalding themselves on stove elements or with hot liquids. There was also a major concern about wandering, dangerous driving or getting lost.

Over the months we noticed, but then he admitted later on that he was forgetting things and that it was getting too dangerous like for him to drive the bus. (KP CG 04)

Wandering was a particular concern to our participants because of the proximity of the woods, where a person might get disoriented and have trouble finding their way home and because of the busy highways on Manitoulin Island. Several participants were aware of stories of a person with memory problems wandering close to a busy road or even hitchhiking. Hitchhiking was usually the result of a person wanting to go somewhere, such as a previous home or to visit someone.

Additional concerns included noticing that a senior was not taking their medications or attending to their own health care, such as monitoring their diabetes. Several participants also noted that a person with significant memory problems might eat too much, forget to eat, or eat inappropriate foods. Finally, one participant indicated that she knew of an older individual who had been sober for many years, but began to drink again because of a loss of judgment caused by dementia.

Poor judgment for sure she had, ah, like, again, she knew, oh no she didn't, Ricky would take her into the beer store and he would buy her beer, like when he was taking care of her, that is what he would do, take her into the beer store and my mom never once when she was sober never once did she step into a beer store in her sobriety, ever. So this was something out of the ordinary for my mom to be going in there and getting cases and cases and blah, blah, blah, and all that stuff. (KP CG 01)

Safety concerns were a significant catalyst for help-seeking. Family members were often quite accepting of memory loss until it began to cause bigger issues related to safety. It seems from the interviews that most caregivers were able to intervene or seek help before the person with dementia was in significant danger or causing harm.

Changing or inappropriate behaviours

Another factor that families sometimes discussed as a trigger that indicated to them that memory loss was more severe than normal aging were changing or inappropriate behaviours. One older adult recounted a story of an older woman who would leave her house without clothes on.

I mean dressing, uh, I know we had to bring one lady in to Little Current, she was outside of her house she had no clothes on. It was morning, but she didn't have...she didn't know how to get dressed and she probably wasn't eating even, and they found her outside in her yard, so it's, it's everything, I guess. Their whole life becomes a challenge, dressing, eating, doing the right things,

you know, like, you don't go out with no clothes on, you know. You just...but they don't know it, they don't realize it. (JP SE 02)

Another caregiver mentioned that her mom had always been careful to keep up her appearance and that she knew something was wrong when her personal hygiene started to decline.

My mom she really took good care of herself she always had her hair done um she wore nice clothes later on she always wore the same clothes and then her shirt was dirty you know and um she was starting she was starting to get more like neglectful in that way um I don't know that ah basically what I noticed with her repeating the stories she was unkempt, um, I think what really woke me up with her was she talked about my dad like he was still alive and I would correct her, eh? (KP CG 01)

Other caregivers mentioned that their family members with memory loss also exhibited changes to their behaviours or personalities such as no longer being interested in participating in activities they once enjoyed, losing the ability to carry out those activities, withdrawing socially, or sleeping a lot during the day.

Withdrawal from work and social activities, like I said, he sits in his room or sits and watches TV. If somebody comes along like, ah, let's go papa, we'll watching television or something he'll go and then when they come back he is so bushed all he wants to do is [sleep]. (KP CG 03)

Although there was some willingness to accept certain changes to a person's behaviour, behaviours that were particularly unusual or interfered with activities of daily living or regular routines usually caused people to take notice that something was wrong.

Yeah, I forgot. You might say "Oh, you were supposed to come for dinner," "Oh, geenandan" that means I forgot. Or you know, they're supposed to uh, pick up somebody at a certain time and they're not there and you know, what's going on you know, this person was supposed to be here and it's not like them to arrive late, eh and then you call them up and say "Oh, geenandan" that's how it is, so you start seeing that pattern it's the responsibility of the family or friends to say hey, you know, they're starting to forget. They forgot me two times in a row. (laughing) But you start monitoring that, eh? (JP Trad 01)

As this participant noted, if a person began to exhibit signs of forgetfulness, such as repeatedly arriving late or forgetting to arrive, people around them should take notice and begin to monitor the situation. If the new or different behaviours were disruptive, dangerous, or combined with safety issues or significant lapses in memory people were likely to take action.

Inability to cope

Families also sought care because they were unable to cope with the changes to their family member's behaviours and abilities. Some individuals with dementia also mentioned that they sought help because were unable to manage their own daily activities or care needs. Although many of the behaviours I have discussed may be considered to be a normal part of aging some families may be more or less equipped than others to cope with the effects of these behaviours.

Um, toward the end, why I say toward the end, I mean toward the end by her going into the nursing home, um, we were having shouting matches. That's how bad it was getting and, um, she was adamant that she was fine, that she could take care of herself and everything and, um, [pause] it got pretty bad. I mean we were actually, she was yelling at me and my voice was raised at her. My patience was very wearing thin with her and, um, I didn't like that. I didn't like that at all. I had to take a step back. I had to have somebody come in and relieve me. I had someone in the community, an elder in the community that came and relieved me and, um, a couple of times while I was working I almost quit my job so I could take care of my mom full time. Um, it got to that point where it was getting really bad so, um, so I tried to appease her, um, by having her back in her home. Um, that didn't work out she just didn't want to leave after that. I kinda knew that was going to happen, um, but long term care told me that if she was to get very difficult to call the ambulance or have her admitted into the hospital and that is where it led to the last part of me taking care of her was having to call her to put her into the hospital and that is how she ended up in the nursing home today [pause] (J CG 01)

As this individual clearly expresses, her mother's condition declined and she became quite verbally aggressive. The daughter felt unable to continue to cope with this behaviour and could not manage the level of care that her mother required, which led to her accepting that she had to enroll her mother in a nursing home.

The ability to manage symptoms and behaviours was influenced by their severity as well as the amount of support available from other family members. Caregivers who shared care-giving responsibilities with other family members seemed to fare better than those who were the sole care provider. Similarly, people with dementia who had regular assistance from family perceived their memory loss to be less of a problem. The presence of conflicting demands also shaped whether or not formal support was sought. Caregivers who were employed outside of the home or were raising young children often had a higher need for formal support than those who were unemployed or did not have children.

Worry about the safety of the person with dementia and fear about the progression of the disease also impacted peoples' ability to cope.

But there are some family members who will bring it forward to us, about the safety issues with that. (JP FG 03)

People reached out for diagnosis or treatment to help them understand what was happening to their loved one or because they needed more support. Some families and individuals needed help early in their dementia journey, and others were more resilient and did not need assistance until a much later stage. In addition to ability to cope with dementia symptoms, denial also played a role in whether people actively seek a diagnosis or other assistance related to dementia.

Reasons people do not seek diagnosis and care

Some people and families do not seek diagnosis or treatment for dementia. This is especially common during the earlier stages of the disease, though in some cases a person with memory loss may be in the moderate or advanced stages of the disease and still have no diagnosis or formal assistance. Here, I consider the reasons why people do not seek care. I examine barriers and enablers to care seeking later in the chapter.

Belief that memory loss is natural

The perception that memory loss is a natural part of the aging process is a key reason that people do not seek diagnosis for memory loss or other symptoms associated with dementia. Because memory loss is not perceived as a medical problem people see no reason to seek care from a doctor. This belief can continue to impact peoples' actions beyond the early stages of the condition since returning to a "child-like" or "infant-like" state is considered to be within the expected range of the progression of aging.

Well, I guess its accepting your life cycle, you know, like I said there in the infant going back into infancy, we need to, to, and ah, one of the things that, ah, you look at the child that, ah, that,

ah, that child is love, you know, and trust and honest[y] and that is the same way with an elder. He has love, trust and honest[y] so that's going back to infancy you know finished our circle of life that it the way I understand this is my understanding of what I was taught. (KP SE 01)

The belief that dementia symptoms might be a normal part of aging were also linked to beliefs about acceptance and the progression of the life cycle. Some participants spoke of their understanding of returning to infancy in the context of traditional teachings.

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

Although in some cases the combination of forgetfulness with other behaviours triggers families to take action, in other cases people do not perceive memory loss to be in any way associated with other behaviours so they may not think there is a reason to seek help. For example, one older gentleman with memory loss was found walking on the highway, yet his family did not recognize that this may indicate a larger problem.

One particular guy that um, I found, he was walking on the highway and in a very dangerous situation, we didn't expect that he walked beyond his front door and it was, so I stopped and got him into the vehicle with assistance of a guy that was riding a bicycle. Anyways, we got him into the vehicle and we took him, the only place we could take him was to the health centre...and find a family member to come pick him up because he wanted to go back home, um, but there was nobody home and um, family didn't see this as a problem. Um, and when I inquired, you know, as to where he was going and what his plans were he, it, you know, was as if he was thirty years old. He was going to do his banking and uh, but it's that word is a – how does a family, all they think is that he's getting old, this is normal. But you know if the um, consequences could have been much, uh, worse, uh, this is a main highway, there's transports, it's a 100 – 8, well it's supposed to be 80, most people are going 100 and yeah, just with his physical, um... (JP FG 02)

This example demonstrates how dangerous it can be if dementia behaviours are not recognized and properly managed. In this instance, it is possible that the man had always hitchhiked to get where he was going and that family members therefore did not make a link between his hitchhiking and his memory problems. These beliefs and behaviours impact help-seeking behaviour beyond dementia. The belief that memory loss is natural ties in to another barrier to care that I will discuss in a subsequent section which relates to First Nations peoples' lack of knowledge relating to Alzheimer's disease and related dementias.

Distrust of biomedicine and concern for privacy

Many First Nations seniors distrust the western medical system and may be resistant to seek care from physicians or other health care providers. This relates in part to a fear that the doctor will prescribe more pills or that they will be sent away from their homes to a nursing home.

Some of them have voiced, like, you know, this is what I did and like, maybe forgetting to turn off the stove or whatever or they have something on the stove and then they totally forget about it until they smell something burning. They do realize like, it is a safety issue, but again, you know, they don't want to go anywhere else, they want to be in their home. (JP FG 03)

Although my focus has been on western medicine in this section, I would like to take the time to note that the majority of our participants also did not seek traditional healing to cope with dementia. The belief that memory loss and other behaviours associated with dementia are a natural part of aging seem to deter people from pursuing any kind of treatment for dementia symptoms.

The following conversation that took place in a focus group with health care staff shows how they try to grapple with the idea that people may not seek care for symptoms of dementia.

I6: Well it could be a cultural thing because um, I've come upon different situations where someone has been, knowingly has all the signs and symptoms of another disease and they don't go to the doctor because that's, they're going to deal with it themselves at home. And a lot of...

I1: Traditional medicine.

I6: Not just traditional medicine, but it's almost like if they don't talk about it it's not there.

(agreement from the group)

15: And there is a lot of that. There is a lot of we don't talk about 'x'. I find, you know, once people are on our program, some of them after lengths and lengths of time will eventually offer some information but, I mean...that is a common theme throughout all of our visits, whether or not they're Alzheimer's or not, is that you get pieces of information as you go, and I mean even when I find one part of the puzzle here at the beginning of October and then in December all of a sudden you've got the rest of the story, which makes everything else make sense. And you're thinking Ok, like is that...you feel responsible for not having gotten that information, but the truth is, these people they offer it up when they're ready.

16: Oh, I think one part of the culture is that we, uh, our elders don't, they have to build that trust first with uh, with that provider...

15: For sure. That's true, yeah.

16:...and they're not going to um, open up you know, their whole life history, um...just because you're asking. They have to have that trust with you and until that trust is there they may not admit to forgetting, they may not admit to, uh, concerns of any health issues until they've got, reached that level. So I think that's what makes, um, nursing and personal care very different in our communities is that what might take you something like ten minutes to do in another non-Native home will take you half an hour in their, uh, private homes on Manitoulin because it's their homes, right? We are guests in their homes and we have to respect that there's boundaries and there's space that they'll let you in, but there's so many...it takes time to get closer, that space is very important. (JP FG 02)

Their experiences suggest that older people often need more time to establish trusting relationships with their health care providers, especially those who are not Aboriginal. A lack of trust coupled with a strong desire for privacy may hold people with memory loss back from asking for help or disclosing their symptoms. Family members may also refrain from disclosing their concerns about an older relative because they respect them and wish to keep their memory problems within the family.

Treatment

Dementia treatment can be approached using a Western biomedical approach, a Traditional Aboriginal approach or some combination of the two. Our informants' perspectives of how dementia could be treated were varied, and often reflected their personal experiences with the condition and their background or training related to medicine. Here, I talk specifically about treatment for dementia, distinct from care for a person with dementia. Care practices will be discussed in the next chapter.

Biomedicine

Several of our participants referenced Western medicine in the context of dementia treatment. The medicines that caregivers referenced when talking about memory loss included Ativan, Seroquel and Haldol (antipsychotics used to control agitation) (Loneragan, Luxenberg, Colford, & Birks, 2002; Rayner, O'Brien, & Schoenbachler, 2006; Singh & Wooltorton, 2005), and Aricept (cholinesterase inhibitor)(Hogan & Patterson, 2002).

Oh, I just uh, I don't know, I just give him an Ativan, that settles him down. (JP CG 06)

She doesn't have a gait. I noticed with my dad he had a gait, like the shuffle, the shuffle. My mom doesn't have that shuffle, but with my dad the shuffle he was on, um, Haldol, eh, Haldol. That can cause the shuffle. Now my mom is on Seroquel, she just started on that. I don't see, she is walking really fast over there at the nursing home [laughter] she just gets up from her chair goes over to her bedroom, oh, you, I've got something and she'd get up and holy smokes and she is not wobbly or anything. (KP CG 01)

Yah, he, they had him on Aricept. But they had to take him off it because it wasn't agreeing with him. So they put him on a new one and he was having dreams and seeing things, like, you know seeing things that were in the bedroom that weren't really there. (KP CG 04)

Side effects were a major concern for caregivers. The hallucinations and shuffling gait mentioned above are specific examples, though participants also spoke of side effects more generally. For example, one person with dementia had been given information about Aricept and chose not to take it because of the possible side effects. Participants were also concerned about the number of pills that were prescribed. They frequently expressed that there were too many medications.

No, and I really don't need it now. I don't think I need it right now, I have enough [shakes pill packet]. (JP PWD 01)

In addition, one caregiver discussed the cost of the medications the doctor had suggested that her father take.

'Cause I don't know if he would be willing to try it that way, take them pills, like, they are pricey mind you they are like \$42 a bottle. (KP CG 02)

On the whole, our participants seemed to want to avoid using western prescription medicines to manage dementia symptoms. Concerns about dosage, effectiveness, cost and side effects were the biggest issues. Also, Western medications and Traditional medicines were perceived by some participants to have negative interactions. Some people expressed that in order to take Western medications people may need to stop using traditional medicine.

Uh, she was [taking traditional medicine] for a while, but we got a little worried after, with so much of the Western medications she was taken there might be a reaction there, eh? So we pretty much took her off of that. (JP CG 01)

Although very few people indicated that they were using traditional medicines to treat dementia, some people were using traditional medicines for other health problems or to promote overall well-being.

Health care providers, primarily physicians, also referenced western medicines. The perception of one physician was that these medicines were not very effective.

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

conflict with some of my colleagues over that, other of my colleagues agree with that approach. With regard to the drugs that affect behaviour, however, then I'm going to prescribe those the same way in an institution as I would in the community. (WW Phys 02)

Another physician noted that part of the problem with the medications is that they are linked to the assessment tools.

Um, I think you need to link the validation tool and to the med, the memory enhanced medication 'cause it's currently, use of them, the medications are currently linked to the current tool that is not particularly valid or useful. Um, what other things, I think it would be one of the problems is the definition of dementia is possibly culturally inappropriate, ah, so, um, that would be the other thing is to sort of work out what is the culturally appropriate definition of dementia in terms of, ah, the disease, if it is a disease, and, ah, um, there's quite a lot of interesting work that might be done there, um, like the historical significance of it and whether it has been there in the community for a long time or we are imposing it at this point or, ah, and maybe they have created ways of understanding it that is helpful in managing it terms of treatment. (KP PHYS 01)

This physician had a very strong understanding of why this might be problematic in a First Nations context. He also saw one of the main benefits of the drug as being the prevention of nursing home admission.

Traditional Approaches to Treatment

Our interview data suggests that the majority of people caring for a person with dementia are not using traditional healing or medicines to cope with memory loss. Many stated that they either were not aware of traditional approaches to dementia treatment or that the person with dementia had ceased using traditional medicines as the disease progressed. In many cases this was because they forgot how to prepare them or no longer had the ability to seek out the plants and other materials they required to make them. Although traditional healing was not discussed as a direct treatment for dementia, some informants talked about using traditional healing more holistically and to help with other health issues or general well-being.

I did see one lady one time who, as soon as I walked in the door, I knew something had changed with her because it was

unbelievable the difference in her, she was just brighter and smiling, and she had went to a sweat lodge, and she had drastic improvement. (JP CW 03)

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

I just kept saying to myself, you know, I'll be ok, and of course, I prayed a lot and I'm sure I got help from up above me. (JP PWD 04)

As far as like Native traditional medicines and stuff like that, um, not that I know of, like I don't think there's really anything kind of set in stone that says well, if you do this, or whatever it would improve your memory. Um, that I know of, other than um, storytelling and, um, just reminiscing with her about different things that happen in the past and like and seeing what she does remember and what she doesn't, kind of thing. Um, yeah, but aside from that I don't think there's really any really anything there other than, you know, praying for her and stuff. (JP CG 03)

The non-traditional herb tea ginkgo biloba was mentioned by one caregiver as something that could be used to help memory. Another caregiver mentioned that their parent took a traditional medicine called ESIGAAMDEG to relax them. Informal family caregivers expressed little other knowledge of traditional medicines used specifically to treat memory loss.

Formal caregivers also had some perspectives on the use of traditional healing in dementia care. Some of these care workers were Aboriginal and others were non-Aboriginal, but in general there was consensus among them that there was little knowledge about traditional treatments for dementia-specific symptoms. This may be in part because many of the care providers who were interviewed were Caucasian and they felt that people likely were not sharing their experiences with traditional healing with them, or they made a conscious effort not to get involved with their clients' choices about traditional healing since they felt it was not their place. The fact that many care providers are Caucasian may mean that traditional individuals are reluctant to share

their traditional beliefs and practices because they feel care providers will not understand or accept them.

One care worker expressed that she had a client who had been attending healing circles, but that she had stopped because she felt that what she shared there was not being held in confidence and was getting out into the community. This same care worker also knew of a client who had participated in, and seen positive results from, a sweat lodge ceremony. She knew of others that used traditional medicines such as liquid cedar. Most of these practices and results were discussed in the context of overall health and well-being and less specifically in the context of dementia.

Care workers felt that some of the reasons that some people were not participating in traditional healing was because they were unsure of the procedures and were worried that they would be told to stop taking western medications, that more families are less traditional than they used to be, or that they had strong Christian beliefs and did not believe in traditional practices. However, care workers expressed that they did consider spirituality to be generally beneficial to clients with dementia.

The two traditional healers in our sample were vague about their treatment of people with dementia. One expressed that there were possible treatments, but that they varied from client to client.

There's different kinds, I can't really, well, it's not something that I can't really talk about either, eh? Because there are different methods and it's usually tailored to the individual and whatever kind of trauma they received and that's what you work with. (JP Trad 01)

This same individual also explained that although some medicines might help, people needed to do more than just rely on medicine to improve symptoms of memory loss or dementia. She firmly expressed that people had to be active and to do things for themselves to promote healing.

There are medicines people can take to um, for that, for that brain to be active again, eh? But they're also having to be doing things that need to uh, you know, mobilize them, because a lot of times, you know, when people are inactive and then that also effects the brain. 'Cause you're not putting new information in, eh? So they start stagnating. I guess that's the best way to describe it, eh? So, I mean, you can only do so much ceremonies, you know but the fact is the person also has to start doing some things eh, that...in traditional healing we teach people how to

take care of themselves, eh? And doing some of those things for themselves, even going out, picking medicines themselves, that's an activity that's actually healing for them to go out and do things on their own. (JP Trad 01)

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

Yeah, I don't know, if I were to have somebody come like that I would probably suggest that they keep busy with what they're doing or uh, uh, doing puzzles and stuff like that. It's mostly the western stuff and uh, any teas that will come up would be B-uh B vitamin teas. And uh, I would have to shucks, I-I know the medicines in Indian, there would be some tea for memory, eh? Yeah, it could be...yeah, that would help their memory there is a tea. That's, that's what I should be taking (hearty laugh) (JP Trad 02)

In addition to the recommendation of keeping busy and doing puzzles, B vitamin teas were also understood to have potential benefits to counteract cognitive decline.

Barriers to Prevention, Care-Seeking, Diagnosis and Treatment

First Nations individuals experience both barriers and enablers to dementia diagnosis, treatment, and care. Some of these factors also influence prevention. The following section examines our participants' perceptions of the factors that help and hinder them in seeking diagnosis, treatment and care for symptoms associated with dementia.

Lack of Biomedical Knowledge

One of the most significant barriers to dementia prevention, diagnosis and care in First Nations communities is a lack of awareness and education about abnormal cognitive decline in old age. Many participants expressed that they were not aware that help was available for people with dementia or where they might locate it. Further, many participants strongly believed dementia to be a natural part of the aging process and did not recognize the difference between normal forgetfulness and the more significant signs and symptoms of dementia. When asked if they had enough knowledge about dementia people responded:

No. No, I would...we should know more about it and how to handle it. (JP CG 04)

No, I guess not. I inquired with one of the nurses, so...and even my brother came to me and asked me "Did you notice Mom is..." um, one of the things that he really noticed is her repeating herself a lot. I mean, I just knew a little bit about things you hear, so, and then I just inquired more about it and to see if we could have her tested and stuff. (JP CG 05)

Some people also expressed that they were not familiar with the term dementia, or that they had heard the term Alzheimer's but did not know much about it.

I've heard it, but I haven't had the problem so it really never dawned on me of anything. I've heard of it, yeah. Like, I think, uh, somebody, uh, had that problem – it was somebody, uh, that I was supposed to be uh, well I shouldn't say supposed, uh, I was related to. (JP PWD 04)

Well, I don't know exactly what it is. (KP SE 05)

Most of the participants in our sample had only vague ideas of where they might access information about memory loss and dementia, and few had actively sought out this information. Some caregivers mentioned pamphlets at the health clinic, and a few people with dementia said that they had been visited by the Alzheimer's society. The trend in our sample was that people who had been informed about dementia had received the information from their health care provider because symptoms were becoming a problem, not because they had sought out the information. This was seen by some health care providers to be problematic, especially in cases where the underlying cause of dementia symptoms is treatable and possibly reversible, such as depression or B12 deficiency.

Maybe not as much. A lot of people just say "well, all my friends are the same as me, so I'm not too worried about it". You know, they just think it's normal to get forgetful as you get older. And, I mean...to some extent it is, but sometimes it's more than that and I think they just, a lot of times just write it off to getting old and think that there's nothing they can do about it. It's the same with depression, it's just part of being old..."I'm supposed to be lonely and I'm supposed to be...whatever" and I don't think they can really see that people can help them. Some do, but a lot don't. I think it's just starting to be a bit more....maybe not more

prevalent, but I think people are getting to have a bit more of an awareness now, but its slow. (JP CW 03)

Access to Health Care

Access to health care is also an issue on Manitoulin Island. Although there are health centres that serve all reserves, there is a limit to the hours of care available, treatment from a specialist usually requires long-distance travel, and services such as respite and adult day programs are particularly limited. During my fieldwork there was only one representative for the Alzheimer's Society responsible for servicing the entire island. Upon follow up two years later, the full-time representative for the Alzheimer's Society had resigned and the new replacement had only part time hours and traveled in from Sudbury. In effect, there is now less support from the Alzheimer's Society than there was in 2011. Although health centres do serve all reserves, some communities are located far away from services and transportation can be difficult to access. Access issues were frequently mentioned by our informants to be a significant barrier to diagnosis and treatment.

I think as far as being in our own community um, like right here in the community the services that are provided not from Mnaamodzawin or Noojmowin-Teg, but in our own community, um, I would say could be, or should be, a lot better than they are, um, the medical transportation, um, used to be provided for her, to take her to her dialysis and her appointments, um, unfortunately, um, due to politics and um, (deep breath/sigh), jealousy I guess, I'm not sure um, like what that would be but, um, services have been denied for her, um, just because of our family name, uh, like I said, a lot of it has to do with politics, um, so we provide the transportation ourselves. (JP CG 03)

The number of hours of care available, both for home care and at the health clinic were also discussed.

It's hard when you want to go to the clinic and you can't see a nurse, you've got to make your days Monday, Wednesday or Friday morning and then only between 8 and 9. I've got to set my clock to go there for my B12 shot or for anything because they're there I guess, um, organizing and researching and thinking about how to um, better uh, help people, the people in the community, start to do these programs. (JP SE 03)

Additional access issues included the high cost of transportation and medications. This was especially difficult for individuals who did not drive or have access to a car.

Concerns about privacy and confidentiality were also an issue for many people. Many participants were concerned that their private information would be spread around the community and this often impeded families from seeking care, especially for mental health issues, including dementia.

I don't know I don't really associate with anybody over here I find, ah, when you talk to people here too much gossip and then the next thing the whole Wiky knows. (KP PWD 03)

Health care providers recognized peoples' concerns about privacy and expressed that they often needed to take extra time with their clients to build rapport and trust.

Probably partly, and partly they may just be being a bit more private about issues within the home, kind of thing. That's what I tend to find, anyhow, with Aboriginal people especially. They don't like to discuss...even somebody I'm visiting for depression or whatever, they don't like to talk about their feelings that much, or sensitive issues I guess, I should say. (JP CW 03)

These care workers expressed that they strongly believed in protecting their clients' privacy.

The fact that we're small communities, and this again was a big surprise to me, the confidentiality thing. For me, that's just part of my code, you know, what comes to me is used in the appropriate manner. Coming into the communities what I didn't realize is that there's not a lot, there's not a lot, there's not a lot of trust. (JP FG 02)

They also expressed concern that fears about a lack of confidentiality might prevent clients from accessing services.

Well it's back to the confidentiality thing again, they don't want to access them. I find a lot of that listening to them talk. "I don't want my stuff aired all over the community." (JP FG 02)

This was one area where Noojmowin Teg and Mnaamodzawin Health Services may be especially beneficial, since they are located outside of all but one of the communities.

A lot of people are afraid to access services at the community level because confidentiality is always an issue and always will be an issue because there's always that trust and the old, you know 150 years ago your mother did this to me so, you know, that kind

of an attitude so a lot of times they'll just bypass the community and come right, you know, approach us directly. Which is fine. (JP CW 06)

Concerns about privacy were also seen as a possible barrier to education and prevention, since people might be unwilling to talk about the issue openly in public.

Well, privacy would be a big issue, I think certain families, depending on the illness, like the prognosis, not everybody wants to, uh, the whole thing out in public, so privacy, I don't know, to deal with the topic openly might be a challenge. (JP FG 03)

In addition, privacy policies can actually make it more difficult for care workers to engage family members in care provision, since they cannot disclose the diagnosis to the family without the permission of the person with dementia.

Well, I've never had anybody come to me. I, uh, asked some family, um, but you know, they'll...it depends on the person, like if it's the person who themselves said yeah, you know I think I've got some concerns about memory sometimes you find the families will yeah, they've talked to them about that um, but for the ones that you see it in, I haven't really 'cause I mean, how do you still go ahead officially and talk to the family without some ok from the person themselves? So that's sometimes where I find that there's a bit of a block to that. (JP FG 02)

Privacy and confidentiality are significant concerns, and people's worry that the community might become aware of their diagnosis or even that they are visiting the health centre, may play into issues of shame and stigma.

Cultural Inappropriateness/Language

A lack of cultural appropriateness in diagnostic and treatment practices can act as a barrier to the identification of dementia. Care workers on Manitoulin noted that there is a lack of culturally appropriate education materials related to dementia. The materials that do exist are in English and do not depict any Aboriginal people.

I1: Well it's just like for cancer or for diabetes, they've actually flipped into the Aboriginal setting which is fairly, I find that more um, more on their level, eh?

I6: User friendly for them?

I1: Yeah.

R: Can you tell me how that's...

I6: well, just their posters, for example uh, for one of the hypertension projects that they have they've uh, taken their national poster and made it more uh, friendly in the sense that they recognize people from the area that are on the posters. (JP FG 02)

Focus group participants from Mnaamodzawin noted that educational materials related to cancer and diabetes had been updated to better represent Aboriginal people and that this would be a beneficial tool for increasing dementia awareness.

There was also some concern about the content of cognitive assessment tools and the lack of training that health care workers received about cultural appropriateness.

Um, they are useful and a lot of times its just giving out basic information, but they probably aren't culturally appropriate in some instances. Even the cognitive tests themselves I don't think are – I use this one a bit...the Kingston one. Yeah, because it's a bit more visual and I find that they are able to...it's a bit longer though, but I find the Aboriginal people relate...and [my doctor] found that too, I think. He was...he started using this a bit more. I'm not sure if he's using it in the communities much now, but he had got some information about it at one point because he was interested in using it in the Wiki nursing home just because he found that it was a bit more culturally appropriate. But educational materials there's...I don't know of any that's for Aboriginal people specifically, and...and like the long term care nurses and those kind of resources on the reserves are educated in traditional healing and medicine a bit more, but none of the rest of us are, really. It's not that we haven't asked for that, but we don't really get invited into that kind of educational opportunities as much as it would probably be good if we did. Although, like I said, a lot of the information we get through the Alzheimer society, and a lot of the materials and things that we hand out are helpful to anyone. (JP CW 03)

One care worker expressed that non-Aboriginal nurses were interested in accessing specific training about how to give appropriate care for First Nations people, but they felt that they were not invited to participate in those kinds of educational opportunities.

Finally, the perception that the Alzheimer's Society was a non-Aboriginal agency also impacted whether people accessed the services they offered.

I think there's definitely the perception that Alzheimer's disease sorry, Alzheimer's society is not an Aboriginal agency, um, and I'm often aware of that, I just uh, sense that, so I would think that that is a barrier and then there's also, um, you know some people don't feel comfortable, um, me coming to their home and so the fact that I don't have an office where they can just drop in, I could see that as being a potential barrier as well um, that being said, you know, if they let me know or if they let somebody know they don't feel comfortable in their own home then we can get office space in any of the communities anyplace, but to pursue that um, requires, you know, the concerted effort to do that, the acknowledgment that you don't want me in your home, versus just stopping in. So, yeah, so I could see that as being a barrier. (JP CW 05)

The local representative from the Alzheimer's Society recognized that some people did not access the services she was able to offer because she was non-Aboriginal and did not have a neutral public office space. Some nurses also noted that they sometimes received resistance from the band leadership if they sought outside services such as mental health nurses. They perceived that the leadership wanted them to use resources within the community instead of bringing services in from outside. However, they also felt that some of their clients were more comfortable talking to a person outside of their community about mental health issues. An additional challenge was that some resources simply were not available in their community, and they had to go outside of the community to ensure that the client's needs were met.

Interpretation

This chapter explores issues surrounding detection, help seeking, diagnosis and treatment related to memory loss and dementia. These four issues are all closely related, and many of the factors associated with knowledge and detection also relate to prevention. It is important to understand how these issues interact because they have implications for the health, safety and quality of life of people and families living with dementia.

In the previous chapter, I began to outline the implications of First Nations perceptions of what differentiates normal, age-related memory loss from dementia. In this chapter, I have continued to explore the ways in which these perceptions can

impact help-seeking behaviours. Most notably, the notion that memory loss is a normal part of aging combined with a lack of understanding of the underlying biomedical mechanisms of dementia often has the effect of delaying help-seeking and diagnosis. In Chapter Three, I discussed First Nations seniors' perceptions of a healthy old age and their desires for their own aging experience. These desires come to the fore again here if we assume that older people with and without dementias likely have a similar desire to remain as engaged and productive as they are able for as long as possible. The issue here is that if dementia goes unrecognized or if help is not sought, people experiencing symptoms may be at a greater risk of withdrawing from friends, family and activities that once defined them as a person. If symptoms are not recognized, family and friends may not know how to respond to these behaviours or may withdraw from the person with dementia because they no longer know how to interact with them. This may threaten personhood, even by Aboriginal standards where personhood may be considered to be more of a communal entity (McMillan, Kampers, Traynor, & Dewing, 2010). Although some families may recognize that the person needs assistance and may provide them with some kind of care, if this care is provided in such a way that does not promote the continued independence of the person with dementia to the desired degree, then they may experience excess disability (McClendon, et al., 2004; Sabat, 2001).

The published literature about the diagnosis and treatment of dementia in Aboriginal peoples is heavily focused on screening and assessment tools, whether they are appropriate for use in Aboriginal settings and how to modify them so that they better represent the cultural beliefs and values of this population (Griffin-Pierce, et al., 2008; Hall, et al., 1993; Whyte, et al., 2005). As I consider the experiences of the participants in my study and the perceptions of the doctors we interviewed, I question whether future research would be better focused on other ways of detecting and diagnosing dementia that do not rely on cognitive testing. Research has consistently demonstrated that there are significant challenges to using cognitive assessment tools in an Aboriginal setting. It is clear that we continue to be unsure of the validity of these tests for Aboriginal people, especially across diverse cultural groups. Aboriginal people have a holistic perception of health and wellness that encompasses the physical, emotional, mental and spiritual realms (Strengthening the Circle "Partnering for Improved Health for Aboriginal People", 2010). As the two physicians we interviewed pointed out, taking the time to talk to the person with dementia, observe their behaviours, and talk to their informal and formal care providers may be a more successful approach to diagnosing dementia that considers a more global and holistic understanding of memory loss and dementia and how it impacts people in their day to day lives.

As I consider all the factors that can impact the identification and diagnosis of dementia I see two main issues. First, the recognition that memory loss has become

problematic, and second, formal diagnosis. The question that emerges is: Does a formal diagnosis matter? Does a biomedical diagnosis increase care, prevent stigma, or reduce shame? Does it change the outcome for people with dementia? It seems that among our participants, a formal diagnosis does not change a family's willingness to provide care. Most First Nations families seem to provide care regardless the presence of a diagnosis of dementia. In cases where families are supportive and inclined to provide care for their elders, a diagnosis does not seem to have a significant impact on care outcomes.

In cases where family members do not step in to provide care, it is often a lack of biomedical knowledge about the signs, symptoms, and effects of dementia coupled with the belief that memory loss is a natural part of aging that impacts their decision not to provide care. In these instances, education about warning signs and symptoms and access to supports that can help people to cope with signs and symptoms is more likely more important than a formal, biomedical diagnosis of dementia. The lack of knowledge that memory loss can be caused by other health issues, or the lack of recognition that dementia symptoms may be dangerous, coupled with beliefs about respect for elders that seem to keep people from entering into the care-giving role or seeking help for cognitive decline. As a result, it appears that increasing awareness of how to identify dementia, how to access support and how to provide care that promotes personhood would be a better use of resources than a continued focus on the development of new diagnostic assessments.

Some work has been done in Australia to determine a culturally safe assessment tool for Aboriginal people. This tool, the Kimberly Indigenous Cognitive Assessment (KICA) differs from other biomedical assessment tools in that it was designed to be appropriate for use specifically with traditionally-oriented Australian Indigenous seniors (LoGuidice et al., 2006; Smith et al., 2009). For example, it uses culturally appropriate pictures that better represent the knowledge and life experience of the seniors it was designed for. The KICA was developed in consultation with linguists, health workers, Elders, and clinicians and has been validated as appropriate for detecting cognitive impairment and dementia in Indigenous Aboriginal seniors living in the Kimberly region as well as the Northern Territory of Australia (LoGuidice, et al., 2006; Smith, et al., 2009). The KICA assessment focuses on testing memory, comprehension, and language abilities. It also assesses some executive function, but there is a need for a more sophisticated tool to address this aspect of cognitive impairment (Smith, et al., 2009).

Although I question the need for an explicit diagnosis above, a diagnosis can be beneficial, and people should be able to get a diagnosis if they desire one. Additionally, diagnosis may be required as a first step towards more advanced testing and treatment. In the introduction to this thesis I referenced two types of dementia, reversible and irreversible. Reversible dementias can include toxic reactions to medication, dietary deficiencies, vitamin B12 deficiency, infections, tumours, head injury, alcoholism, and

depression (Alzheimer Society, 2010). Other dementias, such as Alzheimer's disease, vascular dementia, and Parkinson's Disease dementia are irreversible. Early diagnosis and treatment are especially important for people experiencing reversible dementias (Brodaty, et al., 1998) so they can get early access to treatment and do not suffer unnecessarily. In this situation, a diagnosis may lead to the cause of the dementia being addressed and the dementia being cured. The argument for early diagnosis and detection of irreversible dementias is more complex.

One reason why a diagnosis may be important is in the ability to get a prescription for dementia medicines. However, if there is no treatment or cure for dementia, there may be little value in a diagnosis. In fact, it is possible that a diagnosis could cause undue stress and burden if a person or family learns that mild memory loss is caused by an incurable disease. In some cases, the diagnosis may be so devastating that it leads to depression or even suicide (Downs, 1997; Keightly & Mitchell, 2004). The value of a dementia diagnosis may change as the disease progresses or as advances are made in treatments or cures for the condition (Brodaty, et al., 1998). Currently, there are no drugs that are proven to be effective in reversing or arresting dementia symptoms.

However, a diagnosis may still be valuable if it opens access to services or creates an opportunity for dialogue between people with dementia, their families, and their care providers (Brodaty, et al., 1998). An early diagnosis, in particular, can give people with dementia and their families the opportunity to plan ahead, by increasing the likelihood that the person with dementia will still be competent to be involved in writing their will, organizing advanced directives, settling financial and legal affairs and transferring their power of attorney (Overman & Stoudemire, 1988).

If diagnosis leads to early intervention, training programs for caregivers, and additional services for people with dementia it can be extremely beneficial (Brodaty, et al., 1998). In fact, it can be said that it is not the diagnosis itself that is beneficial, but the information and support that becomes available to people with dementia and their caregivers once a diagnosis is in place (Brodaty, et al., 1998). Unfortunately, appropriate follow-up to a diagnosis, including information about the disease and access to services, is often lacking (Brodaty, 1990). This emerged as a significant problem on Manitoulin Island. I believe that people should have access to a diagnosis if they desire one, but I do not know that a diagnosis of dementia is always relevant to First Nations people, or that the appropriate follow up is happening that makes a dementia diagnosis valuable. More research is needed to better understand if a diagnosis helps families to understand what is happening to their loved one and how to support them so that they can have the most positive experience possible. Regardless, the importance of improving follow up, and increasing education and support is critical to enabling people to better cope with the challenges of age-related cognitive impairment.

I have already discussed how First Nations peoples' perceptions of memory loss and old age can limit help seeking, including diagnosis and treatment. This is a challenge that may be difficult to overcome without imposing a medicalized understanding of dementia on them. The risks here are that they are not gaining access to the knowledge, information and supports that can help them to cope with the dementia symptoms and care needs. Whether or not First Nations people desire a diagnosis, I believe that it is important for them to have access to knowledge about dementia symptoms, prevention, treatment and care as well as supports that can help them to cope with the symptoms. This information should work with cultural beliefs and behaviours associated with aging and memory loss, since there are many positive factors that stem from these beliefs. If people have easy access to this information, they will be better prepared to make informed decisions about their loved one's memory loss and how to deal with it.

Although there are potential dangers associated with a lack of biomedical knowledge of dementia and how to get help, there are also higher level factors that impact peoples' ability to access diagnosis and treatment. Of significant concern were barriers such as culturally inappropriate diagnostic tools, a lack of educational materials related to dementia written in Aboriginal languages and representing Aboriginal people and difficulty in accessing culturally safe support and treatment options.

One of the goals of this thesis was to address the question of what kinds of culturally appropriate care and services need to be developed to support Aboriginal people in their efforts to cope with the effects of dementia. Although I question whether further research regarding cognitive assessment tools is the best use of limited resources related to dementia, a more culturally appropriate method for assessing whether dementia is present and evaluating the level of cognitive decline would be useful in these communities. This is especially true because it emerged from follow-up community consultations with health care organizations that diagnosis is perceived to be a key issue. However, I say this with the caveat that the development of such a tool must be accompanied by the development of a well-defined strategy for what happens after a diagnosis is in place. This is because a diagnosis is only truly useful if it can help people to access the services and supports that they require.

Several types of services and supports were discussed by participants who were interviewed. Some of their desires related to increased access or an increased number of hours of care. For example, greater availability of home care nursing and PSW support were widely mentioned to be important, and a need for respite was nearly universal. In particular, caregivers expressed that evening, overnight, and weekend support would make a significant difference to their care-giving experience. Activities for people with dementia, especially those that would allow them to get out of the house and engage in social contact were also considered to be important, and served the dual purpose of helping the person with dementia to be more active and to have more stimulation and

to give caregivers time to rest or run errands with the knowledge that the person with dementia was safe and well cared for. In addition, culturally safe support groups available with other First Nations people, offered in the Ojibwe would help individuals and families to cope with dementia.

Education and training were also significant needs, not just for family caregivers, but for health care providers at all levels. Physicians need training about cultural safety and appropriate ways to assess dementia in Aboriginal populations. Care workers need a stronger understanding of dementia, the supports available to assist their clients, and training related to dealing with specific symptoms and behaviours related to dementia. Training and education related to what dementia is and how to cope with it is also very much needed by family caregivers. Culturally safe training about how to manage behaviours and cope with the changing needs of the person with dementia would improve the experience of dementia for caregivers as well as care recipients. Finally, language promotion efforts that reflect Aboriginal languages, Aboriginal peoples, and Aboriginal perceptions of dementia may be helpful in educating people about when dementia may be problematic and where to go to get help.

Conclusions

This chapter examined issues around the detection, diagnosis and treatment of dementia in First Nations communities on Manitoulin Island. The data demonstrate that several factors influence Manitoulin First Nations peoples' decisions surrounding dementia diagnosis and care. Among these are cultural beliefs about the nature of dementia, confidentiality and respect for seniors. Since dementia is perceived to be a natural part of the aging process, many individuals and families do not see it as something that requires attention from a doctor. Further, if symptoms have progressed beyond the point that is considered to be a normal part of the aging process beliefs that seniors have the right to make their own decisions and respect for their privacy may hold families back from raising the issue or contacting health care providers about it.

Beyond cultural beliefs and behaviours, there are barriers that can prevent First Nations people from accessing or even having an awareness of possible assistance for dementia symptoms. At a very basic level, one of these factors is a lack of knowledge and education about Alzheimer's disease and dementia. If people do not have the knowledge of dementia symptoms and their implications they are unlikely to seek help for them until they have resulted in some kind of crisis. There are also structural issues including poverty and infrastructure related to care access, such as a lack of resources related to dementia care, and people being unable to afford treatment or the travel involved in accessing it. Further, diagnostic procedures often do not meet the needs of

First Nations people and there is a need for better supports following the detection of the condition.

Culturally appropriate health promotion is needed to make First Nations people aware of the causes of memory loss in old age so that they can identify when memory loss is a problem and have the opportunity to access the information and services they need to make informed choices about how to cope with symptoms of dementia. Ensuring that these materials and services are available and accessible increases the potential for individuals with dementia and their families to have a more positive experience with dementia and to better cope with the challenges that come along with the condition.

Chapter Six: Caring for a person with dementia: Formal and informal care strategies

Introduction

Cultural beliefs and practices shape the experience of dementia for caregivers and care recipients and can significantly impact the identification of memory loss as an issue, the perceptions of person with dementia's needs, and the way that care is provided. This chapter addresses the ways that First Nations cultural beliefs shape care practices for people with memory loss by highlighting care practices and exploring context-specific challenges, strengths, barriers, and enablers to successful dementia care that protects the health, dignity and cultural safety of all involved parties. Coupled with the previous chapter, which considers decision-making and help-seeking behaviours surrounding diagnosis and treatment, I attempt to present a complete picture of the issues surrounding the treatment and care of people with dementia. I consider care-giving and treatment separately because they emerged as unique issues from our interview data.

This chapter begins with a review of the current literature on Aboriginal dementia care-giving before moving on to describe the knowledge and practices of formal and informal dementia caregivers on Manitoulin Island. Seniors' (with and without cognitive decline) perspectives relating to dementia care are portrayed. Quotes from dementia caregivers and care recipients highlight these experiences. Finally, I discuss the implications of the actions that were observed, speak to the changes that are putting pressure on family care practices and explore needs for caregiver education, training, or other interventions. Ultimately, the data in this chapter demonstrate that First Nations caregivers have many strengths and on the whole provide appropriate and well-intentioned care. However, I also demonstrate that there are many barriers that hinder a care environment that provides adequate support to protect the physical, emotional and cultural safety of people with dementia and their caregivers and that cultural change is impacting traditional care practices.

Context

Aboriginal Experiences with Care-giving

Research has consistently demonstrated that care-giving practices are shaped by culture (Dilworth-Anderson, Williams, & Gibson, 2002; Hinton, 2002). As a result, care-giving must be considered in the context of the culture within which it occurs if we hope to understand it fully. Culture shapes the type and amount of care that is given, who provides care, the coping strategies that carers employ, and the use of social supports and formal services (Dilworth-Anderson, et al., 2002; Hinton, 2002). In Aboriginal communities, dementia care is shaped by several factors including the relatively recent development of dementia-type illnesses as an issue facing Aboriginal seniors (H. C. Hendrie, et al., 1993; Sutherland, 2007) and the emerging explanatory models that shape Aboriginal peoples' understanding of the condition (Henderson & Henderson, 2002). Caring and coping strategies may also be influenced by cultural beliefs, language, traditional spiritual beliefs (L. L. Jervis & Manson, 2002), and the unique history of Aboriginal peoples.

Limited published data exist that reflects Aboriginal peoples' experiences with dementia care-giving. It is believed that extended family are the primary caregivers for Aboriginal people in North America. For example, Buchignani and Armstrong-Esther (1999) suggest that informal care provided by spouses, children and siblings accounts for up to 80% of eldercare in Aboriginal communities in Alberta. Similarly, in the United States, family is often the sole or primary provider of care in Indigenous communities (Hennessey & John, 1995; Hennessy & John, 1996; L. L. Jervis & Manson, 2002). The prevalence of informal family care is due, in part, to the traditions of Aboriginal people relating to family care and in part because there are few viable alternatives to dementia care accessible to this population (L. L. Jervis & Manson, 2002). Other factors that influence the provision of care by families include that Indigenous seniors are more likely to live with kin (Buchignani & Armstrong-Esther, 1999) and American Indians have strong cultural value of reciprocity (Hennessy & John, 1996; Lori L. Jervis, Boland, & Fickenscher, 2010; Strong, 1984).

The literature suggests that in addition to family care, community care-giving was common in the past and there are examples of communities pulling together to look out for people experiencing cognitive decline (Lanting, et al., 2011). Some studies have documented situations where community members worked together to keep track of a senior with dementia who was prone to wandering (Graves, Easley, & Charles), 2004; Lanting, et al., 2011; Lombera & Butler, 2009; Sutherland, 2007). However, community structures may be changing and this type of response may be less common in the future. In fact, a significant theme in the literature related to Aboriginal family care-giving is the

impact of culture change on traditional family and community care-giving practices (Chapelski, Sobbeck, & Fisher, 2003; Graves, et al., 2004; Lanting, et al., 2011; Segal & Smith, 2004; Sutherland, 2007).

Although Aboriginal people are still commonly portrayed as living in large, extended family households, that is no longer the reality for many Aboriginal seniors and it is not unusual for seniors to be living alone (Buchignani & Armstrong-Esther, 1999). Changes to traditional family structures, large geographic distances between families, cultural change, and the effects of the residential school legacy and other historical trauma have all put pressure on traditional care-giving practices (Chapelski, et al., 2003; Habjan, et al., 2012; Lanting, et al., 2011). Although family care remains the preferred option, some families are unable to support their elders to the extent that may have been possible in the past. A grandmother's group in Saskatchewan identified that a "big change in culture" was having a significant impact on Cree seniors' health and changing the aging experience (Lanting, et al., 2011:109). Graves et al. (2004) have similarly indicated that a loss of language and cultural values has impacted the role of Alaska Native seniors. Despite these changes, which have led to a decrease in family care for the elderly, it is still recognized that optimal care for seniors is grounded in traditional values and beliefs (Segal & Smith, 2004).

Although informal family care is preferred by Aboriginal people and they report many rewards associated with care-giving, we must be careful not to assume they are free from the problems and stresses associated with caring for a cognitively impaired senior (Buchignani & Armstrong-Esther, 1999; Lori L. Jervis, et al., 2010). In fact, Aboriginal seniors with dementia have particularly complex care needs because they have higher levels of chronic illness and functional impairments and lower socio-economic status than non-Aboriginal Canadian seniors (Buchignani & Armstrong-Esther, 1999; Reading, 1999). These complex needs, coupled with barriers to dementia treatment and care including a lack of awareness of the condition, language barriers, travel, unavailability of local services and distrust of the western health care system (Buchignani & Armstrong-Esther, 1999; Cammer, 2006) may cause a higher level of strain to be experienced by Aboriginal caregivers. In addition, it has been documented that caregivers who provide dementia care experience higher care-giver burden than those who give care to someone with only physical impairments (John, Hennessey, & Roy, 1996).

It has been documented in the literature that Aboriginal caregivers experience diverse stresses when providing dementia care. Among these stresses are worry about the progression of the disease, role strain, financial stress, lack of knowledge about how to provide appropriate medical care, challenging psychosocial aspects of care, strains on family relationships and perceptions of negative effects on their personal health and well-being (Hennessey & John, 1996). They also experience anxiety about the quality of

care they are providing (Lori L. Jervis, et al., 2010; John, Hennessey, Dyeson, & Garrett, 2001) and, in some cases conflicting responsibilities that limit their ability to provide care (Hennessey & John, 1996). To cope with these stresses, Pueblo Indian caregivers reported drawing on cultural resources such as traditional beliefs, extended family, and spirituality (L. L. Jervis & Manson, 2002). Coping strategies also focused on acceptance and adaptation instead of control (Hennessey & John, 1995; L. L. Jervis & Manson, 2002).

Because care-giving can be extremely stressful, it is important to understand how Aboriginal people cope with stress. Iwasaki et al. (2005) have examined stress coping among Aboriginal people with diabetes. The model they developed focuses on Aboriginal peoples' knowledge and strengths. Interdependence and connectedness were identified as a key theme. Social support and having strong relationships were seen to facilitate healing and give people an opportunity to share the burden of their stresses (Iwasaki, et al., 2005). Spirituality and transcendence were also identified as an important stress coping mechanism. Spiritual practices such as smudging, praying, and participating in sweat lodges were described as healing (Iwasaki, et al., 2005). For Cree people, living a good, morally upright, life was an important component of healing (N. Adelson, 2000). Another aspect of effectively coping with stress was the facilitation of Aboriginal cultural identity. Maintaining and promoting identity in this way was perceived to help people cope with stressors in their lives. Continuing on with this theme, self-control, self-determination, and self-expression were described as important in Aboriginal models of stress coping (Iwasaki, et al., 2005). Rounding out the Aboriginal model of stress-coping, leisure, including participating in hobbies and activities and having time to oneself. Iwasaki and Bartlett (2006) describe culturally appropriate forms of leisure (dance, music, sport, art, and spiritual practices) as an avenue for building resilience. Laughter and humour were also seen to ease stress and help people to achieve wellness (Iwasaki, et al., 2005).

Despite the many challenges faced by Aboriginal caregivers, they also expressed satisfaction about their ability to provide care and reported positive aspects of care-giving including emotional rewards, developing better relationships with the care recipient, and seeing improvements in the person with dementia (Hennessey & John, 1996; Lori L. Jervis, et al., 2010). Other positive feelings about care emerged when caregivers developed effective care routines, mobilized assistance from other family members and obtained adequate respite (Hennessey & John, 1996). In order to improve on families' willingness and ability to provide care for seniors with dementia, more supports and interventions need to be developed that allow them a greater chance of achieving success in their care-giving efforts (John, et al., 2001).

We know that opportunities for education and training are underdeveloped in Aboriginal communities. Many families report that they have limited knowledge about how to provide care and that they use trial and error to devise effective care strategies

(Hennessy & John, 1996). These caregivers also express a desire for caregiver training, instruction on techniques for managing care, education about the expected course of the condition, support groups, enhanced care coordination, adult day care, and respite (Hennessy & John, 1996; Keightley, King, Jang, White, & Colantonio, 2011; Lomber & Butler, 2009). This is important because caregivers who are informed and have adequate support may be less prone towards elder abuse (Whitehouse, et al. 1993 in Jervis and Manson 2002). Further, informal care provided by family may reduce institutionalization (Buchignani & Armstrong-Esther, 1999).

A lack of knowledge of dementia, its symptoms and how to provide appropriate care may not be limited to informal family caregivers. Research has shown that nurses in remote northern communities do not perceive dementia to be a prominent issue and may have limited or outdated knowledge of the condition (Andrews, Morgan, & Stewart, 2010). This may be in part because of the focus on the treatment and prevention of more acute issues facing younger people in these communities (Andrews, et al., 2010). Combined with the lack of availability of formal programming for seniors (Buchignani & Armstrong-Esther, 1999) this lack of formal caregiver knowledge puts Aboriginal people at a significant disadvantage when attempting to seek or provide care for a person with dementia. A further issue relating to dementia care and support is Aboriginal peoples' resistance towards nursing homes (Lori L. Jervis, et al., 2010). Aboriginal caregivers have concerns about sending seniors with dementia to long term care facilities outside their communities because it causes a disruption of their familial duty and they feel that they can provide the same level of care themselves (Lomber & Butler, 2009).

However, in some cases people with dementia develop symptoms and behaviours that are very challenging to cope with or caregivers become too ill to provide care. In situations like this it becomes beneficial to have access to long term care such as supportive housing or nursing homes. Chapelski et al. (2003) suggest that there is a need for long term care facilities that are owned and managed by Aboriginal people and integrate intergenerational care, encourage families to be involved with care and incorporate cultural beliefs and practices. There is evidence that this can be an effective approach to care. A study by Brown and Gibbons (2008) showed an example where residents of an assisted living facility for American Indians reported less loneliness, more happiness and greater perceived social support than non-residents. This facility was structured to accommodate residents changing needs and respect their cultural values including social engagement, family time, and community involvement (C. M. Brown & Gibbons, 2008). It is clear that there is a great need for training and services for dementia care that are culturally grounded, supportive of traditional family care practices, and take a holistic approach to care that respects Aboriginal peoples culture and beliefs and help people to cope with the pressures that are impacting traditional care patterns. These themes also emerged from the data gathered on Manitoulin Island and will be discussed in depth below.

Results

Informal family care-giving

Interviews on Manitoulin Island revealed that informal family care is the preferred method of support for seniors with dementia. Family care-giving emerges naturally in First Nations contexts, as extended family care and support for older relatives is a cultural norm that is not dependent on the presence of dementia. Findings from interviews with informal family caregivers demonstrated what it is like for family members to provide care for a person with memory loss on a day-to-day basis. Although we did not explicitly ask people to describe a typical day of care-giving, their responses to other questions highlighted many aspects of what is necessary to support a family member with memory loss. This section portrays several aspects of the care-giving experience including who provides care, where care is provided, and what care entails.

In our sample, the majority of caregivers were spouses (4 wives, 1 husband) and adult children (4 daughters, 1 son). The remaining interview was with a niece and her husband who were caring for an aunt who did not have children of her own. Caregivers ranged in age from a daughter in her twenties to a wife in her eighties. They had been providing care for their relative from between 8 months and 10 years. The mean was 4.5 years. The majority of cases involved female caregivers caring for male care recipients.

Regular care-giving tasks included, but were not limited to, preparing meals, transferring the care recipient from a wheel chair to a chair or bed, bathing, changing diapers if the person was incontinent, dressing, assisting with personal hygiene, organizing medications, providing activities to keep the person entertained, accompanying the person on outings, and providing encouragement and social support. In addition to all of these tasks, many caregivers also had full or part-time jobs, attended school, were raising their own families, were involved in their communities, or had their own health issues to manage.

Care was most often provided in the home of the caregiver or the person with dementia. Some caregivers lived with the care recipient on a full-time basis; others lived-in part-time, rotating with other members of a family care team. Other caregivers lived nearby and provided care on an as-needed basis, by visiting the person with dementia or taking them out to run errands. Often, caregivers brought the person with dementia into their home when care needs increased. However, some family care providers moved into the care recipients' home. At the time interviews were conducted, three of six caregivers in UCCMM communities were spouses who lived with the person with dementia, and the remaining three included a niece and two daughters who did not live with the individual requiring care. In Wikwemikong, more caregivers lived with the

person with dementia. In fact, the sole caregiver (a daughter) who did not reside with her relative with dementia had only recently enrolled her mother in a nursing home after they had lived together for several years.

Living arrangements are fluid and often change based on need. Living with a relative, for example, is not always a permanent arrangement. At least one person with dementia mentioned that she had lived with a grandson for a time, but now lived alone. Another had previously lived with her niece and nephew, but had since moved to her own home. I encountered another family that had enrolled the person with dementia in a nursing home but pulled her out again because they were not happy with the services or with her living away from the family.

Family dynamics can play an important role in shaping who provides care for a person with dementia, and the level of support that families provide to one another can have a significant effect on the ability of caregivers to cope with the changing demands of the care-giving role. In many cases, family members worked together to provide dementia care. Some strategies worked and others did not. Often, one individual was faced with the vast majority of care-giving tasks even when others were available to provide additional support. Some individuals were the sole care provider and did not have assistance from others in the family. Spouses usually cared for one another but would receive occasional help from their adult children when needed.

I had to cancel my trip out west for October. I have to have someone stay here with him because I know he'll be wanting to make fire. That is the thing that worries me the most is going down the stairs, I don't know. The furthest I ever go is M'Chigeeng, you know, that is just a phone call away but to go any further than that, I can't. I think that, you know, I might have some kind of a break when [my son] moves back in December. That way he can bring the wood in and stuff like that, split, 'cause I just don't like the idea of him swinging that axe, like, he gets out of breath easy, eh, and that is when he starts you know getting his dizzy spells.(KP CG 02)

In other situations adult children or other extended family members would share care-giving duties.

I took care of my mom for that period of time and so did my brother. My other siblings did try to like, um, when she first came out, um, but they seen how hard it was and they seen how hard it was with her repeating her stories, um, they just found it difficult and they...she needed a lot of doctor's care so, um, um, her

medications, her appointments and all of that kind of stuff they just couldn't do it. So it ended up that I was the only care taker in the end and then I was burning out toward the end, but [Dr. Simpson] was the one again that made ah, um, the recommendation again for to go in and the nurse with long term care helped me to fill in the application for CCAC. It was supposed to be, initially it was suppose to be, um, what do you call that? Respite. As it turned out by the time respite came [laughter] I need her in there full time, yeah. (KP CG 01)

Families tended to work out amongst themselves who was best suited or most willing to step in and provide care based on their circumstances when the need for care arose. However, sometimes one person was left with no option but to take on care-giving because other family members were unwilling or unable to help. In some cases, disagreements or misunderstandings about the amount of care required and the division of responsibilities caused tension and conflict between family members. Although many family caregivers were uninformed about options for formal support, family care was often supplemented by assistance from personal support workers and in-home nursing services.

Reasons for providing care

Caregivers were asked why they took on the care-giving role. Almost all informants replied that it was because of their relationship to the person requiring care and a desire to support them in their time of need. Some informants elaborated on this and specifically mentioned a feeling of filial responsibility or reciprocity. For example, one daughter caring for her mother expressed that her mother had raised her and she felt that she should give back and provide for her in her time of need.

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

Another daughter mentioned that her parents had helped to raise her children so she could go to college. She felt that it was her responsibility to repay them for their help by caring for them as they aged.

Um, my mom took care of my kids while I was going to school, um, college. She supported me, um, I felt that it was my [turn] to take care of my parents when my dad took ill, um, so I took care

of both of them. My dad had Alzheimer's and, ah, I took, I quit my full time job, went into nursing, went into part time nursing, um, which gave me evening shifts so I was able to take them out, do their business, do their groceries, pay their bills and what not and when my dad passed on I, my mom told me it's time for somebody else to take care of her, take care of her, so I did that, I let family take care of her but in end it got hard for the family. (KP CG 01)

Spousal caregivers talked about their relationship with the care recipient, and spoke of the mutual support they provided one another throughout their lives.

'Cause he got real sick. 'Cause of he's got back injury and, uh, his nerves are so bad. So I have to watch all the time. He has his good days and his bad days. Today is a good day. (JP CG 06)

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

Well, I had to because he's my husband. (KP CG 05)

Some participants expressed that they provided care because there were no other options available. However, at least one caregiver countered this statement by expressing that she did not feel negatively about her lack of choice in the matter. It is clear that not all family members take on a care-giving role. Some individuals are unable to provide care because of conflicting demands in their lives (employment, child rearing, etc.) or because of large geographical distances separating families. In some cases, certain family members are unsuitable caregivers because of alcohol use and drug addictions. Further, the lingering effects of the residential school system have fractured traditional family structures and stressed traditional care-giving practices. These pressures will be discussed later in the context of care-giving challenges.

Onset of care-giving: Identification of a need for support

To best understand care-giving it is important to understand when people begin to notice that there is problem. What are the precipitating factors that cause people to realize that something is wrong with their relative? As was discussed in greater depth in the previous chapter, cultural understandings of memory loss and dementia can impact when, where and how people seek or provide care, diagnosis or treatment. First Nations caregivers on Manitoulin Island entered into care-giving for several reasons. Although all of the participants discussed here were providing care for a person with symptoms of

cognitive decline at the time of the interview, memory loss was not always the primary reason they began to provide care. When asked when they began to provide care, the majority of caregivers in our sample stated that it was another illness or injury that acted as a catalyst to the need for care and not dementia. Seven out of eleven caregivers indicated that diabetes, amputations, stroke, cancer, back injury, or heart surgery were the reason that they initiated care. One caregiver explained that the person with dementia had called them and asked for help. Only three caregivers gave dementia or Alzheimer's as the specific reason they had begun to act as a caregiver.

Although a care relationship usually arose because the older person requested assistance in some area or their life, or because they were experiencing some kind of health issue that required care, not all older people were receptive to accepting care from their family members. Many attempted to maintain their independence as much as they could and some denied that they needed assistance.

And I'm alone now, my hubby is gone and uh, so...and I don't mind it, I like being by myself, I'll have them saying, they ask me sometimes, you know, people are concerned about me staying alone, but I enjoyed it, I enjoy it. And I say to myself, nobody steps on my toes and I don't step on theirs (laughs) so that's the theory that I have in the back of my mind for...so I don't mind it. (JP PWD 01)

Often, family support began with small-scale assistance with activities such as transportation, grocery shopping or home maintenance. Few care relationships were initiated primarily because of symptoms of memory loss. However, recognition that an older relative was exhibiting signs of forgetfulness, repeating stories, having difficulty recognizing people, losing their sense of time, getting lost or disoriented in familiar locations, forgetting life events such as the passing of a spouse, neglecting hygiene and appearance, driving dangerously, leaving the stove on, or being unable to complete familiar tasks or hobbies often triggered a more significant care-giving relationship. These factors were sometimes noticed in conjunction with other health issues such as strong pain medications following an amputation, chemotherapy, or a stroke. In these cases, the memory loss was often linked to other health issues and not necessarily perceived as an issue in and of itself. When this was the case, the caregiver often expressed that they hoped it would improve over time, but that they started to get worried when time went by and the symptoms did not clear up. In several cases, informants mentioned that they originally attributed these behaviours to either another health issue or the natural aging process. Often it took a combination of many of these behaviours, a marked deterioration or change in the person experiencing symptoms, or a frightening episode for the caregiver to take action.

Care Strategies

Appropriate care strategies for a person with dementia were discussed with several kinds of participants in our study including seniors, people with dementia, and family caregivers. Peoples' perceptions of appropriate dementia care were shaped by their personal experiences with the condition. Those with the most insights into dementia care had generally encountered dementia within their own family or had worked in eldercare in some capacity. Seniors in particular had valuable insights into how care might best be provided to people with dementia. These perceptions likely reflect their own desires for their aging experience and how they might like to be treated if they experienced cognitive impairment. I found many seniors' comments about dementia care to be insightful and they were notably descriptive. Unfortunately, the interviews that were carried out with people with dementia did not reveal much data about their preferences of how they would like to be cared for. When the people with dementia in our sample spoke about treatment and care they usually said they felt they received generally good care from their doctors. However, they were much quicker to praise the care they received from PSWs and nurses. Nearly all of them mentioned the importance of their family in providing support. All of the strategies discussed below are examples of care practices devised by informal family caregivers or recommended by seniors.

Social Stimulation, Visiting and Communication

Social stimulation and visiting were considered to be a very important component of dementia care by all types of informants in our sample. Seniors spoke about the importance of social stimulation, visiting and communication. They talked about how important it was for a person with dementia to still feel that they had a purpose and were part of society and that it was important for others around them to create an environment that supported this. This sentiment strongly echoes the feelings that older people had about their own aging experience and the desire to maintain meaning and purpose in their lives. Caregivers also recognized that talking and listening to a person with dementia were important. These actions were perceived to combat loneliness and depression and to bring the person joy.

Like I say, sometimes all you have to do is listen to them and they feel better, I could say, even my they feel better and I don't, I don't, I could say, whatever they say I don't repeat it. If they have a little have personal complaints they tell me you know I, I don't repeat what they say and they know that they only sometimes it helps them sometimes it helps me for people to have confide in somebody they know they trust it helps to get their problems off their chest to somebody that's not going to say oh, that's what goes on over there. (KP SE 03)

Social activities that took place outside of the home, such as church or BINGO were also seen to be important because they were usually a positive experience and gave a person the chance to experience a change of scenery. Many informants recognized that people with dementia often did not have many opportunities to engage with others and that loneliness was a real problem.

A visit, take them, take them out if you can, move them out from the home to experience what's out there, like take them for a ride somewhere that they don't very often go, talk to them about different things, don't let them dwell on their loneliness or aloneness (laughs), that's what I'd do if I saw someone really in bad shape, I'd try and go get them out, take them. 'Cause I had worked with an older lady here, she was up, up, near 90 when she died, eh? Used to take her out to Meldrum Bay, we'd take a picnic lunch and take her to the lake over there and we'd sit down and have a picnic, which she really enjoyed. They like to get out when, when you take them somewhere. (JP SE 04)

Friendly visiting volunteers were seen as a simple solution to this problem that would have big impacts. Unfortunately, no such program or service currently exists in any of the communities in our sample. Although people with dementia do get visited by nurses and personal support workers, these individuals are not permitted as part of their job description to just sit and visit, which is sometimes what a person needs most. One of our senior participants suggested that she would be interested in visiting others in the capacity of a friendly visitor, but that she was unable to because of a lack of transportation.

There's not even somebody that would visit some of these people that uh, would talk to them, you know, and try to make them feel they're still part of the society, so they kind of maybe stay put and do their own thing. Now nobody to go tell them Ok, this is what is happening, this is what you should try to do or help them out. That's what they should have here, they should have somebody visit elders... I'd do a lot more, you know, I'd go and visit elders, I could go to the nursing home and visit people, you know I always think that I could do that kind of stuff, but then I don't have a car. (JP SE 03)

Friendly visiting is a low cost solution that could be organized using volunteers from the community. It may be valuable for communities to consider this option in more depth when devising care protocols for people with dementia.

Redirection

Another common care practice that was discussed in our interviews was redirection. Caregivers expressed that when the person they were caring for became agitated or distressed that they would try to change the subject or introduce a different activity to help the person to calm down.

Uh, we talk to her and we go and make her laugh and then we come home. (JP CG 04)

Just keep reminding her and um, if she's too moody, I'm just "Ok, I'll see you later" (both laugh) Go home, "I'm going to leave you be now" (JP CG 05)

These actions helped them to avoid conflict with the person with dementia and maintain harmony in their relationship.

I witnessed redirection being used in Wikwemikong by a daughter caring for her mother. She expressed to me that when they went on outings and returned to their house her mother would get distressed because she would not recognize where she was currently living as her home. She would get agitated and refuse to go inside, insisting repeatedly that she wanted to go home. The daughter expressed that initially she had tried to convince her mother that this was her home by explaining when and why they had moved there, but that this tended to cause more upset and agitation. Over time she developed a new strategy to get her mother into the house. When her mother said she wanted to go home, the daughter would agree with her, but just say that they had to stop in here first to visit a friend. She noted that often redirecting her mother's anxiety this way would be enough to convince her to go into the house and that once she was in the building she generally forgot that it was not the place she believed to be her home.

Another participant told me about a person with dementia she had seen in the nursing home who regularly got agitated and upset when caregivers woke her up or tried to put her to bed. This senior, who was at that time working in the nursing home, talked to the woman and found out that she was not sure where she was and was remembering things about her younger life at home, such as her responsibility to go fishing or care for the pigs. Once caregivers began to recognize this and work with the patient by allowing her to look out the door to say goodnight to the pigs before bed or by telling her she had to get up in the morning because it was time to go fishing she became more relaxed and easier to work with.

She wanted to get out, she wanted to go home, she wanted to go home and look she had she forgot about her little pigs, little pigs all of them all of them little pigs. I know one of them used

to tell her, “don’t worry about those little pigs. I already locked them up,” one of them will say that, “I already looked after your little pigs, I say don’t worry about them,” they say, “okay, now you should go to sleep,” they say and then she’d be okay. She [would] worry about her pigs, she would worry about her cat, she would worry about her dog, you know? Things like that, I could say, some of them used to wait to get along you have to go along with them (KP SE 03)

Another example of how this approach works was also given in relation to the same person with dementia.

I guess she wanted to go home, she wanted to go home, she didn’t want to go to sleep. I guess the worker took her out to the front door and the door, she opened the door. “Okay then [Shirley], go, go home then.” It was really windy, [Shirley] answered, “why don’t you close this door? You are making it very cold and windy in here.” You know, sometimes you got a laugh out of her, too. “Close the door, you better close the door,” and that was it. “Well, I think it’s time you go to sleep.” They brought her to bed put her to sleep. (KP SE 03)

It is apparent in both instances that this approach helped the person with dementia to calm down and feel more comfortable. Such a strategy is easy to teach and implement and may have benefits for informal family caregivers on Manitoulin Island.

Respect and Focus on Abilities

Seniors also believed that people should focus on the abilities of a person with dementia, and not on the things they were no longer capable of. This perception included the idea that a person’s remaining abilities should be accepted and that they should be supported in what they are still able to do.

So when he started to, when it was his turn to sing he, he was jumping 3 different songs, he was using 3 different songs. So I really looked at him, eh, he starts off with the song [and] while he’s singing that song he is jumping into another song and then he ends it with a different song. So I looked at him. Wow, I thought, and his voice wasn’t the same and, ah, you could tell he was struggling with that song and after a while I asked someone, “wow, is he forgetting his songs?” “Oh he’s getting old,” they said, so, but I notice there was still people dancing, no one

stopped dancing. They were still dancing and, ah, nobody went over there to tell him, "hey you can't sing anyway why don't you get out of here." No way, eh? I remember there was one song he used to sing and that was a real good song I think it was Saturday night he started to sing that song, wow. I'm going to go over there and there was 3 other guys that came and sat with, we sat with him, eh, so we sang the song and he laughed periodically the old man, "I forgot how it goes," he said, "I'm forgetting," he said. "Yah," I said. So Sunday he was kinda talking about that, he'll start them off and then he, he forgets how it goes along the way. "When something pops up I just keeps going with it," he said. Like in a pow wow setting I know they shouldn't be thrown out, but say I haven't seen anybody, like, say somebody [is] doing a pipe ceremony and then he forgets what he's doing, I don't think even that they would tell him to pack his stuff and leave. You feel sorry for them instead and you have mercy on them like with all of that stuff that they knew, eh, and then they are forgetting it. (KP SE 04)

In this example, the elder was permitted to continue in his role as a singer at the pow wow. The other participants accepted that he was having some trouble, but respected him enough to allow him to continue to have a meaningful role.

Seniors also spoke about the belief that people experiencing memory loss should be treated calmly and with respect, and that touch was important.

I will see ah the patient and they will make the sign of the cross. That's the way I approach them so they know, ah, that I am a deacon but the, you know, so it's ways that and I'll usually just go and touch them, ah, and say, how you're, how they feel, you know, ask them. So it's a very important part of, ah, touching is a very important part of, you know, that you need to praying, touching is a very important part of when you're going to visit them, you know, you hold hands. (KP SE 01)

One participant expressed that people around a person with dementia should be gentle with them and agree with them instead of pointing it out when they make mistakes.

Well I don't really know of anyone around here how they are cared for these days. People are just put in the nursing home, but there should be, there should be other ways they could be helped,

how they could be healed. Be comfortable is how I would say it [pause]. They should not be handled with anger those people who are poor [pause]. One should not think anything of when that person has done something wrong. You shouldn't say, "I didn't tell you this," after you have told them to do it this way but they are doing it a different way, "no not this way," "it's okay, thank you," is all that should be said. (KP SE 02)

The perspective that seniors should be treated gently and allowed to continue on in their roles is reflective of larger cultural values related to respect and acceptance.

Challenges and Caregiver Stress

Informal caregivers face many challenges and stresses when caring for a person with dementia. The stresses faced by caregivers are very well documented in the literature, which has focused to a large extent on caregiver burden and burnout. In this section I pinpoint several of the challenges and stresses that were identified by the family caregivers in our sample. All of these factors, coupled with the lack of time that caregivers have to rest and recuperate from the demands of providing care full time cause them a lot of stress. There are few supports such as respite or support groups available in Manitoulin First Nations communities to help to alleviate this stress. These services are greatly needed to prevent stressed caregivers from experiencing burnout and developing issues with their own physical or mental health.

Round-the-Clock Care

One of the most significant challenges faced by informal caregivers assisting a person with dementia is the constant nature of their care needs. Although the intensity of care required may vary from person to person and at different stages in the disease, most caregivers expressed that one of the most notable aspects of dementia care was the need to provide near-constant supervision.

Like he went himself one time like he went down the hill he usually go down there and smoke over there and stands there and wave at everybody [laughter]so when he was coming home he missed our street So he kept on going This is after um that nurse came to wash him And after that he wanted to go smoke outside and he took off so the that Mitch was still here and then I says where is he he was suppose to be out here smoking but he was nowhere and then he was ready to leave facing that way and then he says I don't see him no where so I have to pick up my jacket and it was cold at the time And I got my jacket tried to look

for him And he gave me a ride so we went over there so he wasn't nowhere so we went that way looking at the streets nowhere so we just kept on going so we catch up to him to Kodiak street down that way That's quite a ways So we brought him home walking real fast I think he was almost panicking or something so he didn't say anything He said he was just looking for our vehicle Yah so ever since so I brought him home so ever since I really watch even when he goes outside and sometimes during the night he wanted to smoke but I so I have to stay awake until he comes back in And I always have to wake up every movement that he makes to see if he's okay or he goes to the washroom comes back down. (KP CG 05)

Supervision was needed to prevent safety issues such as wandering, falling or burning things on the stove, as well as to keep the person comfortable and ensure that they were not hungry, thirsty or in need of assistance for personal hygiene.

Tiresome in the way that you don't get enough sleep because she does her toilet, ah, toilet there during the night sometimes. That's, you know, I don't know, I can be called five times a night sometimes, 6 times, but other than that, um, (clears throat) that's the hardest part, I guess, just trying to keep up with getting enough sleep. (laughs) Yeah. (JP CG 01)

Making sure the person with dementia was adequately supervised to prevent them from doing unsafe activities was an on-going challenge of dementia caregivers. Almost all caregivers in the sample expressed that they had dealt with some kind of safety concern while providing dementia care.

Caregivers have many concerns about caring for a person experiencing cognitive decline. One of their most significant worries is about the safety of the person with dementia. As discussed previously, dementia can cause many types of behaviours. Some of the concerns that caregivers had included worry about the person with dementia burning things on the stove, wandering into the woods or out onto the road, getting lost, not managing their health properly including doubling up on medications or forgetting to take them or diabetics not managing their sugar levels. Caregivers were also concerned about the nutritional status of people with dementia. They worried about them eating too much or too little or eating food that was improperly cooked or past its use-by date.

A person with dementia's needs occur throughout the day, but also during the night, which impacted the ability of caregivers to obtain adequate sleep. The twenty-four hour

a day care needs also mean that caregivers often had to sacrifice their free time and even activities that they enjoyed or carried out to maintain their own health and well-being. Family caregivers have to make many sacrifices in their own lives and may be balancing many roles and responsibilities including full or part-time employment, education, raising their children or managing their own health. As dementia progresses care demands increase and care can become a full-time 24 hour a day, seven day a week job. It can become more and more difficult for a caregiver to balance the needs of the care recipient with other responsibilities in their life. Additionally, caregivers often have little time to themselves to rest and recover and this can build up into burnout and the health of the caregiver can decline to the point that they are unable to provide care.

In addition to the demands of dementia care, family caregivers also often had to assist the person with dementia with other complex health needs such as managing diabetes or other health issues. On top of keeping the person with dementia safe and supporting them in their activities of daily living, caregivers reported doing basic wound care, managing medications, and monitoring other illnesses.

Unmet Needs and Access to Resources

Not having access to resources that can support efforts to provide good quality care can increase the challenges of care-giving. Caregivers in our sample referenced several areas in which they felt that their needs were not being met. These included: difficulties with transportation, a lack of hours of home care services, lack of availability of respite, inadequate knowledge of available services and how to access them, and a lack of social support and friendly visiting for the person with dementia.

Transportation, um, cause right now he has to travel, he has to travel in the village to see the nurse for that, eh? (KP CG 02)

Other problems that were mentioned include a lack of follow up from health care professionals (including traditional healers) and slow response time from housing committees in the communities to address issues such as ramps and hand rails needed for the safety of the person with dementia.

The [traditional healer] was over once, but, uh, she never come back again I believe, maybe she, maybe she, uh, she has to be invited, I don't know. (JP CG 01)

Some families also expressed that they were not receiving services because of community politics or having “the wrong last name”.

The medical transportation, um, used to be provided for her, to take her to her dialysis and her appointments, um,

unfortunately, um, due to politics and um, (deep sigh), jealousy I guess, I'm not sure um, like, what that would be but, um, services have been denied for her, um, just because of our family name, uh, like I said, a lot of it has to do with politics. (JP CG 03)

The lack of confidentiality and the ability to keep a diagnosis private was also a significant concern of many families. There is a need for a place where families feel that they can safely go for help that will maintain their privacy and confidentiality.

The one thing that would have benefited me and I should have I should have pursued it was, um, support group. I think that is what is needed because then you know there is somebody else out there. Maybe what I'm trying, okay, I came across that, this is what I did, how about trying that, you know? Like the different tools or techniques that is not on the information I received, you know, maybe there is something different, you know, and the support group would be, um, again, with native people, it would have been, it would have been good. If I had a support group, yeah, of native people, yeah. (KP CG 01)

Family caregivers also expressed a lack of biomedical knowledge about dementia. For example, one adult daughter expressed that after providing ten consecutive years of care, first for her father and then for her mother, both with Alzheimer's disease, she still had very little knowledge of the services and supports that were available and how to access them. This issue was discussed in the previous chapter in the context of diagnosis and help seeking, but also has implications for informal family care-giving.

The worry of what was coming next also caused a lot of anxiety for family members who were providing care.

At times I sit by myself and think you know what's in store? You know, how bad is it gonna get, what are going to be the symptoms to look for? How am I going to handle it cause I'm living here by myself with him and [pause] I mean, the doctor did tell us when he was first diagnosed that it will probably progress fast cause he got it at such a young age. (KP CG 04)

A lack of knowledge about the expected course of the disease and how to anticipate and plan for the future needs of the person with dementia were a significant concern.

Physical and Emotional Strain

Dementia caregivers face physical and emotional strain as a part of their care-giving experience. Common challenges include a lack of sleep from having to provide night time care and the physical challenges of lifting and transferring the person with dementia.

I injure myself periodically lifting her, but you know, uh, it's something that has to be done. (JP CG 01)

The stress of care-giving can also cause emotional strain. One caregiver worried that her husband would pass away since he slept late in the mornings, and another had trouble coping when her mother failed to recognize her.

Sometimes in the morning he doesn't get up till 10 and that scares me, I've got to go in there and see if he's still breathing. Knowing that's how his grandfather and his father passed on. (JP CG 02)

I came in one morning and went in and changed her, you know, did what I had to do and started her breakfast and I had a doctor's appointment so I had to leave and she started asking my dad "oh, where's that nice nurse that was in this morning?" She did not realize it was me, um, so that was, that was kind of a red flag for me and I thought, oh, you know, and it kind of hurt, you know, I don't want her to forget who I am. (JP CG 03)

Emotional strain can also be caused by anxiety about how the symptoms might progress, stress related to juggling conflicting demands, interpersonal struggles with the PWD or other family members related to care, or grieving the loss of the person with dementia as their condition deteriorates.

Caregivers also had trouble dealing with changes to the care recipient's personality or attitude. One caregiver struggled to explain to her mother why she needed care and that she could not just leave if she did not like where she was. She talked about how tiring it was to always have to repeat herself and tell her mother what she could and could not do.

She started taking off. She started leaving the house, ah, she went out toward outside the community, she did not know where she was, um, her sense of direction was right off, her suspiciousness of me was hard to take, her wanting to leave out of my care was hard to explain to her, that she couldn't. I tried to

explain to her I [was] trying to take care of her best interest and her health I guess repeating myself. I guess it's starting to getting tiring toward the end. (KP CG 01)

Additionally, many caregivers expressed that suspicion or combativeness were common behaviours and that constantly deflecting conflict and trying to disprove the suspicions of the person with dementia caused a lot of strain.

Coping

The ability of caregivers and people with dementia to cope with the challenges associated with the disease is shaped by many factors. Some coping ability is inherent to individuals and their personalities. However, the supports a person has available to them through family, culture, community, or formal services also play a significant role in their ability to cope. Here I consider both personal coping strategies including spirituality and humour and external coping mechanisms such as respite and support groups.

Three main themes emerged from the interview data about how caregivers coped with the stresses of care-giving. The most common two methods were very positive, spirituality and humour.

I think a lot of that has to do with our spirituality, you know. Like every day, for me anyways, I put my tobacco down and ask for guidance for that day to be strong. (JP CG 02)

No, I if I did not have my faith I wouldn't be able to cope with anything. I have a lot of faith, that's what keeps me going. (JP CG 06)

Individuals with traditional beliefs and those with Christian beliefs both used prayer to help them manage the challenges and to bring them peace of mind. Humour was also used as an outlet to relieve stress about dementia and dementia care.

No it's not really but ah we joke about it so it's ways to help us be in harmony (KP SE 01)

Humour is a very important part of First Nations culture and the Ojibwe language. Many caregivers laughed as they told stories about situations they had encountered with the person with dementia. Seniors often made light of situations in which they forgot something and jokes and light teasing were also used if someone around you was being forgetful.

Unfortunately, not all coping mechanisms are positive. One male caregiver in our sample talked about using alcohol as a means of coping with the stress of care-giving.

Yah, I love my beer. It helps, and I can go into drugs or but I don't take those I just stay to beer, because that's my coping mechanism, does that make sense? I know where I could get drugs but that is really going to fry my brain, as though my brain is not fried out already. (KP CG 03)

This caregiver recognized how stressed he was from caring for his parents and that he needed some sort of outlet. From this example it becomes especially clear that caregivers need a positive way to express their frustration and get some relief.

Coping is also influenced by formal services. Individuals who have access to support groups, medical care, respite, and other services have a better chance of coping with dementia than those who face it without support. It is hard to accurately measure the true impact of formal support from the interview data because so many people felt that they did not have adequate support to help them cope with their relative's cognitive decline. However, these individuals did recognize that it would be easier to cope if they had access to more hours of home care, regular respite, and training about what to expect and how to cope with symptoms and behaviours.

Strengths and Benefits

Although care-giving can be challenging and stressful, many of our informants spoke about positive gains that resulted from their care-giving experiences. Despite the strain that care-giving put on these individuals, they rarely expressed resentment of the person they were assisting. By contrast, family caregivers spoke warmly of how good it made them feel to be able to make life safer and easier for their family member who was experiencing memory loss.

It's just to see him have a good day would be reward enough to, like, to be himself even just a brief time during the day, you know? (KP CG 04)

Many people expressed that they were glad that they were able to have the time and capacity to provide care and that they felt that they experienced benefits from seeing their family member calm and happy. Many caregivers learned to celebrate the small successes, when their family member had a good day or was able to complete a task.

The rewards was taking care of my mom as long as I could. Um, you could see they say they go back in stages, eh, you should

have seen my teenage teeny bopper and her together. She was like a teenager all over again. It was like taking care of two teenagers and she would be nudging [Julia] there and they would be joking around and, you know, they were like the best of friends, eh, and then you could see my mom declining after that, eh, she moved out of that teenager stage then she moved into a more child like stage, um, and that is where I found it hard with her and my step son here, she'd hug him and she'd talk to him and you could see where she would going. She declined. The initial stage was where she was going way back, back on the farm probably when she was younger and then the teenager and then the child she was going backwards in her stages of what she remembers but I really enjoyed taking care of my mom in those 7 months in those 10 months that I've had her, um, I was glad to have her by my side, um, the sad part was seeing her go through that and the behaviours and her erratic behaviour that was hard on me. (KP CG 01)

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

There are also benefits to care provided by family for the care recipient. Seniors or people with dementia who had good support from family members expressed that they were grateful for the assistance they received.

And like I said, I have a, my aunt there, helped me a lot and she always take me here, take me there, you know "I'm going to Sudbury," you know, "you want to come with me?" and so, I, "Ok," just to get me out of the house, you know. (JP PWD 04)

Although participants did not often explicitly express the benefits of having family members provide them with care, it was clear that seniors appreciated having family present to assist them with transportation, home maintenance, or shopping. One individual mentioned that it was because of her family that she was able to identify that there was a problem with her memory. Those seniors or people with dementia who did

not have family support would usually mention that there was a lack of attention or visiting from their family. These individuals also appeared more worried about what would happen to them if they got sick or their dementia progressed. Participants with good family support seemed to feel more at ease about their future.

A further benefit of family care is intergenerational contact. Seniors who received care from their families were often exposed to their adult children, their grandchildren, and in some cases their great grandchildren. This exposure to other family members provided opportunities for socialization and stimulation. Participants who spoke of regular visits with family generally seemed happier and less lonely.

Formal Care-Giving

Although family care was the preferred approach to care, it is clear that not all people with dementia had adequate support and some people needed to rely on formal services to help them to cope with cognitive impairment.

Some of them don't have families. Some of them this is... we're [PSWs] the only ones they see. (JP FG 01)

On the whole, care workers such as nurses and personal support workers expressed a growing concern over declining amounts of family care and the level of strain that it puts on the health care system in their communities, which is already stretched beyond capacity in many ways.

I5: Well yeah, I would say so because, I mean, especially with one of ours, like we've got one that the family's been, we've been trying to have them involved right from the get go and it just seems, it's been such a struggle to get them on board with realizing the safety issues and the um, just the everyday logistics of doing things and somehow it's that well, you know, she's an elder, she needs the care so give her the care, and that's a big thing, it's like if they're an elder, well, you know what, you need to take care of our elders. And it's like that whole you need to take care of them, my mother is an elder, my father is an elder and you need to take care of them because that is what you are here to do.

I6: It's what you get paid to do.

I5: Yeah, basically (JP FG 02)

They noted that although there was the strong Aboriginal tradition of families taking care of their elders that this was changing and that many families now expected that this care would be provided by health care workers. Some families put immense pressure on home care workers to care for their family members but rarely stepped in themselves to help even though formal care is not available on evenings and weekends unless the family can afford to hire private nursing staff.

I: Well, and that can go either way too, like in the family, no, that's the nurses, that's the PSWs job.

I5: That is very frustrating.

I1: That is the biggest thing too, but uh...

I6: Unless the doctors actually diagnose them they won't accept that fact that uh...

I1: Not necessarily.

I6: that this is always going on, that we see it on a regular basis. And also with the PSWs because they have closer contact.

I5: But then it also can be that um, say, "that's the nurse's job"

I1: Yeah, or the PSWs, that's their job, we're not going to intervene or...

I5: It's like that's the...somehow our job.

I1: It's 24 hours too, it's not a 7 hour thing.

I5: They don't realize we're just there to assist, not...

I1: And then they get mad, they get frustrated and it's like "I want this, I want this, I want this," this is what you're paid for and it's like...care plan's done. (JP FG 02)

In some cases a person with dementia had little or no family support. In these situations, care would fall exclusively on in-home nurses or personal support workers. Care workers felt a great deal of strain in this situation since they were very aware of the high level of needs of the person with dementia, but were only able to provide care during designated hours, usually 8am-4pm, Monday to Friday. Evening and weekend care is virtually non-existent.

And I think the recognition too, from families, something they mentioned earlier is just the safety issues they, uh, you know, we're able to go in, provide safety checks throughout the week um, but the weekend we don't know if family is going to make that commitment. (JP FG 02)

In actuality, few care recipients would even be eligible for forty hours of care per week, let alone full-time, round-the-clock support. In between the care hours that these people were allotted, home care workers would often stop by for security checks just to make sure everything was alright, but this is just a stop-gap measure and is unlikely to do much in keeping a person with dementia safe in the long term, especially considering the tendency for people with dementia to become active during the night and with the long stretch of time between Friday evening and Monday morning.

This commentary by formal care workers contrasts the strong values expressed by informal caregivers about the importance of family care, and their descriptions of the care that they provided to their senior relatives. This may be reflective of the pressures that Aboriginal families face today as changing demographics, large geographical distances, disruptions in traditional family structure and conflicting demands draw First Nations families away from traditional practices related to eldercare.

R: So, do you guys work with any clients that have family members that are involved in their care?

I1: No.

I2: No.

I1: I had one with a family, a huge family, you know.

R: But no one was involved in their care?

I1: That's the sad part.

I2: Its left on your shoulders, you do it, that's your job. (JP FG 01)

I think family support could fall on either side of that. Yeah, some families are really good or some certain members are really good and then other families aren't so good and yeah, so that family support, we know it's really important but we don't know how it's going to roll out for that clients needs sometimes. (JP FG 03)

Formal care providers were also concerned about the safety issues that accompany dementia and were often stressed about what might happen to a person with dementia over the weekend or in the evenings when care workers were not there to provide assistance. Another issue here, especially in the earlier stages, or if a person had not been formally diagnosed (and even sometimes if they had) was getting family to take notice of the dangers and do something about it. Of course, many families worked very hard to ensure the safety of the PWD, but some families did not seem aware of the true magnitude of the issue and other families just were not involved at all. This issue was also discussed in Chapter Five as it has significant implications for identification of dementia, diagnosis, and help seeking as well as care-giving.

Lack of Biomedical Knowledge, Education and Training

A lack of knowledge of the disease, both what symptoms look like and how treatment and care might be accessed and provided is a significant issue that brings risks for the safety and well-being of caregivers and care recipients alike. A lack of knowledge of how to provide appropriate care is an issue for both informal and formal caregivers. In fact, personal support workers were generally frustrated with the lack of information they received regarding their clients' diagnosis and their needs and also by their inability to affect change in the person's life by communicating the need for diagnosis or other care from higher level health care professionals, especially physicians. Communication between members of care teams at different levels was observed to be better among UCCMM staff than in Wikwemikong.

One example of the challenges that can occur when formal caregivers lack training related to dementia care was discussed by a personal support worker in Wikwemikong. She has a client who often has aggressive outbursts, especially when her PSW attempts to prepare her for her bath and bathe her. The PSW approached me and asked if this type of behaviour was normal. We conversed about how the client might feel about being undressed and bathed by someone who she might not recognize. I tried to assure the PSW that this type of behaviour would not be unexpected for a person with dementia and that there might be ways to cope with it. However, the PSW said that she had never been trained to deal with these types of situations and that she became frightened and frustrated when her client behaved this way. The personal support worker told me that in these situations she often felt that she had no choice but to leave the client's home because she was so overwhelmed. Although personal support workers try their best to meet the needs of their clients using intuition and trial and error their lack of dementia-specific training often hinders them from providing high quality care.

It is clear that this type of situation is undesirable for many reasons. On the one hand, if a care worker is not trained on what types of behaviours to expect from a person with dementia and how to care for them, they may unwittingly provide care that

is insensitive, inappropriate, or even harmful to the client. In this case, for example, the client faced an extremely stressful situation every time it was bath day. Because the care worker did not have any strategies for how to approach the situation in a sensitive manner the client may have faced additional stress and anxiety. Further, because the client resisted the bath so adamantly it is possible that they did not receive their bath that week, additionally; the client was left alone in an agitated state which could be dangerous.

During my field work steps were being taken on Wikwemikong in particular to improve the training for personal support workers, though this did not relate specifically to dementia care. Upon my return visit in June 2013, it became apparent that there had been some improvements to PSW's knowledge of dementia and dementia care. Six PSWs from Wikwemikong attended my presentation. When I spoke to them afterward it was clear that they had received a significant amount of training regarding caring for people with dementia. These individuals expressed that they came to the presentation because they were interested in furthering this knowledge.

Nursing Homes

As discussed briefly earlier in this paper, alternatives to home care, especially those that involve supportive housing, are scarce on Manitoulin Island. There was a general resistance towards the idea of putting a person with dementia into a nursing home.

No, no. I'll care for as long as I can possibly. (JP CG 02)

I'm going to be here no matter what. No matter how hard it is for me, um, I'm not going to – and I told my dad that too, I said, worse comes to worse and I actually have to, you know, to move in here with my family um, that's something that we're willing to do because, um, I would never send my Mom to a home. You know, no matter how bad it gets, you know, we could all take turns caring for her, um, and I know, like, how difficult it can be, um, my uncle had Alzheimer's and there were times of, you know, going over to visit and um, and his wasn't like extreme, I would say, um, but it was scary. (JP CG 03)

However, some caregivers expressed that they had little choice but to put the care recipient into long term care when care demands became too much to handle. Other caregivers recognized that if the person they were caring for declined beyond a certain point that they might have to consider nursing home placement. This was often framed as an undesirable last resort.

If he gets to the point where he is harmful to himself or myself then I would probably consider something like [a nursing home] (KP CG 04)

R: Yah, would you ever consider moving into a nursing home?

I: Whenever he's not, um, later on he's so helpless or whatever...

R: Um hum

I: if I can't take care of him.

R: Physically?

I: Yah, but I want to keep him as much, as long, as I can. (KP CG 05)

Care workers also reported that their clients tended to avoid nursing homes unless some of the care demands became very challenging.

Yeah, I can think of one lady, she stayed until she was 93, and another gentleman he was uh, he was 82. But they do the best to keep them in the house as long as they can. Usually the big, the big deciding factors are the incontinence problems and uh, uh night activities, wandering away and things like that. (JP CW 06)

Other caregivers recognized that their own health may lead to them enrolling the care recipient in a nursing home.

R: And would you continue to care for him in your home if it got worse?

I: I don't think so.

R: So what alternative would you look for?

I: I would have to put him in the....hospital I guess.

R: Would you consider a long term care facility or a nursing home or something?

I: Mm hmm.

R: Yeah. And at what point would you find that that would be necessary?

I: When I couldn't look after him anymore.

R: Mm hmm. And when might that be? What types of things would make it too hard for you to care for him?

I: Oh, if I got sick. (JP CG 06)

R: Um hum. You think you'll continue to care for him in the home?

I: Yeah

R: Would you ever consider moving into a long term care?

I: Me?

R: Yeah, well him.

I: Him? Well gosh, I don't know about that probably not.

R: So never at any point?

I: Well if it has to, you know where I can't do it no more. (KP CG 02)

There was a small group of participants who perceived that there had been a shift in care practices and that people were being put in nursing homes more frequently. They expressed that some people no longer cared for their parents as they should.

Well, it's like nursing home...those people who get old they are put there, but before people cared for their parents until death. Now this doesn't happen anymore, like I could say they don't want to be bothered or take the time to provide what an elder would need. The people, the young people, but they could make a place for those who have Alzheimer's they could make a home for them or there could be education for those who care for the elderly it is different way of taking care of them. (KP SE 02)

Although few other people expressed a concern that more people were being put into nursing homes, it is apparent that this is a reality for some.

There are several reasons why Aboriginal caregivers prefer to avoid nursing homes. Part of the resistance relates to the location of nursing homes. Very few nursing homes are located on reserve. Especially in rural and remote communities nursing homes can be far away, out of home communities, and hard for families to visit.

'Cause there's no, there's the only long term care nursing home is in Wiky, it's closed and then the other ones aren't on First Nations, so you're taking them away from their family, their culture, everything. (JP CW 07)

I observed the challenges of this first hand when I drove a senior from her home in Wikwemikong to visit her father in the nursing home in Gore Bay. She mentioned that it had been months since she had been able to visit her father because of a lack of transportation.

There are also concerns about the cultural appropriateness of nursing homes and that the care recipient will not get access to traditional foods or nature. People have negative perceptions of nursing homes and feel that it is not right to send their family member away. There is the perception that people decline or die faster in the nursing home and that they are not treated well there. Further, the institutional atmosphere of nursing homes may be reminiscent of residential schools which may contribute to the resistance many Aboriginal families have to using them. Families may fear that their loved one will be re-traumatized in that environment. For example, one informant spoke of how her mother had spent time in the hospital for TB when she was younger and that was a negative experience. She worried that enrolling her mother in a nursing home might bring those negative feelings back to the surface.

Cultural Safety

Questions about the importance of cultural safety in dementia care elicited many responses. Among the most important were language and communication. Language was perceived by families and care workers alike as a very important component in best care practices for people with dementia. Care workers who spoke the language found it easier to build rapport and trust with clients and clients often expressed that they found it beneficial to have a support worker who could communicate in their Aboriginal language, especially when it was their first language. Some care workers who did not speak Ojibwe expressed that even showing a willingness to learn and to try and to use Ojibwe words they were comfortable with was well received by their clients. However, it was also noted that many care workers today do not speak the language, even if they are First Nations. The need for trained Native language speakers was recognized, as was

the need for support groups and educational materials that better reflect First Nations people and their language. Materials in the language for prevention, diagnosis, treatment, care and support were all considered to be important.

Another factor that was considered to be significant was taking things slow and proceeding with respect at a pace the clients were comfortable with. Care workers in particular discussed the need to take the time to build trust and rapport and recognized that this could be a slow process. They had learned that it was better not to rush their Aboriginal clients and to take the time to listen to their stories. Compassion was also considered to be an important trait and this was something that care recipients and their families often expressed that they appreciated a lot. These factors relating to care are similar to issues that have been identified relating to assessment and diagnosis in Chapter 5.

There are other ways that cultural safety plays into dementia care. For instance, some participants expressed that seniors in their community sometimes have trouble explaining their symptoms to a doctor. There was also an example related to the willingness or ability of First Nations clients, particularly seniors, to explain any traditional medicines they might be taking to their doctor.

Interpretation

Throughout this chapter I have highlighted the experiences of informal and formal dementia caregivers on Manitoulin Island. I have also presented seniors' perspectives of appropriate care for people experiencing cognitive decline. The dominant care pattern for First Nations people with dementia is informal family care provided in the home by a female relative. Care is usually provided by one primary caregiver and supplemented by support from other family members, community members, or formal services including home-care nursing and personal support workers. Informal caregivers provide care ranging from occasional assistance with activities of daily living to round-the-clock care that encompasses everything from feeding to dressing to emotional support.

Participants expressed that family and community care are consistent with traditional beliefs surrounding reciprocity, support, and respect for seniors whereby families have a filial responsibility to care for relatives as they age. Within this tradition, family members expect that they will provide support for older people in their lives as the need arises. This is consistent with the care-giving practices of other North American Aboriginal groups as documented in the literature (Hennessy & John, 1996; Lori L. Jervis, et al., 2010; L. L. Jervis & Manson, 2002). The commonly held perspective that aging is a natural part of the lifecycle and that older people may experience a second childhood or return to infancy and thus require extra support is also a part of the dominant First Nations worldview. Participants expressed that it was natural for seniors to need

support as they grow older. However, a senior who is experiencing dementia requires significantly different care than a senior who is experiencing a “normal” and expected aging trajectory. This quickly became apparent to participants who were coping with a family member with dementia, especially in the moderate and late stages of the condition.

Research with mainstream seniors has demonstrated many benefits to care recipients of being cared for at home including delayed enrollment in nursing homes, slower decline and longer life expectancy (McClendon et al. 2004; McClendon et al. 2006; Mittleman et al. 2006). In addition, informal family care can reduce pressure on already overstrained local health care systems. I observed that a family care model had many strengths and that there were benefits to this approach to care for both the person with dementia and their family members. Benefits that relate to family care include that people with dementia have more access to emotional support and cognitive stimulation and benefit from being cared for by people who know their interests and history. Additional benefits include more culturally appropriate care that reflects the language and beliefs of the care recipient, helps maintain continuity in families, and provides the opportunity for older adults to have a meaningful role that respects traditional values of teaching and passing on knowledge, which can benefit both older people and younger generations. The preference for family care over nursing home care is another strength of the caregivers I interviewed.

Family caregivers who were interviewed for this project expressed that there were rewards to providing care for a loved one with dementia, such as improved relationships and a feeling good about being able to help. However, there were also challenges and stresses that significantly impacted their lives. Care for a person with dementia involves coping with potentially extreme behaviours including forgetfulness, repetitiveness, suspicion, anxiety, personality changes, and aggressiveness. In addition, there are increased safety concerns since forgetfulness can lead to burning things on the stove, mismanagement of medications, and wandering. As the disease progresses, people with dementia may lose the capacity to carry out normal activities of daily living including feeding, dressing, and toileting themselves and may also develop issues related to mobility, continence, and communication. To complicate matters, each individual experiences dementia differently and it can be hard to predict which symptoms they will develop and how quickly they may deteriorate. All of these factors have significant implications for caregivers in their attempts to support a person with dementia.

The physical and emotional demands of care-giving can take their toll, and caregiver stress and burnout have been well documented in the published literature (Alspaugh, et al., 1999; Alzheimer Society, 2010; Dunkin & Anderson-Hanley, 1998). Caregivers in my research expressed several aspects of care-giving that make them feel physically and emotionally strained. I found that although many caregivers spoke of the positive

aspects of care-giving, there was evidence that the challenges of caring for a person with dementia, with or without co-morbid health issues, did have some adverse effects. The need to provide constant supervision, limited support, conflicting demands, and uncertainty about how the disease might progress can all contribute to negative outcomes. Some caregivers in our sample pointed to injuries, increased symptoms of other medical problems and a lack of sleep as the health impacts of care-giving. Another referenced high levels of emotional stress that were difficult to deal with, and described turning to alcohol. The stresses of care-giving are known to have possible adverse effects on the physical and mental health of caregivers including increased rates of depression, family stress, and even caregiver death (Belle et al., 2006; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999).

First Nations caregivers may be additionally burdened since the seniors they are caring for are more likely to have multiple co-morbid health conditions and they are less likely to have access to adequate and culturally relevant formal supports including education and training (Buchignani & Armstrong-Esther, 1999). This was very evident in our sample. The majority of caregivers were caring for a person who was experiencing dementia symptoms as well as coping with another illness or injury such as diabetes-related amputations, heart disease or cancer. They were also attempting to overcome challenges such as inadequate formal training related to the care they were providing and a lack of formal supports and services.

Family care for elders is an Aboriginal tradition, but contemporary pressures and demographic changes are putting pressure on this practice. Factors that are influencing dementia care and drawing families away from more traditional care patterns include the shift from extended to nuclear families, large geographical distances between family members, more women working outside the home, substance abuse problems in families, and the on-going impacts of residential schools and out-adoptions which have fractured traditional family structures. This has created a shift in the expectations families have for giving and receiving care. Although eldercare is traditionally a family responsibility, dementia is an emerging problem and there is not necessarily a precedent for dementia care. Care for a senior with dementia is much more challenging than care for a senior who has only physical health concerns. A lack of knowledge of the disease and how to care for the person experiencing symptoms may lead to shame, stigma and fear.

Ensuring that caregivers are well informed about optimal strategies for caring for a person with dementia is very important for the well-being of formal and informal caregivers alike. Education and training have many benefits. First, they can take the guesswork out of caring for a person with dementia. As some of our participants mentioned, they figured out how to provide care using trial and error. Although many of them ultimately came up with strategies that worked, there were some false starts

along the way, efforts that did not work or that did not have the desired effect. Ineffective care strategies can increase the strain on both care givers and care recipients. For care recipients, it can lead to increased anxiety, agitation, and behaviours. This, in turn, can negatively impact the caregiver who has to manage these responses. If the person with dementia is agitated, they may be more difficult to care for which can increase the challenges faced by the caregiver, and the cycle reinforces itself, as a caregiver who is exhausted and frustrated is unable to provide optimal care. Frustrated and exhausted family caregivers are more likely to raise their voices, handle the care recipient roughly, make threats, and generally provide a poorer quality of care (Williamson, et al., 2001) as well as experiencing more negative outcomes to their own health and well-being (Hepburn, Tornatore, Center, & Ostwald, 2001).

Education and training are important tools in combating the challenges associated with care-giving. Education can reduce the anxiety that caregivers have about the progression of the disease because people can be trained on what to expect, and how to cope with specific symptoms and behaviours along the way (Schulz et al., 2002). There were several participants in this study who would very clearly benefit from caregiver training as part of their care-giving journey. This was apparent in both formal and informal care-giving context. One example of this was the PSW whose client became aggressive whenever she attempted to prepare her for a bath. If this PSW had a better understanding of dementia and how to manage behaviours she may have been more successful in bathing her client. Training in how to cope with dementia-related behaviours would likely have made her feel more confident in her skills and reduced her stress level. Increased confidence and high efficacy in managing difficult behaviours can reduce the risk of caregivers/care workers developing depression (Glueckauf, Stine, Bourgeois, Pomidor, & Rom, 2005).

There is an extensive literature about interventions for caregivers of people with dementia. These include psychosocial approaches, role training, cognitive-behavioural therapy, and many other strategies (Glueckauf, et al., 2005; Hepburn, et al., 2001; Schulz, et al., 2002). Caregiver intervention studies have repeatedly demonstrated that these interventions are associated with positive outcomes including increased service utilization, delayed institutionalization of the person with dementia, reduced adverse psychiatric symptoms, reduction of depression, greater mastery of care-giving skills, and increased quality of life (Hepburn, et al., 2001; Schulz, et al., 2002). The proven benefits of caregiver interventions reflect many of the needs and values of participants in my research. Health care providers identified a need for community members to seek health services, especially for diagnosis. Further, family caregivers expressed a lack of knowledge of services that were available, meaning that they often were not accessing them. Further, there was a strong desire to avoid institutionalization, which is proven outcome of caregiver training interventions.

It has been shown that the most effective caregiver interventions have multiple approaches, are targeted to the specific needs and situations of caregivers, and are fairly intensive (M. S. Mittleman, Ferris, Shulman, Steinberg, & Levin, 1996). Although stand-alone interventions can be effective, the optimal approach is to have caregiver education and training available as part of a comprehensive system encompassing multiple services and supports for both the caregiver and the care recipient (Ostwald, et al., 1999). Further research needs to be done to determine the training needs of First Nations people and to develop a culturally safe program of caregiver and care worker training. If such a program were devised, it would be important that it be coupled with other supportive services. It has been demonstrated in the literature that when caregiver training programs are coupled with other supports, such as respite or care partnerships with other family members and trained professionals, they have the potential to greatly reduce the burdens associated with dementia care-giving and to enhance the quality of life of both caregiver and care recipient (Brodaty, Green, & Koschera, 2003; Brodaty, Roberts, & Peters, 1994; Doody, Stevens, & Beck, 2001; Ducharme et al., 2011). Further, caregivers who are well-informed and have access to the supports they need may be less prone towards elder abuse (Whitehouse, et al. 1993 in Jervis and Manson 2002) and caregiver training has been shown to reduce or delay institutionalization (M. S. Mittleman, et al., 2006; Schulz, et al., 2002).

Although no caregiver intervention studies to date have been carried out with Aboriginal peoples, there is evidence that interventions such as role training and cognitive behavioural therapy are effective across diverse cultural groups (Belle, et al., 2006). More research is required to determine the types of interventions that would be most effective in supporting First Nations family caregivers. However, it seems likely that educational programming that explains the disease and its progression and suggests strategies for coping with dementia-related behaviours would be a good starting point and would have some benefits to informal caregivers. A similar educational program for home-care workers would also be useful. Building resilience and capacity for dementia caregivers could be achieved in a number of ways. In addition to education about the disease and training related to care-giving strategies, caregivers should be given tools to help them care for themselves and protect their own well-being. Culturally appropriate stress-coping mechanisms, such as those discussed by Iwasaki et al. (2005) relating to diabetes would also be useful in helping First Nations families cope with the strains related to dementia care-giving. Indeed, participants referenced that spirituality and humour were strategies that they regularly used to help them to cope. Finding ways to support caregivers (and people with dementia) to promote and maintain their identity, exert control over their lives and health care, and engage in leisure activities would also be appropriate in helping them to cope with the stresses of dementia (Iwasaki, et al., 2005).

Designing interventions for First Nations families on Manitoulin Island may prove to be challenging due to constrained service availability, large geographic distances, and a lack of formal care provider knowledge of optimal dementia care strategies. However, research in other rural areas has shown that telephone-based interventions have equal or greater benefits than face-to-face interventions, so that may be an option to consider (Glueckauf, et al., 2005). What is important is that any attempt to design an intervention strives to meet the needs of the target population. In a First Nations context, this involves a consideration of language, culture, and spiritual beliefs to ensure adequate cultural safety. Our participants consistently indicated that family care-giving is the preferred mode of care for people with dementia and that they preferred to avoid nursing home placement as much as possible. Since we know that caregiver interventions can delay or prevent institutionalization (McClendon, et al., 2004, 2006; M. S. Mittleman, et al., 2006) it seems likely that this kind of intervention would be well suited for use in an Aboriginal context and would help to support their care goals.

Although it is crucial to consider the health and well-being of the caregiver when considering interventions, we must be careful not to lose sight of the needs and desires of the care recipient. A key area to consider in relation to the design of care strategies is the desires that seniors have expressed that they have for their own old age. People with dementia often face challenges related to autonomy and maintaining a purpose in their lives. There are barriers that prevent these individuals from engaging fully with others around them and the activities that they enjoy. A crucial role of the caregiver is their ability to facilitate and enable the person with dementia to maintain the activities and relationships they take pleasure in. Seniors in our sample consistently expressed that they desire to stay active, engaged, and maintain a purpose in their lives. The seniors I interviewed disclosed that they want to maintain a degree of independence, continue to participate in activities they enjoy, and stay socially engaged. In all likelihood, these desires would remain even if they developed dementia.

The reason why it was so important for me to investigate successful aging in the beginning of the thesis relates directly to care-giving outcomes. Caregivers usually intended to keep the care recipient as safe and healthy as possible. Further, they often make an effort to support the care recipient in having a high quality of life. Family caregivers are especially poised to do this because they understand the full context of the life of the person with dementia. They know their histories, their fears, the things they enjoy, the foods they like, and all the other little quirks of their personalities. They can use this information to help the person with dementia to maintain as much normalcy in their life as possible. This is one of the reasons why family care is so much more beneficial than institutionalized care where staff has little time to get to know much about the patient and their history. However, many of the benefits of family care may be counteracted if family caregivers do not know how to provide appropriate care.

There is evidence from interviews with formal caregivers that cultural change and other factors are eroding the family care approach to care for seniors on Manitoulin Island. The literature similarly indicates that family care may be on the decline because of changes to traditional family structures, large geographic distances between families, cultural change, and the effects of the residential school legacy and other historical trauma (Chapelski, et al., 2003; Habjan, et al., 2012; Lanting, et al., 2011). Although family care remains the preferred option among people in my sample, some families are unable to support their elders to the extent that may have been possible in the past when it was more common for extended families to reside together. Although family members strongly agree that family care is the optimal choice for dementia care, we know that there are seniors living in the community who lack support and rely on formal services to keep them safe.

Canadian health policy is shifting towards a model more focused on home care for seniors, shifting the responsibility for eldercare off the government and on to families (Parrack & Joseph, 2007). This is happening at a time when families are facing many conflicting demands that often do not allow them to take on a full-time care-giving role. Aboriginal families today are often more fragmented and separated by large geographical distances as younger generations leave the reserve to seek economic opportunities. Women, the most frequent providers of eldercare, are also more involved in the workforce than they were in the past. The number of seniors in Aboriginal communities is on the rise, yet the number of available caregivers is shrinking (Habjan, et al., 2012; Parrack & Joseph, 2007). As this demographic shift occurs it will be increasingly important to ensure that there is policy in place to protect the needs of this vulnerable segment of the population and that adequate services and supports are available to ensure that seniors receive the care they need.

There are several conflicting factors at work in Aboriginal communities today. First, the desire to avoid nursing homes and keep people with dementia in the home to be cared for; second, the pressures that are making home care less feasible for many families and leaving them few options but to consider nursing home placement; third, the shift in government perceptions of who is responsible for seniors. How can these be reconciled? Culturally relevant formal supports that can assist families to continue to provide care in the home are needed. Participants in this research expressed many services that would be useful to them including adult day programs, increased respite, support groups, and more hours of home care. However, there is also a need for better care and support options for situations where the person with dementia has deteriorated beyond the point that families can manage their care or for individuals who lack the family support to stay in their homes unassisted. Supportive housing that offers a range of levels of care is one option. Although First Nations people prefer not to use nursing homes, there are situations where there is little choice but to rely on this type of facility. Some research in the United States has shown that nursing homes can be better

designed to reflect the needs of Aboriginal peoples and that there is a need for more facilities that are tribally owned and run (Chapelski, et al., 2003). There is also evidence that facilities that are structured to accommodate Aboriginal values such as social engagement, family, and community involvement can be beneficial to seniors in need of long term care and can increase happiness and perceived social support and reduce loneliness (C. M. Brown & Gibbons, 2008).

The need for increased support was a strong theme in my interviews with informal as well as formal caregivers. Family members and formal care providers need more education relating to dementia and its progression. They also require training about coping with specific behaviours such as wandering, aggression, repetition, and safety. In addition to this education and training, family caregivers also require support and opportunities for respite and stress reduction. Home care nursing and PSW support are recognized to be extremely helpful, but caregivers repeatedly expressed that they needed more opportunities to have some time for themselves to maintain their health and emotional resilience. Culturally appropriate support groups, increased hours of respite, access to evening, weekend, and overnight care, and dementia-specific programming for people with dementia were all desired and would have a positive impact for caregivers and care recipients if implemented.

Conclusions

This chapter examined many aspects of dementia care-giving among First Nations people on Manitoulin Island. Interviews with people with dementia, family caregivers and healthy seniors all indicated that informal family care provided in the home is the preference for caring for people experiencing cognitive decline. There are many benefits to in-home care provided by family, but there are also many pressures that are limiting the ability of families to provide this care to the same degree that they may have in the past. Changing demographics are threatening families' ability to care for seniors as they were cared for traditionally. The impacts of these changes have been noted by formal care workers who have raised concern about seniors with dementia living alone and lacking support. Just as culture change may be impacting the incidence of dementia, so too is it influencing when, why and how people provide care.

Formal and informal caregivers on Manitoulin Island need more education and training related to dementia. More culturally relevant services and supports need to be developed if we hope to ensure that adequate and appropriate care is available for people with dementia. Training for caregivers about dementia and how it progresses and strategies for coping with symptoms and behaviours are needed to ensure that care recipients are treated respectfully and that their personhood is preserved. Training for informal caregivers has also been shown to be effective in improving the care-giving

experience for family members who are providing care. In conjunction with caregiver training, culturally appropriate supports such as respite, adult day care, and supportive groups are needed to support First Nations peoples' goals of keeping people out of nursing homes and to provide high quality support for caregivers and care recipients alike so that they have a more positive experience with dementia.

Chapter 7: Conclusions

Introduction

The goal of my PhD research was to better understand First Nations peoples' lived experiences of aging and dementia. At the beginning of this thesis I set out to explore the perspectives of First Nations people on Manitoulin Island relating to successful aging, understandings of dementia, practices surrounding the detection of this condition, and treatment and care of people experiencing age-related cognitive decline. This was an ethnographic study that used a community-based participatory action approach that involved community stakeholders in all aspects of the research design, data collection, and dissemination. I took a phenomenological approach to data analysis, focusing on participants' lived experiences with aging and age-related cognitive decline.

This research provides an important contribution to the study of aging and dementia because there is little published literature that reflects First Nations peoples' cultural understandings of aging and dementia. This is significant not only because it contributes to an often overlooked aspect of dementia in the academic literature, but also because Aboriginal communities have identified a need for this research. There is a lack of understanding of First Nations peoples' lived experiences with aging and cognitive decline, including the factors they perceive to impede them from achieving a successful old age and their challenges in coping with dementia. This research contributed a multifaceted analysis of the impacts of dementia in Manitoulin First Nations communities including a discussion of why understanding and promoting successful and healthy aging is so important in the study of dementia and its potential to be used to shape policy and programming relating to aging and dementia in First Nations communities.

Research Questions and Approach

In the introduction to this thesis I set out to answer seven main questions. These questions were: How does culture shape aging and the specific experience of dementia? What does it mean to be and become old in contemporary First Nations communities? What constitutes "successful" and healthy aging for First Nations seniors on Manitoulin Island? How are Alzheimer's disease and dementia identified and explained? When, where, and how do First Nations people seek help for dementia? How are people with dementia cared for in First Nations communities? What are the unique needs of First Nations patients relating to ADRD treatment and care? What culturally appropriate care strategies can/need be developed for this population to be integrated with existing

services and improve the dementia experience for both caregivers and people with dementia?

To answer these questions, I carried out interviews and focus groups with 59 individuals who lived or worked in First Nations communities on Manitoulin Island. These included people with dementia, family caregivers, seniors, health care workers, and traditional healers. These interviews produced rich data which I analyzed using a hermeneutic phenomenological approach with the goal of presenting a holistic representation of the lived experiences of aging and dementia that considered multiple influences over the life course. The remainder of this chapter contains a summary of the findings of this research, a discussion of larger themes that cut across the four key chapters. This chapter concludes with a discussion of the possible limitations of this project and recommend possible areas for future research.

Discussion of Research Findings

The four main body chapters of this thesis examine four significant topics related to aging and dementia that I sought to better understand from the outset of this research project. These include perceptions of successful aging, understandings of dementia, diagnosis and treatment, and care-giving. I chose these four areas as the primary chapters of my thesis because each of them has distinct and important implications for understanding the lived experience of First Nations individuals, families and communities coping with Alzheimer's disease and dementia. In this concluding chapter, I summarize my key findings and discuss some of the major themes that cross-cut these four topics. Here, I ponder the implications of this new knowledge about experiences of aging and dementia for the development of community interventions to help people to cope with the impacts of this disease.

There are two common portrayals of Aboriginal seniors in the academic literature, one is of Elders who are repositories of cultural and linguistic knowledge, who are highly respected in their communities (Assembly of First Nations, 2007; Yee, 1990); the other is of seniors who are poor, lack education, and are suffering from multiple co-morbid health issues (N. Adelson, 2005; Cooke, et al., 2008; Reading, 1999). Although both of these portrayals represent some Aboriginal seniors, neither does justice to the diversity of their lived experiences or their desires related to aging. In this research, I gave seniors an opportunity to voice their opinion about what it means to be and become old in contemporary First Nations communities, what factors influence a person's ability to age successfully, and how culture shapes their aging experience. The interviews I conducted with seniors produced extremely rich data that paint a much more complete picture of the experiences of contemporary First Nations seniors than I encountered in the literature.

Understanding experiences with aging at a basic level, what seniors desire in their old age, and the barriers and enablers that influence peoples' aging experience provide important context for understanding experiences of dementia. This data helps us to understand what is at stake for a senior if they lose their memory and can also act as a proxy for culturally appropriate understandings of personhood and quality of life. By this, I mean that if we know what a person values as part of their aging experience we can better determine what their needs might be. In the case of dementia, we can assume that a person with dementia has values similar to those of other seniors and can strive to provide care that supports these values even if a person has altered abilities caused by cognitive impairment. I will discuss this idea again later in relation to care-giving.

Senior participants expressed that aging is a time of changing roles and status in their families and communities. They expressed that it was common to shift from a focus on physical tasks and activities to a role more centered around teaching and passing on knowledge as they grew older. Seniors discussed the importance of interaction with their families as they aged, especially contact with their grandchildren. Interactions with family were important to them not only because their adult children often provided them with support if it was required, but also because they got joy out of the social interactions and opportunities to share knowledge and advice. Seniors expressed that there were several advantages to growing older including leisure time to spend however they pleased, increased freedom, respect, and opportunities to become involved in new activities. However, they also mentioned that there were challenges associated with growing older such as declining health and changing abilities.

Key to the idea of successful aging, according to my participants, is active engagement in life across biological, psychological, behavioural, and socio-cultural spheres. Biological factors that influence successful aging relate to physical and cognitive health. Health was considered to be important because being frail or ill could impede a person from engaging in activities of daily living and other areas of life that they enjoyed. Changing physical and cognitive abilities were understood to shape a person's aging experience in that good health allowed them to continue to do things independently, whereas poor health might restrict a person's ability to engage in life as much as they wanted to. However, acceptance of and adaptation to changing health and abilities was considered to be much more significant than health issues themselves for defining a person as successfully aged. That is to say that a person who was quite ill could still be perceived to be a successful ager so long as they made efforts to continue to participate in life to the fullest degree that their abilities allowed.

Participants in this research expressed a holistic perception of health focused on well-being in physical, mental, emotional and spiritual spheres. Healthy aging, in particular, was perceived to be characterized not by a lack of illness, but instead by an

active engagement with life, a positive attitude and a willingness to accept and adapt to changes in health and abilities. This perception parallels a broader understanding of health held by Aboriginal people where, “health is viewed as a state of well-being, not the absence of illness” (Martin-Hill, 2009). It is also consistent with understandings of healthy aging in other Aboriginal groups where adaptability, willingness to transmit cultural knowledge to younger generations, and continued contributions to community life are valued as indicators of aging well (Abonyi & Favel, 2012; Collings, 2001; Lewis, 2009).

Attitude, adaptability, autonomy and control also emerged as very significant themes. I believe this is because together, they had the power to influence almost all of the other themes across the biological, behavioural, and socio-cultural spheres. If a person had a positive attitude and a willingness to engage in activities, and to adapt to the changing circumstances in their life and if they had enough autonomy and control to influence their ability to act on those desires then they were in a very good position to enjoy a successful old age. This is because attitude often shapes behaviour, and those who had a positive outlook and perceived that aging could be a positive time in their lives were more likely to engage in the types of behaviours that helped them to ensure that they would achieve a successful old age such as seeking out cognitive and social stimulation, getting physical exercise, avoiding smoking and alcohol consumption, and making efforts to eat well. The importance of autonomy, control and adaptability are well documented in the mainstream literature to have positive impacts on cognitive, psychological, and physical outcomes (Brandtstadter & Baltes-Gotz, 1990; Langer & Rodin, 1976; Rowe & Kahn, 1987). Of course, attitude alone does not override all of the barriers that exist that might impede a person’s efforts to age well. Poverty, illness, and a lack of access to adequate services and supports can have powerful effects against even those with the best intentions to age well.

This thesis focuses specifically on health and well-being in old age. However, one of the key points that emerged repeatedly is the recognition that health in old age cannot be separated out from health in other periods in the life course. As I discussed in several places, a person’s health as they age is shaped by exposure to stressors and protective factors throughout their entire lives. Loppie-Reading and Wien (2009) state that these social determinants of health begin to shape a person’s lifelong health profile as early as conception. Over an entire lifetime, inequalities in exposure to health stressors (poverty, food security, housing, etc.) can compound, leading to an increased vulnerability to infection, mental health issues and chronic disease (Loppie-Reading & Wein, 2009). The factors that emerged in the interview data as barriers and enablers to aging well align very closely with known social determinants of health.

When I recommended a focus on health promotion related to aging during the dissemination process, some health staff expressed a concern about how they might do

so. They expressed to me that it was difficult to focus on aging when there were so many other pressing health issues to deal with among their clientele. It is necessarily difficult to focus on the end of the life course when there are so many problems plaguing Aboriginal communities that impact younger people or the population as a whole. However, there are two issues at play when considering health promotion related to aging well: we must strive to assist people who are seniors *now* to enjoy a healthier aging experience, but we must also plan ahead and look to the seniors of the *future*. Focusing on health promotion strategies for larger health issues in these communities is not at odds with the goal of promoting healthy aging. In fact, I believe quite the opposite to be true. A strategy for promoting behaviours consistent with a healthy old age may actually have effects that are congruent to the needs of the community in other areas of health, and vice-versa. For example, many of the recommended behaviours and lifestyle choices that seniors associate with healthy aging are also known risk reduction practices against multiple other chronic illnesses (i.e. diabetes, heart disease). Supporting people to engage in behaviours such as eating healthy foods, engaging in physical activity and reducing stress has a wide range of benefits across all age groups.

In Chapter Four, I discussed local explanatory models of age-related memory loss, Alzheimer's disease and dementia. I identified two main perceptions of memory loss. The first was a more traditional understanding of memory loss as a normal and natural part of the aging process, the second was a more medicalized understanding which recognized that in some circumstances, memory loss and other symptoms associated with cognitive decline could be pathological, abnormal, and cause for concern. This tension between the perception that memory loss is natural and that memory loss may be pathological is consistent with First Nations peoples' understandings of dementia in other parts of Canada (Hulko, et al., 2010; Lanting, et al., 2011).

Participants perceived there to be many different factors that influenced the development of dementia. Although memory loss was primarily perceived to be a natural part of the aging process, other factors such as head injury, prescription medications, other illnesses, and genetics were also seen to play a role. Emotional, physical, and spiritual trauma, stress, and imbalance in the areas of the medicine wheel, were also believed to potentially impact a person's cognitive health. In addition to these physiological and psychosocial factors, changes to lifestyle and culture were seen to influence a person's risk for developing dementia. Indeed, the long-term effects of colonialism, including the dispossession of land, sedentarization, disrupted cultural continuity are a known determinant of Aboriginal peoples' health (Czyzewski, 2011). Participants perceived that traditional ways of life involved higher levels of physical activity, cognitive stimulation and social engagement, as well as healthier diets and thus, were protective against cognitive decline. They explained that in the past seniors were more frequently involved in physical work such as baling hay, chopping firewood or

berry picking, and that they had spent more time visiting with their neighbors. They saw the sedentary lifestyle of people today, environmental contamination, and a reliance on store-bought foods to be leading to poor health and an increase in ADRD.

Cultural change was also perceived to impact aging and health because of changes to seniors' roles and relationships in their communities, particularly the loss of social capital and social networks. Loneliness and isolation were seen to be a negative outcome of lifestyle changes since visiting was less common and some individuals lived alone without any family support. It was frequently expressed that in the past seniors had more clearly defined roles in their families and communities. These roles were often characterized by responsibilities such as teaching, keeping the fire, or caring for grandchildren. Seniors' traditional roles in their families were perceived to foster intergenerational closeness and respect. As a person grew older it was expected that care would be provided to them by their extended family.

The recognition that changes to culture have impacted the ability to age successfully and the development of dementia are key to the analysis of this thesis and emerged as a central theme to both perceptions of seniors' abilities to age well and the perceived increase in the prevalence of dementia in First Nations communities. This was apparent in two key areas: first, environmental and lifestyle factors that have impacted seniors' ability to stay physically and cognitively active; and second, changes to social roles and extended family structures that have increased the risk for isolation and loneliness. Changes in social roles and demographics have also impacted traditional care-giving patterns. Other studies have also highlighted the significance of cultural change in relation to Aboriginal seniors' health. For example, a study with Aboriginal grandmothers in Saskatchewan, named a "big change in culture" as having a significant impact on seniors' ability to age well and avoid cognitive decline (Lanting, et al., 2011:109). Cultural change and disruption in traditional life ways resulting from the colonial legacy have also been linked to a wide variety of other health issues among Aboriginal people, particularly issues related to mental health (Martin-Hill, 2009). Supports that encourage and enable seniors to participate in activities that reflect their cultural values of traditional ways of life would likely have a significantly positive effect on promoting successful aging and preventing dementia.

For example, seniors who participated in this research expressed that some of the factors that enable a person to age well and prevent dementia are closely tied to traditional First Nations teachings and spirituality. Attitude, particularly a willingness to accept changes to health and abilities, and the use of humour to diffuse stress and tension are examples of such factors. Many participants spoke of the importance of seeking balance between the physical, mental, emotional, and spiritual realms to achieving a healthy old age. The seven grandfather teachings of wisdom, love, honesty, respect, humility, bravery and truth were also seen to contribute to a person's ability to

age well. Cultural activities such as pow wows and ceremonies were perceived to be opportunities for social and cognitive stimulation, and speaking Ojibwe was also perceived to have benefits for a person's health, especially their cognitive health. Finally, it was expressed that healing from current and historical trauma was important to empowering individuals to live a healthy life.

In Chapter Five and Chapter Six, I discuss help seeking, diagnosis and treatment, and informal care-giving for dementia. Although treatment and care are closely related I felt that it was important to separate them into distinct discussions for the purpose of this thesis because they emerged as discrete issues in the interviews. In particular, family care-giving was something that happened quite naturally and was an expected aspect of not only dementia, but also normal aging. Most seniors and people with dementia expressed that their families were either already providing them with some kind of support or that they knew that they would be prepared to support them when the time came and they needed, or were ready for, help. By contrast, seeking formal help, diagnosis or treatment, were much less commonly discussed and it became quite clear that receiving care from family for symptoms of memory loss was in no way related to, or hinged on, a medical diagnosis. Families tended to provide care because they loved and cared about the person with dementia and became aware that they needed support, and not because the person was diagnosed with dementia.

Chapter Five explored help-seeking, diagnosis, and treatment from the perspectives of health care workers and physicians as well as people with dementia, family caregivers and seniors. The data from this chapter shows that health care workers perceive there to be some problems with western diagnostic approaches to dementia in First Nations communities, particularly relating to the relevance of test content and the outcomes of having a diagnosis. By this, I point to the idea that diagnosis in many cases does not lead to improved outcomes because of a lack of services available on Manitoulin Island, and the fact that at this time there are no medications that are proven to be effective in slowing or improving cognitive decline, and there is no cure. It has been suggested in the literature that in cases where there is no treatment, cure or support available that a diagnosis may actually be detrimental to clients (Downs, 1997; Keightly & Mitchell, 2004). However, diagnosis can be extremely valuable in that it can allow people with dementia and their families to plan ahead, or lead to access to interventions and support (Brodsky, et al., 1998; Overman & Stoudemire, 1988). Based on the current need for dementia-specific supports on Manitoulin to assist people in coping with dementia, I suggest that future research and planning should focus on improving supports, services, and culturally appropriate education related to dementia before putting significant efforts into remedying the multiple problems that exist in formal diagnostic tools.

Care-giving is a hugely important part of ensuring that a person with dementia has the best possible experience in coping with the challenges associated with cognitive impairment. There was a strong consensus among all of my participants the preferred modality of dementia care was care provided in the home by family members. The benefits of care provided in the home by people familiar to the person with dementia are also widely recognized in the literature, especially if caregivers are well-trained (M. S. Mittleman, et al., 2006; Schulz, et al., 2002; P.J. Whitehouse, Lerner, & Hedera, 1993). Home care provided by family members is beneficial because the location is familiar, and family members are generally better able to provide culturally appropriate care and speak to the care recipient in their Native language than care provided by formal health services. In addition, the care of a senior relative in the home can help to maintain continuity in families and conserve senior's roles in their family, which has benefits across multiple generations.

I have previously discussed the idea that it is important to understand perceptions of successful aging because people who develop dementia likely still have the same desires as healthy seniors, even if they are unable to communicate those desires to the people who are providing care for them. Caregivers, both formal and informal, need training relating to caring for a person with dementia so that they can attempt to provide the highest level of care for their client or relative. This care, in the best case scenario, would support people with dementia to engage in activities they enjoy, maintain a purpose in life, eat healthy foods, get some exercise, and have social contact. In short, care for a person with dementia should support their personhood and respect that they are still capable of meaningful engagement with the world around them. If formal and informal caregivers were better trained, there is a higher likelihood that they would be able to provide care that better supports the continued personhood and meaningful engagement of people with dementia in their own lives.

Seniors, people with dementia, and family care givers all recognized that there were benefits to care provided in the home. These benefits have also been widely reported in the published literature. Documented benefits to home care in the literature include delayed enrollment in nursing homes, slower decline, and longer life expectancy (McClendon, et al., 2006; M. S. Mittleman, et al., 2006). Further, family care provided in the home was expressed as a strong preference by participants. For all of these reasons, it is important to ensure that First Nations caregivers have access to adequate training and support to allow them to continue to provide care in the home for as long as possible.

The biggest challenges expressed by informal caregivers were the round-the-clock nature of dementia care, a lack of knowledge of how to cope with dementia-related behaviours, and unmet needs relating to access to respite and other resources. This lack of knowledge of how to provide appropriate care and lack of respite from the daily

demands of care-giving were major contributors to physical and emotional strain. Caregiver stress can have adverse effects not only for the caregiver, but also for the person with dementia since stressed caregivers may be more prone to yelling, rough treatment, and elder abuse (Williamson, et al., 2001). Although family care is preferred by all parties, exhausted and burnt-out caregivers often have little choice but to enroll the person with dementia in a nursing home. This was not perceived to be a desirable option. Health care providers and local services are very aware of the need for increased hours of care for seniors with dementia and the importance of respite and in-home support in assisting family caregivers to cope with the demands of providing care. However, the resources available in each community are limited. There is a significant need for better supports targeted at people with dementia and their caregivers.

Family caregivers expressed that they attempted to provide care that centered around social stimulation, visiting, communication, redirection, respect and focusing on the remaining interests and abilities of the person with dementia. These approaches all have the potential to be effective, but can become more difficult to implement as the person with dementia's cognitive abilities decline, especially if adverse behaviours begin to emerge. Even the most well-intentioned caregiver can struggle to stay calm and supportive of a person with dementia who is acting out when they are exhausted and have had no time to rest and recover from the very demanding aspects of care-giving. Even formally trained caregivers can find it challenging to provide care for a person with dementia, so the strains on a person with no training and little support can be significant. Caregiver interventions, such as training and education, would be greatly beneficial to formal and informal caregivers on Manitoulin Island. The benefits of training caregivers in strategies for coping with the needs and behaviours of the person with dementia have been well documented in the literature and include increased service utilization, reduced depression, delayed institutionalization, and increased quality of life (Hepburn, et al., 2001; Schulz, et al., 2002). Since caring for a person with dementia in the home for as long as possible is desirable to First Nations people, and generally has better outcomes for the person with dementia, supports should be put in place that allow families to care for a person with dementia throughout the various stages of the disease.

It is apparent from the data that was gathered during my fieldwork that several types of supports would benefit people with dementia and their caregivers. Education and training related to dementia is required on several levels. Physicians and specialists need to be better informed about how to provide culturally appropriate treatment that reflects Aboriginal peoples' understandings of dementia and healing. Home care nurses and PSW require training about providing care to a person with dementia and managing specific behaviours. Family caregivers would also benefit from education and training related to the identification of dementia, how the disease progresses, strategies for providing safe and supportive care, and information about what services and supports

are available. Further, community-based supports are required to help support family caregivers to continue to provide care in their homes for as long as possible. The types of services that are needed include evening, overnight and weekend support, increased hours of respite, support groups that reflect local language and culture, and specific programs for people with dementia to attend where they can engage in activities appropriate to their level of cognitive capacity and benefit from social interactions. It is imperative that these services be culturally safe and reflect Aboriginal peoples' understandings of health, dementia, personhood and quality of life.

Further, demographic and cultural changes are impacting some families' ability to provide care for seniors with dementia. In many cases, family members have dispersed and no longer live close enough to the person with dementia to provide care, or adult children have full-time jobs or other conflicting responsibilities that prevent them from providing senior family members with the care they need. Seniors with dementia who do not have family care must rely on other services and supports, but this can be problematic when communities do not have enough resources to supply the supports that are needed. Just as more supports are needed to assist family members in providing care for relatives with dementia, so too is there a need for services designed to benefit seniors who do not have family to care for them, but wish to age in place in their own communities. Such services might include increased hours of home care or supportive housing that bridges the gap between independent living and nursing home care.

The focus of dementia treatment and care programming should be on caring versus curing. Although no specific traditional medicines were known to combat dementia, supportive care and the healing of trauma were seen to be key components of helping a person to cope with the effects of the disease. Healing is an important concept to consider, not only in relation to dementia, but to broader understandings or and experiences with health in an Aboriginal context. As one traditional healer in our sample expressed, it is important for people to heal from both current and historical trauma if they hope to prevent dementia and maintain their health as they age. She expressed that helping people to find balance in their lives and empowering them to stay engaged in life are key to coping with the effects of cognitive decline.

The importance of healing from trauma is also discussed extensively in the Aboriginal health literature at the individual level as well as the community level. Iwasaki et al. (2005), for example, discusses that healing is a significant factor in helping people to cope with stress related to diabetes. Their article demonstrates that enculturation, self-determination, connectedness and leisure can have protective benefits and facilitate healing. The importance of self-determination and the restoration of cultural values, language and spirituality have also been identified as important components of both individual and community healing (Warry, 1998). This type of approach to healing would have many benefits in relation to dementia. Addressing social determinants of

Aboriginal peoples' health, including the long-term effects of colonialism, has the potential to be a powerful factor in the prevention of dementia for First Nations people living on Manitoulin Island. Further, culturally appropriate stress-coping strategies could be beneficial on many levels. For example, not only is stress management a recommended risk-reduction strategy in relation to dementia, but caregivers are also in need of ways to cope with the strains of providing dementia care.

Dementia is a complex problem that can have significant impacts for individuals, families, and communities. Overall, this thesis has presented important data that speaks to the interconnectedness of culture, ways of life, and health across the life course in relation to aging and dementia. The data presented here shows that although there are challenges in coping with dementia at individual and community levels, there are also many strengths in Aboriginal peoples' response to this disease. As strategies are developed to help communities to cope with dementia, these strengths should be recognized and supported.

Limitations

There are a few limitations to this research. First, it was challenging to locate individuals with a clear clinical diagnosis of dementia. The findings of this research represent people who are experiencing symptoms of memory loss and dementia, but do not necessarily represent people who have been specifically diagnosed with Alzheimer's disease or related dementias. This may have impeded my ability to make clear statements about experiences with Alzheimer's disease and related dementias, but also had the benefit of better representing the perceptions and experiences of our sample across a wide spectrum of experiences with memory loss, which helped to highlight the fact that a diagnosis is not regularly sought out, nor does it necessarily impact the response that individuals and their informal caregivers have in relation to care and support.

Another limitation is that no one in a long term care (nursing home) environment was interviewed. These individuals were not purposely excluded in the design of this project, but the strategy that was used to recruit participants did not facilitate their participation. This is particularly true in the case of individuals who were living in nursing homes outside of their local community, as is often the case in Aboriginal contexts. As a result, this research can be said to give a good representation of community-dwelling seniors and people with dementia, but does not adequately represent the voices of individuals living in institutionalized settings. These individuals may be even more marginalized than their community-dwelling counterparts and it will be important to seek out their voices in future efforts to understand First Nations peoples' experiences with dementia.

Possible areas for future research

Throughout the research and writing process of this project, I have developed several ideas for future research projects. I have also identified areas where further research or interventions are desired by participants on Manitoulin Island. One area that I think has the potential to prove to be useful are intervention studies, on several levels. Because of the known need for further education and training of both formal and informal caregivers relating to dementia care in an Aboriginal context, I believe that working with these individuals to learn more about their needs and to implement training programs that are relevant to their situation would be productive. The need for training for informal family caregivers as well as for formal health care staff was also recognized by health service providers and caregivers who participated in this project.

Not only would this type of research contribute to filling a gap in the academic literature pertaining to intervention studies related to dementia in Aboriginal populations, but it would also help to meet the needs of family members coping with dementia as well as health care staff. This would benefit caregivers in their ability to provide good care, and possibly have broader effects on their quality of life and the quality of life of the people they provide care for. In addition, appropriate training might reduce caregiver strain and may allow people with dementia to live in their homes and communities for a longer period of time. This is desirable since avoiding institutionalization is a shared value of the participants in this study. Research of this type could build on the data compiled in this thesis using further consultations with participants at the community level to determine needs and methods of delivery (i.e. in person or tele-health) that would best suit the community.

In line with the development of care-giver and care-worker training related to dementia, there is a possibility to devise culturally appropriate health promotion materials to educate people about healthy aging, dementia, care-giving and coping. The need for such health promotion materials that represent Aboriginal people, their language and their understandings of dementia was indicated as a desire of several participants in this study.

Another area of research that I think is promising relates to intergenerational studies. The importance of contact between seniors and children was discussed frequently throughout the course of my research. Seniors, families, care providers, and traditional healers all recognized there were potential benefits to bringing children and seniors together. A study that looked at the degree to which seniors and children have opportunities to interact, both formally (i.e. through community programming) and informally (i.e. at family gatherings), how they interact in these settings, and the benefits that each perceives that they gain from these interactions might have interesting results

that would help us to understand the true impacts of intergenerational contact. Specifically, I think that this would be an interesting opportunity to use photovoice³.

Finally, I think there is a continuing opportunity to pursue deeper understandings of cultural perceptions of healthy aging and dementia by engaging in more detailed research. I see several opportunities here, including research that focuses more explicitly on the importance of culture, language and life ways on the maintenance of health in old age or implementing a more sensitive approach to engaging in meaningful research with people with dementia, such as utilizing specially designed interview techniques or extending the participatory aspect of the research to include people with dementia in designing research that they perceive to be relevant.

Conclusions

This thesis has provided a rich description of the lived experience of First Nations people coping with dementia. I have provided a detailed explanation of how First Nations seniors understand successful aging, showing that they have a great desire to maintain an appropriate level of autonomy and stay active and engaged in many aspects of life as they grow older. The understanding of what constitutes a successful aging experience for First Nations seniors that is presented here is one of the only descriptions of its kind in the literature. Understanding seniors' hopes and desire for their own old age, and the barriers and enablers that they encounter as they try to achieve a positive aging experience is very important to the study of aging in general and dementia more specifically. In particular, knowledge of what First Nations seniors value as they age can be used to devise sensitive and culturally safe interventions relating to the care of First Nations people with dementia, since it is likely that people with dementia share the same desires for their old age as non-impaired seniors. It emerged from this data that successful aging is defined not by the absence of illness, but by a continued engagement with life to whatever degree is congruent with a person's abilities. If care practices and supports are put in place that can support First Nations people with dementia in being as engaged as possible in their lives, then they, too, may have a better opportunity to enjoy a successful old age.

In addition to presenting a new understanding of successful aging in First Nations communities, this thesis presents an in-depth documentation of First Nations people's understandings of and experiences with dementia. Data is presented that suggests that

³ Photovoice is a participatory research approach in which participants are given a camera and asked to take pictures to help them tell their story. One pictures have been taken they are used to promote dialogue and generate knowledge creation between the participant and the researcher (Wang and Burns 1997).

overall, memory loss is considered to be an accepted, and even expected, part of the aging process. However, there is tension between the perception of memory loss as a natural outcome of growing older and the idea that a more severe and worrisome type of memory loss can occur. Interview data also revealed that dementia is perceived to be a growing problem and that changes to culture and life ways, primarily caused by the long-term impacts of colonialism such as sedentarization and disruptions to family structure and cultural continuity may be a primary cause of this increased prevalence of cognitive impairment in First Nations seniors.

Finally, this thesis speaks to practices related to help-seeking, treatment, and care. I have shown that First Nations people highly value informal care provided in family and community settings, and that traditional, family and community-oriented approaches to care have many benefits including increased access to emotional support, culturally safe care that reflects the language and beliefs of the care recipient, the maintenance of continuity in families, and opportunities for seniors to retain meaningful roles such as teaching and passing on knowledge. However, I have also demonstrated that changes to culture and demography are putting pressure on the ability of families to provide care for senior family members. Further, community supports that enable families to provide care in their homes are lacking, which increases the likelihood that caregivers will experience strain and burnout and may have to resort to institutionalized care. There is a significant need for education and training related to dementia care for formal and informal caregivers on Manitoulin. Such training, coupled with increased availability of culturally safe dementia-related services and supports such as adult day programs, support groups, respite, and supportive housing would greatly improve the chances for people living with dementia and their caregivers to have as positive and experience as possible in coping with this disease.

This thesis has presented a holistic interpretation of the lived experiences of aging and dementia among First Nations people on Manitoulin Island, Ontario. By privileging the diverse voices of people with dementia, seniors, caregivers, traditional healers, and health care professionals I have been able to demonstrate that experiences of aging and dementia are inter-related and inter-connected, and that the best way to ensure healthy in aging is to promote health at all stages of the life course.

References

- Abonyi, S., & Favel, M. (2012). Marie's Story of Aging Well: Toward New Perspectives on the Experience of Aging for Aboriginal Seniors in Canada. *Anthropology and Aging Quarterly*, 33(1), 11,20.
- Adelson, N. (2000). *Being Alive Well: Health and Politics of Cree Well-Being*. Toronto: University of Toronto Press.
- Adelson, N. (2005). The Embodiment of Inequality: Health Disparities in Aboriginal Canada. *Canadian Journal of Public Health*, 96, S45-S61.
- Affleck, G., Tennen, H., Pfeiffer, C., & Fifield, J. (1987). Appraisals of control and predictability in adapting to a chronic disease. *Journal of Personality and Social Psychology*, 53, 273-279.
- Alspaugh, M. A. L., Stephens, M. A. P., Townsend, A. L., Zarit, S. H., & Greene, R. (1999). Longitudinal Patterns of Risk for Depression in Dementia Caregivers: Objective and Subjective Primary Stress as Predictors. *Psychology and Aging*, 14(1), 34-43.
- Alzheimer Society. (2010). *Rising Tide: The Impact of Dementia on Canadian Society*.
- Andrews, M. E., Morgan, D. G., & Stewart, N. J. (2010). Dementia Awareness in Northern Nursing Practice. *Canadian Journal of Nursing Research*, 42(1), 56-73.
- Assembly of First Nations. (2007). *Sustaining the Caregiving Cycle: First Nations People and Aging*. Ottawa, Ontario: A Report from the Assembly of First Nations to the Special Senate Committee on Aging.
- Ayers, L., Kavanaugh, K., & Knalf, K. A. (2003). Within-Case and Across-Case Approaches to Qualitative Data Analysis. *Qualitative Health Research*, 13, 871-883.
- Baer, H., Singer, M., & Susser, I. (2003). *Theoretical Perspectives in Medical Anthropology Medical Anthropology and the World System* (2nd ed., pp. 31-54). Westport, CT: Praeger.
- Bandura, A. (1977). Self-Efficacy: Toward a unifying theory of human agency. *American Psychologist*, 37, 122-147.
- Bartlett, R., & O'Connor, D. (2010). *Broadening the Dementia Debate: Towards Social Citizenship*. Bristol: The Policy Press.
- Barton, S. S. (2004). Narrative Inquiry: Locating Aboriginal Epistemology in Relational Methodology. *Journal of Advanced Nursing*, 45(5), 519-526.
- Bassett, R., Bourbonnais, V., & McDowell, I. (2007). Living long and keeping well: Elderly Canadians account for success in aging. *Canadian Journal on Aging*, 26(2), 113-126.
- Battiste, M. (2000). *Reclaiming Indigenous Voice and Vision*. Vancouver, B.C.: UBC Press.
- Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S., & Gallagher-Thompson, D. (2006). Enhancing the Quality of Life of Dementia Caregivers from Different Ethnic or Racial Groups: A Randomized, Controlled Trial. *Annals of Internal Medicine*, 145(10), 727-216.

- Benner, P. (2000). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In P. Benner (Ed.), *Interpretive Phenomenology: Embodiment, Caring and Ethics in Health and Illness*. Thousand Oaks: Sage Publications.
- Berg, L. D., Evans, M., Fuller, D., & The Okanagan Urban Aboriginal Health Research Collective, C. (2007). Ethics, Hegemonic Whiteness, and the Contested Imagination of 'Aboriginal Community' in Social Science Research in Canada. *ACME: An International E-Journal for Critical Geographies*.
- Berghmans, R. L. P., & Ter Meulen, R. H. J. (1995). Ethical Issues in Research with Dementia Patients. *International Journal of Geriatric Psychiatry*, 10, 647-651.
- Bernard, H. R. (1994). *Research Methods in Anthropology: Qualitative and Quantitative Approaches*. Thousand Oaks: SAGE Publications, Inc. .
- Best Start Resource Centre. (2010). A Child Becomes Strong: Journeying Through Each Stage of the Life Cycle. Toronto, Ontario, Canada.
- Bird, G. (1993). The first circle - native women's voice. In P. Perreault & S. Vance (Eds.), *Writing the Circle: Native Women of Western Canada*. Norman, Oklahoma: University of Oklahoma Press.
- Blandford, A., & Chappell, N. (1990). Subjective well-being among Native and non-Native elderly persons: Do differences exist? *Canadian Journal on Aging*, 9(4), 386-399.
- Bond, J. (1999). Quality of life for people with dementia: approaches to the challenge of measurement. *Ageing and Society*, 19(5), 561-579.
- Bond, J., & Corner, L. (2001). Researching dementia: Are there unique methodological challenges for health services research? *Ageing and Society*, 21(1), 95-116.
- Borofsky, R. (2008). Studying "Culture" Scientifically is an Oxymoron: The Interesting Question is Why People Don't Accept This. In M. J. Brown (Ed.), *Explaining Culture Scientifically* (pp. 275-296). Seattle, WA: University of Washington Press.
- Bowling, A. (1993). The Concept of Successful and Positive Aging. *Family Practice*, 10(4), 449-453.
- Boyatzis, R. E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development*. Thousand Oaks, California: Sage Publications, Inc.
- Brandtstadter, J., & Baltes-Gotz, B. (1990). Personal control over development. In M. M. Baltes & P. B. Baltes (Eds.), *Successful Aging: Perspectives from the behavioural sciences* (pp. 197-224). Cambridge, England: Cambridge University Press.
- Brandtstadter, J., & Rothermund, K. (1994). Self-percepts of control in middle and later adulthood: Buffering losses by rescaling goals. *Psychology and Aging*, 9, 265-273.
- Brant, C. C. (1990). Native Ethics and Rules of Behaviour. *Canadian Journal of Psychiatry*, 35, 534-539.
- Brodsky, H. (1990). Low Diagnostic Yield in a Memory Disorders Clinic. *International Psychogeriatrics*, 2, 149-159.

- Brodaty, H., Clarke, J., Ganguli, M., Grek, A., Jorm, A., Khachaturian, Z., et al. (1998). Screening for Cognitive Impairment in General Practice: Towards a Consensus. *Alzheimer Disease and Associated Disorders*, 12(1), 1-13.
- Brodaty, H., Green, A., & Koschera, A. (2003). Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia. *Journal of the American Geriatrics Society*, 51(5), 657-664.
- Brodaty, H., Roberts, K., & Peters, K. (1994). Quasi-Experimental Evaluation of an Educational Model for Dementia Caregivers. *International Journal of Geriatric Psychiatry*, 9(3), 195-204.
- Brown, C. M., & Gibbons, J. L. (2008). Taking Care of Our Elders: An Initial Study of an Assisted Living Facility for American Indians. *Journal of Applied Gerontology*, 27(4), 523-531.
- Brown, M. J. (2008). Introduction: Developing a Scientific Paradigm for Understanding Culture. In M. J. Brown (Ed.), *Explaining Culture Scientifically* (pp. 3-16). Seattle, Washington: University of Washington Press.
- Buchignani, N., & Armstrong-Esther, C. (1999). Informal Care and Older Native Canadians. *Ageing and Society*, 19(1), 3-32.
- Caelli, K. (2000). The Changing Face of Phenomenological Research: Traditional and American Phenomenology in Nursing. *Qualitative Health Research*, 10(3), 366-377.
- Cammer, A. (2006). *Negotiating Culturally Incongruent Healthcare Systems: The Process of Accessing Dementia Care in Northern Saskatchewan*. MA, University of Saskatchewan, Saskatoon.
- Canadian Institutes of Health Research. (2006). CIHR Guidelines for Health Research Involving Aboriginal People. In C. I. o. H. Research. (Ed.).
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2010). Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.
- Cannuscio, C., Block, J., & Kawachi, I. (2003). Social capital and successful aging: The role of senior housing. *Annals of Internal Medicine*, 139(5, part 2), 395-399.
- Cattarinich, X., Gibson, N., & Cave, A. (2001). Assessing Mental Capacity in Canadian Aboriginal Seniors. *Social Science and Medicine*, 53(11), 1469-1479.
- Chapelski, E. E., Soback, J., & Fisher, C. (2003). Long-term care preferences and attitudes among Great Lakes American Indians. *Care Management Journal*, 4(2), 94-100.
- Chipperfield, J. G., & Greenslade, L. (1999). Perceived Control as a Buffer in the Use of Health Care Services. *J Gerontol B Psychol Sci Soc Sci*, 54B(3), 146-154.
- Clark, M., & Anderson, B. G. (1980). *Culture and Aging: An Anthropological Study of Older Americans*. New York: Arno Press.
- Clarke, J. A. (1992). *On Their Own Terms: Health Perceptions of Urban Native People*. M.A., McMaster University, Hamilton, Ontario.

- Climo, J. (1992). The Role of Anthropology in Gerontology: Theory. *Journal of Aging Studies*, 6(1), 44-55.
- Cohen, D. (1991). The Subjective Experience of Alzheimer's Disease: The Anatomy of an Illness as Perceived by Patients and Families. *The American Journal of Alzheimer's Care and Related Disorders*, 6(3), 6-11.
- Collings, P. (2001). "If you've got everything, it's good enough": Perspectives on successful aging in a Canadian Inuit community. *Journal of Cross-Cultural Gerontology*, 16(2), 127-155.
- Connelly, D. M., & Mersich, J. (1997). Seniors Maintaining Active Roles Together evaluation report (SMARTer): Sustainability of Community-based Volunteer-led Group Exercise Programs for Older Adults at Three Sites Across Canada: Victorian Order of Nurses.
- Cooke, M., Guimond, E., & McWhirter, J. (2008). The Changing Well-Being of Older Adult Registered Indians: An Analysis Using the Registered Indian Human Development Index. *Canadian Journal on Aging*, 27(4), 385-397.
- Crazy Bull, C. (1997). A Native Conversation about research and Scholarship. *Tribal College Journal of American Indian Higher Education*, 9(1), 17-23.
- Crotty, M. (1996). *Phenomenology and Nursing Research*. Melbourne: Churchill Livingstone.
- Czyzewski, K. (2011). Colonialism as a broader social determinant of health. *The International Indigenous Policy Journal*, 2(1), 1-14.
- Desjarlais, R., & Throop, C. J. (2011). Phenomenological Approaches to Anthropology. *Annual Review of Anthropology*, 40(87-102).
- DeWalt, K. M., & DeWalt, B. R. (2002). *Participant Observation: A Guide for Fieldworkers*. Walnut Creek: Altamira Press.
- Dewing, J. (2002). From ritual to relationship: A person-centered approach to consent in qualitative research with older people who have dementia. *Dementia*, 1(2), 157-171.
- Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, 6(1), 11-25.
- Dickson, G., & Green, K. L. (2001). Participatory action research: Lessons learned with Aboriginal grandmothers. . *Health Care for Women International*, 22(5), 471-482.
- Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of Race, Ethnicity, and Culture in Caregiving Research: A 20 Year Review. *The Gerontologist*, 42(2), 237-272.
- Doody, R. S., Stevens, J. C., & Beck, C. (2001). Practice Parameter: Management of Dementia (An Evidence-Based Review): Report of the Quality Standards Subcommittee of the American Academy of Neurology. . *Neurology*, 56(9), 1154-1166.

- Dowling, M. (2007). From Husserl to van Manen: A review of different phenomenological approaches *International Journal of Nursing Studies*, 44(131-142).
- Downs, M. (1997). The Emergence of the Person in Dementia Research. *Ageing and Society*, 17, 597-607.
- Downs, M. (2000). Dementia in a Socio-Cultural Context: An Idea Whose Time has Come. *Ageing and Society*, 20, 369-375.
- Ducharme, F. C., Levesque, L. L., Lachance, L. M., Kergoat, M.-J., Legault, A. J., Beaudet, L. M., et al. (2011). "Learning to Become a Family Caregiver" Efficacy of an Intervention Program for Caregivers Following Diagnosis of Dementia in a Relative. *The Gerontologist*, 51(4), 484-494.
- Dunkin, J. J., & Anderson-Hanley, C. (1998). Dementia Caregiver Burden: A Review of the Literature and Guidelines for Assessment and Intervention. *Neurology*, 51(1, Supplement 1), S53-S60.
- Edie, J. M. (1987). *Edmund Husserl's Phenomenology: A Critical Commentary*. Bloomington: Indiana University Press.
- Eizenman, D. R., Nesslerode, J. R., Featherman, D. L., & Rowe, J. W. (1997). Intraindividual Variability in Perceived in an Older Sample: The MacArthur Successful Aging Studies. *Psychology and Aging*, 12(3), 489-502.
- Ermine, W. (2000). *A Critical Examination of the Ethics in Research Involving Indigenous Peoples*. Master of Education, University of Saskatchewan, Saskatoon, Saskatchewan.
- Ermine, W., Sinclair, R., & Jeffery, B. (2004). *The Ethics of Research Involving Indigenous Peoples*. Saskatoon: Indigenous Peoples' Health Research Center.
- Evans, M., Hole, R., Berg, L. D., Hutchinson, P., & Sookraj, D. (2009). Common Insights, Differing Methodologies: Toward a Fusion of Indigenous Methodologies, Participatory Action Research, and White Studies in an Urban Aboriginal Research Agenda. *Qualitative Inquiry*, 15(5), 893-910.
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 80-92.
- Fetterman, D. M. (2010). *Ethnography: Step-By-Step*. Thousand Oaks, California: SAGE Publications, Inc.
- Finkelstein, S. A., Forbes, D. A., & Richmond, C. A. M. (2012). Formal Dementia Care among First Nations in Southwestern Ontario. *Canadian Journal on Aging*, 31(3), 257-270.
- Fitzgerald, J. M. (1996). The distribution of self-narrative memories in younger and older adults: Elaborating the self-narrative hypothesis. *Ageing, Neuropsychology, and Cognition*, 3(3), 229-236.

- Flammer, A. (1995). Developmental analysis of control beliefs. In A. Bandura (Ed.), *Self-efficacy in changing societies* (pp. 69-113). Cambridge: Cambridge University Press.
- Franklin, N. C., & Tate, C. A. (2009). Lifestyle and Successful Aging: An Overview. *American Journal of Lifestyle Medicine, 3*(1), 6-11.
- Frohlich, K., Ross, N., & Richmond, C. (2006). Health Disparities in Canada Today: Some Evidence and a Theoretical Framework. *Health Policy, 79*(2), 132-143.
- Fuller-Iglesias, H., Smith, J., & Antonucci, T. C. (2009). Chapter 1. Theories of Aging from a Life-Course and Life-Span Perspective: An Overview. *Annual Review of Gerontology and Geriatrics, 29*, 27-56.
- Gadamer, H.-G. (1975). *Truth and Method*. New York: Seabury Press.
- Garrett, M. T., Garrett, J. T., Torres-Rivera, E., Wilbur, M., & Roberts-Wilbur, J. (2005). Laughing it up: Native American Humor as Spiritual Tradition. *Journal of Multicultural Counseling and Development, 33*(4), 194-204.
- Geertz, C. (1973). *The Interpretation of Cultures*. New York: Basic.
- Gelfand, D. E. (2003). *Aging and Ethnicity: Knowledge and Services*. New York: Springer Publishing Company.
- Giorgi, A. (2000). The status of Husserlian phenomenology in caring research. *Scandinavian Journal of Caring Science, 14*, 3-10.
- Glass, T. A., de Leon, C. M., Marttoli, R. A., & Berkman, L. F. (1999). Population based study of social and productive activities as predictors of survival among elderly Americans. *British Medical Journal, 319*, 478-483.
- Glueckauf, R. L., Stine, C., Bourgeois, M., Pomidor, A., & Rom, P. (2005). Alzheimer's Rural Care Healthline: Linking Rural Caregivers to Cognitive-Behavioural Intervention for Depression. *Rehabilitation Psychology, 50*(4), 346-354.
- Glymour, M. M., Errel, K. A., & Berkman, L. F. (2009). Chapter 2. What can life-course epidemiology tell us about health inequalities in old age? . *Annual Review of Gerontology and Geriatrics, 29*, 27-56.
- Graham, H., & Stamler, L. L. (2010). Contemporary Perceptions of Health from an Indigenous (Plains Cree) Perspective. *Journal of Aboriginal Health, 6*(1), 6-17.
- Graves, K., Easley, C., & Charles, K. G. P. (2004). Conference of Alaska Native Elders: Our View of Dignified Aging: National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders.
- Griffin-Pierce, T., Silverberg, N., Connor, D., Jim, M., Peters, J., Kaszniak, A., et al. (2008). Challenges to the Recognition and Assessment of Alzheimer's Disease in American Indians of the Southwestern United States. *Alzheimer's and Dementia, 4*, 291-299.
- Habjan, S., Prince, H., & Kelley, M. L. (2012). Caregivers for Elders in First Nations Communities: Social System Perspective on Barriers and Challenges. *Canadian Journal on Aging 31*(2), 209-222.

- Haig-Brown, C., & Dannenmann/Kaamatweyaashiik, K. (2002). *To Be in Good Relation: The search for community*. Paper presented at the International Society for Cultural Research and Activity Theory, Amsterdam.
- Hall, K. S., Hendrie, H. C., Rodgers, D. D., & Prince, C. S. (1993). The Development of a Screening Interview in Two Distinct Languages. *International Journal of Methods in Psychiatric Research*, 3, 62.61-62.14.
- Hampton, E. (1995). Redefinition of Indian Education. In M. Battiste & J. Barman (Eds.), *First Nations Education in Canada: The Circle Unfolds* (pp. 5-46). Vancouver: UBC Press.
- Harris, M. B., Begay, C., & Page, P. (1989). Activities, family relationships and feelings about aging in a multi-cultural elderly sample. *International Journal of Aging and Human Development*, 29(2), 103-117.
- Harris, P. B. (2008). Another wrinkle in the debate about successful aging: The undervalued concept of resilience and the lived experience of dementia. *The International Journal of Aging and Human Development*, 67(1), 43-61.
- Harris, P. B., & Keady, J. (2008). Wisdom, resilience and successful aging: Changing public discourses on living with dementia. *Dementia*, 7(1), 5-8.
- Hart-Wasekeesikaw, F. (1996). *First Nations Peoples' Perspectives and Experiences with Cancer*. Master of Nursing, University of Manitoba, Winnipeg.
- Hartman-Stein, P. E., & Potkanowicz, E. S. (2003). Behavioural Determinants of Healthy Aging: Good News for the Baby Boomer Generation. *Journal of Issues in Nursing*, 8(2), 1-26.
- Hayflick, L. (1994). *How and Why We Age*. New York: Ballantine Books.
- Health Canada. (2004). *Transfer of Health Programs to First Nations and Inuit Communities. Handbook One - An Introduction to Three Approaches, revised March 2004*. Ottawa: Minister of Supply and Services Canada.
- Henderson, J. N., & Henderson, L. C. (2002). Cultural construction of disease: A "supernormal" construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerontology*, 17, 197-212.
- Henderson, J. N., & Traphagan, J. W. (2005). Cultural Factors in Dementia: Perspectives from the Anthropology of Aging. *Alzheimer Disease and Associated Disorders*, 19(4), 272-274.
- Hendrie, H. C., Hall, K. S., & Pillay, N. (1993). Alzheimer's Disease is Rare in Cree. *International Psychogeriatrics*, 5(1), 5-14.
- Hendrie, H. C., & Hanson, D. (1972). A Comparative Study of the Psychiatric Care of Indian and Metis. *American Journal of Orthopsychiatry*, 42(3), 480-489.
- Hendrix, L., & Swift Cloud-Lebeau, F. H. (2006). Working with American Indian Families: Collaboration with Families for the Care of Older American Indians with Memory Loss. In G. Yeo & D. Gallagher-Thompson (Eds.), *Ethnicity and the Dementias* (Second Edition ed., pp. 147-162). New York: Routledge.

- Hennessey, C. H., & John, R. (1995). The Interpretation of Burden among Pueblo Indian Caregivers. *Journal of Aging Studies, 9*, 215-229.
- Hennessey, C. H., & John, R. (1996). American Indian Family Caregivers' Perceptions of Burden and Needed Support Services. *Journal of Applied Gerontology, 15*, 275-293.
- Hepburn, K. W., Tornatore, J., Center, B., & Ostwald, S. W. (2001). Dementia Family Caregiver Training: Affecting Beliefs About Caregiving and Caregiver Outcomes. *Journal of the American Geriatrics Society, 49*(4), 450-457.
- Hinton, L. (2002). Improving Care for Ethnic Minority Elderly and Their Family Caregivers Across the Spectrum of Dementia Severity. *Alzheimer Disease and Associated Disorders, 16*(Supplement 2), S50-S55.
- Hogan, D. B., & Patterson, C. (2002). Treatment of Alzheimer's Disease and Other Dementias - Review and Comparison of the Cholinesterase Inhibitors. *Canadian Journal of Neurological Science, 29*(306-314).
- Hubbard, G., Downs, M., & Tester, S. (2002). Including Older People with Dementia in Research: Challenges and Strategies. *Aging and Mental Health, 7*(5), 351-362.
- Hulko, W., Camille, E., Antifeau, E., Arnouse, M., Bachynski, N., & Taylor, D. (2010). Views of First Nation Elders on Memory Loss and Memory Care in Later Life. *Journal of Cross-Cultural Gerontology, 25*(4), 317-342.
- Hulko, W., & Stern, L. (2009). Cultural Safety, Decision-Making, and Dementia: Troubling Notions of Autonomy and Personhood. In D. O'Connor & B. Purves (Eds.), *Decision-making, Personhood and Dementia: Exploring the Interface* (pp. 70-87). London, UK: Jessica Kingsley.
- Hurst, S., & Nader, P. (2006). Building Community Involvement in Cross-Cultural Indigenous Health Programs. *International Journal for Quality in Health Care, 18*(4), 294-298.
- Inui, T. S. (2003). The need for an integrated biopsychosocial approach to research on successful aging. *Annals of Internal Medicine, 139*(5, part 2), 391-394.
- Iwasaki, Y., & Bartlett, J. (2006). Culturally Meaningful Leisure as a Way of Coping with Stress among Aboriginal Individuals with Diabetes. *Journal of Leisure Research, 38*(3), 321-338.
- Iwasaki, Y., Bartlett, J., & O'Neil, J. (2005). Coping with Stress Among Aboriginal Women and Men with Diabetes in Winnipeg, Canada. *Social Science and Medicine, 60*(5), 977-988.
- Jacklin, K. (2007). *Strength in Adversity: Community Health and Healing in Wikwemikong*. Doctor of Philosophy, McMaster University, Hamilton, Ontario.
- Jacklin, K., & Kinoshameg, P. (2009). Developing a Participatory Aboriginal Health Research Project: "Only if it's going to mean something". *Journal of Empirical Research on Human Research Ethics, 53-68*.

- Jacklin, K., Walker, J. D., & Shawande, M. (2013). The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. *Canadian Journal of Public Health, 104*(1).
- Jacklin, K., & Warry, W. (2004). The Indian Health Transfer Policy in Canada: Toward Self-Determination of Cost Containment. In A. Castro & M. Singer (Eds.), *Unhealthy Health Policy: A Critical Anthropological Examination* (pp. 215-234). Walnut Creek, CA: Altamira Press.
- Jervis, L. L., Boland, M. E., & Fickenscher, A. (2010). American Indian Family Caregivers' Experiences with Helping Elders. *Journal of Cross-Cultural Gerontology, 25*, 355-369.
- Jervis, L. L., Cullum, C. M., & Manson, S. M. (2006). American Indians, Cognitive Assessment and Dementia. In G. Yeo & D. Gallagher-Thompson (Eds.), *Ethnicity and the Dementias* (Second Edition ed.). New York: Routledge.
- Jervis, L. L., & Manson, S. M. (2002). American Indians/Alaska Natives and Dementia. *Alzheimer Disease and Associated Disorders, 16*(Supplement 2), S89-S95.
- John, R., Hennessey, C. H., Dyeson, T. B., & Garrett, M. D. (2001). Toward the Conceptualization and Measurement of Caregiver Burden Among Pueblo Indian Family Caregivers. *The Gerontologist, 41*(2), 210-219.
- John, R., Hennessey, C. H., & Roy, L. C. (Eds.). (1996). *Caring for Cognitively Impaired American Indian Elders: Difficult Situations, Few Options*. Washington, D.C. : Taylor & Francis.
- Jolanki, O. (2004). Moral argumentation in talk about health and old age. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine 8*, 483-503.
- Kart, C. S. (1987). The End of Conventional Gerontology. *Sociological Health and Illness, 9*, 76-87.
- Kaufert, J. M., & Shapiro, E. (1996). Cultural, Linguistic and Contextual Factors in Validating the Mental Status Questionnaire: The Experience of Aboriginal Elders in Manitoba. *Transcultural Psychiatric Research Review, 33*, 277-296.
- Keightley, M. L., King, G. E., Jang, S. H., White, R., & Colantonio, A. (2011). Brain Injury from a First Nations Perspective: Teachings from Elders and Traditional Healers. *Canadian Journal of Occupational Therapy, 78*(4), 237-245.
- Keightly, J., & Mitchell, A. (2004). What Factors Influence Mental Health Professionals when Deciding Whether or Not to Share a Diagnosis of Dementia with the Person? . *Aging and Mental Health, 8*(1), 13-20.
- Kemper, E. A., Stringfield, S., & Teddle, C. (2003). Chapter 10. Mixed Methods Sampling Strategies in Social Science Research. In A. Tashakkori & C. Teddle (Eds.), *Handbook of mixed methods in social and behavioural research* (pp. 273-296). Thousand Oaks, CA: Sage Publications, Inc. .
- Kitwood, T. (1997). The Experience of Dementia. *Aging and Mental Health, 1*(1), 13-22.

- Kitzinger, J. (1994). The Methodology of Focus Groups: The Importance of Interaction Between Research Participants. *Sociology of Health and Illness*, 16(1), 103-121.
- Kleinman, A. (1978). Concepts and a Model for the Comparison of Medical Systems as Cultural Systems. *Social Science and Medicine*, 12, 85-93.
- Koch, T. (1995). Interpretive approaches in nursing research: the influence of Husserl and Heidegger. *Journal of Advanced Nursing*, 21(827-836).
- Kovach, M. E. (2009). *Indigenous Methodologies: Characteristics, Conversations, and Contexts*. Toronto: University of Toronto Press.
- Kramer, B. J. (1996). Dementia and American Indian Populations *Ethnicity and the Dementias* (pp. 175-181). Washington, D.C.: Taylor and Francis.
- Langer, E. J., & Rodin, J. (1976). The effects of choice and enhanced personal responsibility for the aged: A field experiment in an institutional setting. *Journal of Personality and Social Psychology*, 34, 191-198.
- Lanting, S., Crossley, M., Morgan, D., & Cammer, A. (2011). Aboriginal Experiences of Aging and Dementia in a Context of Sociocultural Change: Qualitative Analysis of Key Informant Group Interviews with Aboriginal Seniors. *Journal of Cross-Cultural Gerontology*, 26(1), 103-117.
- Laverty, S. M. (2003). Hermeneutic Phenomenology and Phenomenology: A Comparison on Historical and Methodological Considerations. *International Journal of Qualitative Methods*, 2(3), 21-35.
- Leonard, V. W. (1994). A Heideggerian phenomenological perspective on the concept of person. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness*. Thousand Oaks: Sage.
- Lewis, J. P. (2009). *Successful Aging Through The Eyes of Alaska Native Elders: What it Means to be an Elder in Bristol Bay, Alaska*. University of Alaska, Fairbanks.
- Lock, M., & Scheper-Hughes, N. (1990). A Critical-Interpretive Approach in Medical Anthropology: Rituals and Routines of Discipline and Dissent. In T. M. Johnson & C. F. Sargent (Eds.), *Medical Anthropology: Contemporary Theory and Method* (pp. 47-72). New York: Praeger.
- LoGuidice, D., Smith, K., Thomas, J., Lautenschlager, N. T., Almeida, O. P., Atkinson, D., et al. (2006). Kimberley Indigenous Cognitive Assessment Tool (KICA): Development of a Cognitive Assessment Tool for Older Indigenous Australians. *International Psychogeriatrics*, 18(2), 269-280.
- Lombera, S., & Butler, R. (2009). *Aging, Dementia and Cognitive Decline: Perspectives of an Aboriginal Community in British Columbia*. Paper presented at the Association of Neuroscience Annual Meeting.
- Lonergan, E., Luxenberg, J., Colford, J. M., & Birks, J. (2002). Haloperidol for agitation in dementia. *Cochrane Database Systematic Review*, 2.
- Loppie-Reading, C., & Wein, F. (2009). Health Inequalities and Social Determinants of Aboriginal Peoples' Health: National Collaborating Centre for Aboriginal Health.

- Louis, R. P. (2007). Can You Hear Us Now? Voices from the Margin: Using Indigenous Methodologies in Geographic Research. *Geographical Research, 45*(2), 130-139.
- Maar, M. (2004). Clearing the Path for Community Health Empowerment: Integrating Health Care Services at an Aboriginal Health Access Centre in Rural North Central Ontario. *Journal of Aboriginal Health, 54*-64.
- Macaulay, A., Commanda, L., Freeman, W. L., Gibson, N., McCabe, M. L., Robbins, C. M., et al. (1999). Participatory Research Maximises Community and Lay Involvement. *British Medical Journal, 319*(7212), 774-778.
- Marshall, M. N. (1996). Sampling for qualitative research. *Family Practice, 13*(6), 522-526.
- Martin-Hill, D. (2009). Traditional medicine and restoration of wellness strategies. *Journal of Aboriginal Health, 5*(1), 26-42.
- McClendon, M. J., Smyth, K. A., & Neundorfer, M. M. (2004). Survival of Persons with Alzheimer's Disease: Caregiver Coping Matters. *The Gerontologist, 44*(4), 508-519.
- McClendon, M. J., Smyth, K. A., & Neundorfer, M. M. (2006). Long-Term Care Placement and Survival of Persons with Alzheimer's Disease. *Journal of Gerontology: Psychological Sciences, 61B*(4), 220-227.
- McMillan, F., Kaspers, D., Traynor, V., & Dewing, J. (2010). Person-centered care as caring for country: An Indigenous Australian experience. *Dementia, 9*(2), 163-167.
- Menec, V. H., & Chipperfield, J. G. (1997). Remaining Active in Later Life: The Role of Locus Control in Seniors' Leisure Activity Participation, Health, and Life Satisfaction. *Journal of Aging and Health, 9*(1), 105-125.
- Minkler, M. (1999). Introduction. In M. Minkler & C. Estes (Eds.), *Critical Gerontology: Perspectives from Political and Moral Economy*. Amityville: Baywood Publishing Company, Inc.
- Minkler, M., & Estes, C. (Eds.). (1991). *Perspectives on Aging: The Political and Moral Economy of Growing Old*. Amityville: Baywood Publishing Company, Inc.
- Mittleman, M. S., Ferris, S. H., Shulman, E., Steinberg, G., & Levin, B. (1996). A family intervention to delay nursing home placement of patients with Alzheimer's disease. *JAMA, 276*, 1725-1731.
- Mittleman, M. S., Haley, W. E., Clay, O. J., & Roth, D. L. (2006). Improving Caregiver Well-Being Delays Nursing Home Placement of Patients with Alzheimer's Disease. *Neurology, 67*, 1592-1599.
- Morceri, V. M., Kukull, W. A., Emanuel, I., Van Belle, G., Starr, J. R., Schellenberg, G. D., et al. (2001). Using census data and birth certificates to reconstruct the early-life socioeconomic environment and the relation to the development of Alzheimer's disease. *Epidemiology, 12*(4), 383-389.

- Morceri, V. M., Kukull, W. A., Emanuel, M. D., van Belle, G., & Larson, E. B. (2000). Early-life risk factors and the development of Alzheimer's disease. *Neurology*, *54*(2), 415.
- Morse, J. M., & Field, P. A. (2000). *Qualitative Research Methods for Health Professionals* (2nd ed. ed.). Thousand Oaks: Sage.
- NAHO. (2008). *Cultural Competency and Safety: A Guide for Health Care Administrators, Providers, and Educators*. Ottawa, Ontario: National Aboriginal Health Organization.
- NAHO. (2009). *Cultural Competency and Safety in First Nations, Inuit and Metis Health Care*. Ottawa: National Aboriginal Health Organization.
- Narduzzi, J. L. (1994). *Mental health among elderly Native Americans*. New York, N.Y.: Garland Pub.
- Neihardt, J. G. (1972). *Black Elk speaks: Being the life story of a holy man of the Ogalala Sioux with an introduction by Vine Deloria*. Lincoln: University of Nebraska Press.
- Newbold, K. B. (1997). Aboriginal Physician Use in Canada: Location, Orientation and Identity. *Health Economics*, *6*(2), 197-207.
- Ory, M. G. (1995). Aging, Health, and Culture: The Contribution of Medical Anthropology. *Medical Anthropology Quarterly* *9*(2), 281-283.
- Ostwald, S. W., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing Caregiver Burden: A Randomized Psychoeducational Intervention for Caregivers of Persons with Dementia. *The Gerontologist*, *39*(3), 299-309.
- Overman, W., & Stoudemire, A. (1988). Guidelines for Legal and Financial Counselling of Alzheimer's Disease Patients and their Families. *American Journal of Psychiatry*, *145*, 1495-1500.
- Parrack, S., & Joseph, G. (2007). The Informal Caregivers of Aboriginal Seniors: Perspectives and Issues. *First Peoples Child and Family Review*, *3*(4), 106-113.
- Passuth, P. M., & Bengston, V. L. (1988). Sociological Theories of Aging: Current Perspectives and Future Directions. In B. J. Birren & V. L. Bengston (Eds.), *Emergent Theories of Aging*. New York: Springer Publishing Co.
- Polacca, M. (2001). American Indian and Alaska Native Elderly. In L. K. Olson (Ed.), *Age Through Ethnic Lenses: Caring for the Elderly in a Multicultural Society*. Lanham, Maryland: Rowman and Littlefield.
- Rayner, A. V., O'Brien, J. G., & Schoenbachler, B. (2006). Behaviour Disorders of Dementia: Recognition and Treatment. *American Family Physician*, *73*(4), 647-652.
- RCAP. (1996). *Volume 3: Health and Healing*. Ottawa: Supply and Services Canada.
- Reading, J. (1999). *An Examination of Residential Schools and Elder Health*. Ottawa: First Nations and Inuit Regional Health Survey Steering Committee.
- Richmond, C., Elliott, S. J., Matthews, R., & Elliott, B. (2005). The political ecology of health: perceptions of environment, economy, health and well-being among 'Namgis First Nation. *Health and Place*, *11*(4), 349-365.

- Richter, R. W., Weiner, M. F., & Rosenberg, R. N. (1994). The First Study of Dementia Within the Cherokee Nation of Oklahoma. *Neurobiology of Aging*, 15(Supplement 1), S41.
- Riley, P. (2007). *Language, Culture and Identity: An Ethnolinguistic Perspective*. London: Continuum.
- Rodin, J., Timko, C., & Harris, S. (1985). The construct of control: Biological and psychological correlates. In C. Eisdorfer, M. P. Lawton & G. L. Maddoz (Eds.), *Annual Review of Gerontology and Geriatrics* (Vol. 5, pp. 3-55). New York: Springer.
- Rogers, S. L., & Friedhoff, L. T. (1996). Donepezil Study Group, The Efficacy and Safety of Donepezil in Patients with Alzheimer's Disease: Results of a US multicentre, randomized, double-blind, placebo-controlled trial. *Dementia*, 7(6), 293-303.
- Rosenberg, R. N., Richter, R. W., Risser, R. C., Taubman, K., & Prado-Farmer, I. (1996). Genetic Factors for the Development of Alzheimer Disease in the Cherokee Indian. *Archives of Neurology*, 53, 997-1000.
- Rowe, J. W., & Kahn, R. L. (1987). Human Aging: Usual and Successful. *Science*, 237, 143-149.
- Rowe, J. W., & Kahn, R. L. (1997). Successful Aging. *The Gerontologist*, 27(4), 433-440.
- Rowe, J. W., & Kahn, R. L. (1998). *Successful Aging*. New York: Random House.
- Ryff, C. D. (1989). Beyond Ponce de Leon and life satisfaction: New directions in quest of successful ageing. *International Journal of Behavioural Development*, 12(1), 35-55.
- Sabat, S. (2001). *The Experience of Alzheimer's Disease: Life through a Tangled Web*. Oxford: Blackwell.
- Sabbagh, M. N., Silverberg, N., Walker, D., Connor, D., Seward, J. D., Crocker-Sabbagh, I. P., et al. (2004). Case Series of Clinically Probable Dementia with Lewy Bodies in Two Native Americans. *Alzheimer Disease and Associated Disorders*, 18(4), 259-260.
- Salee, D., Newhouse, D., & Levesque, C. (2006). Quality of Life of Aboriginal People in Canada: An Analysis of Current Research. *IRPP Choices*, 12(6), 1-38.
- Sarkisian, C. A., Hays, R. D., & Mangione, C. M. (2002). Do older adults expect to age successfully? The association between expectations regarding aging and beliefs regarding health care seeking among older adults. *Journal of the American Geriatrics Society*, 50(11), 1837-1843.
- Scheidt, R. J., Humphreys, D. R., & Yorgasson, J. B. (1999). Successful Aging: What's Not to Like? *The Journal of Applied Gerontology*, 18, 277-282.
- Scheper-Hughes, N. (1990). Three propositions for a critically applied medical anthropology. *Social Science and Medicine*, 30(2), 189-197.
- Schulz, R., & Heckhausen, J. (1999). Aging, Culture and Control: Setting a New Research Agenda. *J Gerontol B Psychol Sci Soc Sci*, 54B(3), 139-145.

- Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L. M., et al. (2002). Dementia Caregiver Intervention Research: In Search of Clinical Significance. *The Gerontologist*, 42(5), 589-602.
- Segal, B., & Smith, S. L. (2004). Establishing Best Practices for Alaska Native Elders: National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders.
- Ship, S. J. (1997). Ageing and Cultural Diversity: A Cross-Cultural Approach *Our Nations Elders Speak*. Kahnawake, Quebec: National Indian and Inuit Community Health Representatives Organization.
- Silverman, H. (1987). *Inscriptions: Between Phenomenology and Structuralism*. New York: Routledge Kegan Paul.
- Singh, S., & Woollorton, E. (2005). Increased mortality among elderly patients with dementia using atypical antipsychotics. *Canadian Medical Association Journal*, 173(3), 252.
- Skinner, J. H., Teresi, J. A., Holmes, D., Stahl, S. M., & Stewart, A. (2002). *Multicultural Measurement in Older Populations*. New York: Springer Publishing Company.
- Small, G. W., Rabins, P. V., & Barry, P. P. (1997). Consensus Statement: Diagnosis and Treatment of Alzheimer's Disease and Related Disorders. *JAMA*, 278(16), 1363-1371.
- Smith, K., Flicker, L., Dwyer, A., Marsh, G., Sadhana, M., Almeida, O. P., et al. (2009). Assessing Cognitive Impairment in Indigenous Australians: Re-Evaluation of the Kimberly Indigenous Cognitive Assessment in Western Australia and the Northern Territory. *Australian Psychologist*, 44(1).
- Smylie, J., Kaplan-Myrth, N., Tait, C., Martin, C. M., Chartrand, L., Hogg, W., et al. (2004). Health Sciences Research and Aboriginal Communities: Pathway or Pitfall? . *JOGC*(211-216).
- Spiegelberg, H. (1982). *The phenomenological movement: A historical introduction*. The Hague, Netherlands: Martinus Nijhoff.
- Spiriduso, W. W., Francis, K. L., & MacRae, P. G. (2005). *Physical Dimensions of Aging* (Second ed.). Champaign: Human Kinetics.
- Starks, H., & Trinidad, S. B. (2007). Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research*, 17(10), 1372-1380.
- Statistics Canada. (2005). Projections of the Aboriginal Populations, Canada, Provinces and Territories. Ottawa: Minister of Industry.
- Steptoe, A., Wright, C., Kunz-Ebrecht, S. R., & Iliffe, S. (2006). Dispositional optimism and health behaviour in community-dwelling older people: Associations with healthy ageing. *British Journal of Health Psychology*, 11(1), 71-84.
- Stoller, E. P., & Gibson, R. D. (1997). *Worlds of Difference: Inequalities in the Aging Experience* (Second ed.). Thousand Oaks, CA: Pine Forge Press.

- Stone, A. A., Schwartz, J. E., Broderick, J. E., & Deaton, A. (2010). *A snapshot of the age distribution of psychological well-being in the United States*. Paper presented at the National Academy of Sciences.
- Strengthening the Circle "Partnering for Improved Health for Aboriginal People". (2010). Aboriginal Health Strategy. Saskatoon, SK.
- Strong, C. (1984). Stress and Caring for Elderly Relatives: Interpretations and Coping Strategies in an American Indian and White Sample. *The Gerontologist*, 24, 251-256.
- Struthers, R., & Peden-McAlpine, C. (2005). Phenomenological research among Canadian and United States Indigenous Populations: Oral Traditions and Quintessence of Time. *Qualitative Health Research*, 15(9), 1264-1276.
- Sutherland, M. (2007). New Visions and Understanding: Alzheimer's Disease and Related Dementias with Aboriginal Individuals - Roundtable Forum. Sudbury, Ontario.
- Thornton, J. E., & Winkler, E. R. (1988). *Ethics in Aging: The Right to Live, The Right to Die*. Vancouver: The University of British Columbia Press.
- Tornstam, L. (1992). The *quo vadis* of gerontology: On the scientific paradigm of gerontology. *Gerontologist*, 32, 318-326.
- Tulle-Winton, E. (1999). Growing Old and Resistance: Toward a New Cultural Economy of Old Age. *Ageing and Society*, 19, 281-299.
- van Manen, M. (1997). *Researching Lived Experience: Human Science for an Action-Sensitive Pedagogy* (2nd Edition ed.). London, Ontario: The Althouse Press.
- Vogt, W. P. (1999). *Dictionary of Statistics and Methodology: A Nontechnical Guide for the Social Sciences*. London: Sage.
- von Faber, M., van der Weil, A. B., van Exel, E., Gussekloo, J., Lagaay, A. M., van Dogen, E., et al. (2001). Successful Aging in the Oldest Old: Who can be Characterized as Successfully Aged? *Archives of Internal Medicine*, 161(22), 2694-2700.
- Waid, L. D., & Frazier, L. D. (2003). Cultural Differences in Possible Selves in Later Life. *Journal of Aging Studies*, 17, 251-268.
- Walsh, F. (1996). The concept of family resilience: Crisis and challenge. *Family Process*, 35(3), 261-281.
- Warry, W. (1998). *Unfinished Dreams: Community Healing and the Reality of Aboriginal Self-Government*. Toronto, Ontario: University of Toronto Press Incorporated.
- Weiner, M. F., Rosenberg, R. N., Svetlik, D., Hynan, L. S., Womack, K. B., White III, C., et al. (2003). Comparison of Alzheimer's Disease in Native Americans and Whites. *International Psychogeriatrics*, 15(4).
- Wepa, D. (2007). *Keynote presentation at the Cultural Safety Symposium, Westbank, BC*.
- Werner, E. E., & Smith, R. S. (1982). *Vulnerable but invincible: A study of resilient children*. New York: McGraw-Hill.
- Whitehouse, P. J., & Gaines, A. D. (2006). Building a Mystery: Alzheimer's Disease, Mild Cognitive Impairment, and Beyond. *Philosophy, Psychiatry, Psychology*, 13(1), 61-74.

- Whitehouse, P. J., Lerner, A., & Hedera, P. (1993). Dementia. In K. M. Heilman & E. Valenstein (Eds.), *Clinical Neuropsychology* (pp. 603-645). New York: Oxford University press.
- Whitehouse, P. J., & Rabins, P. V. (1992). Quality of life and dementia. *Alzheimer Disease and Associated Disorders*, 6, 135-137.
- Whyte, S. R., Cullum, C. M., Hynan, L. S., Lacritz, L. H., Rosenberg, R. N., & Weiner, M. F. (2005). Performance of Elderly Native Americans and Caucasians on the CERAD Neuropsychological Battery. *Alzheimer Disease and Associated Disorders*, 19(2), 74-78.
- Wilkinson, H. (Ed.). (2002). *The Perspectives of People with Dementia: Research Methods and Motivations*. London: Jessica Kingsley Publishers.
- Williamson, G. M., Shaffer, D. R., & The Family Relationships in Late Life Project. (2001). Relationship quality and potentially harmful behaviours by spousal caregivers: How we were then, how we are now. *Psychology and Aging*, 16(2), 217-226.
- Wilson, K. (2003). Therapeutic landscapes and First Nations peoples: an exploration of culture, health and place. *Health and Place*, 9(2), 83-93.
- Wilson, K., Rosenberg, M. W., Abonyi, S., & Lovelace, R. (2010). Aging and Health: An Examination of Differences between Older Aboriginal and non-Aboriginal People. *Canadian Journal on Aging*, 29(3), 369-382.
- Yee, B. W. K. (1990). Gender and Family Issues in Minority Groups. *Generations*, 14(3), 39-42.

Appendix A

Interview Guide: Caregivers/Family Members

Instructions:

This interview guide is designed to be used with the individual(s) providing daily care to the person with ADRD living at home. This could be a family member(s), a friend, or a spouse.

The caregivers interviewed can be providing care to one of our participants; however, this is not necessary. If they are the caregiver for one of our participants please cross-reference the interview numbers on the interview guide, summary, and consent.

Adjust the language you use depending on how the participant has described the memory problems the person is having; for example, words such as ‘forgetfulness’ ‘memory problems’ ‘memory loss’ can be used interchangeably. Only use words such as ‘confusion’ when the participant has described this as a symptom. Avoid “dementia” or “Alzheimer’s Disease” unless the participant is aware and agrees that this is the diagnosis of the person in their care.

Assure the participant that this information is being used for research and will not be shared with the person’s doctor, nurses or anyone else. What they tell us will have no impact on the care their loved one or client receives from any individual or service and what they tell us will be treated with confidentiality and respect.

Reminder: The ten signs of dementia:

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, at work or at leisure
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

Interview Questions

Determine if the participant would like to have the interview conducted in their language. Make necessary arrangements.

Review the Information Letter with the participant. Review the consent and have them sign it. Ask permission to tape the interview.

TURN ON DIGITAL RECORDER. Select Folder Number Three

Red light should be solid (make sure TVs and radios etc are turned off). PLEASE STATE THE INTERVIEW CODE NUMBER ON THE RECORDER BEFORE YOU BEGIN.

Explanatory Models

1. How long would you say you have been the main caregiver for [insert person's name]
2. How did you come to be the main caregiver for [insert person's name]? What is your relationship to this person? (parent, spouse, sibling...)
3. Can you describe for me the type of memory/cognitive issues [insert name] is having? (forgetfulness, confusion, hallucinations)
 - a. How severe are his/her symptoms?
 - b. Has [insert name] ever been diagnosed with a type of dementia or Alzheimer's disease? (which type?)
 - i. How was he/she diagnosed? By who? What method/test?
4. Was there a period when [insert name] was first experiencing difficulties with his/her memory that s/he denied she was having problems or pretended nothing was wrong? Did that make it more difficult to seek help or get a diagnosis?
5. When did [insert name] first begin to experience symptoms related to their memory/Alzheimer's disease/dementia?

- a. What were the first signs/symptoms you noticed?
 - b. Why do you think the symptoms started when they did? OR What do you think has caused him/her to experience this type of memory/cognitive problem?
6. [Refer to the ten symptoms of dementia list] Are there other symptoms or behaviours of dementia that you have noticed?
 7. Are there behaviours or things that [insert name] does that you find difficult to cope or deal with? Can you give me an example or tell me more about how that makes you feel?
 8. How would you explain or describe what is happening to [insert name] when they experience any of these symptoms?
 9. When this first started happening did you feel like you had enough knowledge and information about illnesses such as Alzheimer's and dementia to help [insert name]? Do you feel like you have enough now? Where have you gone to find this information? Who has helped you understand this better?

Probe if they speak their language: were things explained to you and [insert name] in the language? If yes, Was that important to you and [insert name]. If not, do you think that would have been helpful? Why?

10. Have you ever talked to a traditional healer or Seer about memory loss/dementia and what the illness might mean for an Aboriginal person?
 - a. Is [insert name] taking any traditional medicine or herbal medicines to help with their health? Can you tell me what kind (and for what reason)
 - b. Has [insert name] ever been involved in a traditional ceremony or healing since they began having problems with their memory? Can you tell me about that?
11. Do you think there is anything that makes this kind of memory loss/dementia/confusion different for [insert name] because they are an Aboriginal person?
12. Tell me about what it is like to look after someone who is suffering from [insert appropriate diagnosis]. (How does it affect you?)

Probe: What are the challenges and what are the rewards?

13. Is there anything that makes it easier for you to be in this caregiver role? (personality, culture, community services, respite etc).
 - a. What makes it difficult?
14. What made you decide that you would take on this role? (probes: based on what? Gender, age, culture. beliefs about appropriate care, responsibility, no other choice,).
15. Are you fearful of [insert name's] symptoms getting worse? What do you think will happen? Do you think you will continue to care for [insert name] in the home? Would you ever consider moving [insert name] to a long term care facility – at what point?
16. Have [insert name]'s memory problems ever affected your relationship with him/her? Can you tell me how? Is there a particular incident or time that you would like to tell me about ?

Community Services and Support

17. Do you know of any services in your community that are available to help people with memory problems/ADRD? Does [Insert name] use any of them? Why or Why not?
18. Are there any activities or social events that seem to help [insert name] or that s/he really enjoys?
19. Is there anything (any support) that isn't available to you in this community that would make your job as a caregiver easier or more rewarding? Probe: need or access to respite care?
20. Is there anything that makes it hard for you to get care for [insert name] from the doctor? Nurse? Community programs (personal support workers/home care)? Healers?
 - a. Are you happy with the care you are getting from each of these people?
 - b. Is there anything that you think could be done to give [insert name] better care or make it easier for him/her to get care?

21. Do you find this community a good place to be to get the kinds of services you need to help [insert name] with his/her memory problems? Do you find the community members and leadership supportive of her/him and his/her needs?
22. Have you ever accompanied [insert name] to a doctor or specialist appointment? Do you do this often?

Series of Probes:

- a. If yes, can you tell me about that/those appointments?
 - b. Where were the appointments? Was it difficult to get there?
 - c. Did the doctor/specialist seem to understand what [insert name] was experiencing?
 - d. Has [insert name] ever had difficulty describing his/her symptoms to the physician or other health care workers? Can you tell me about that? What happened? How was that handled? Do you think this was a good solution? If not, what would have been better?
 - e. Does the Doctor talk directly to [insert name] or to you? Do you ever act as an interpreter? What is that like?
 - f. In general how is the relationship with the doctor?
23. (If they speak an Aboriginal language) How would you describe what is happening to [insert name]'s memory in your language? How would you express that in English? / How can we help those who speak English, like doctors, understand that better?
24. Those are all of the questions I have for you. Do you think there is anything I have missed? Is there anything else you think we should know?

Thank you for helping us with this study. It will take us about two years to finish up all of our work. When we are done we will be providing copies of our findings to the health centre/friendship centre and you can ask to have a copy. You can also contact the people on the information page to get a copy of the results.

Appendix B

Interview Questions for Community Members Experiencing ADRD

Instructions:

These interviews are to be conducted with people who are experiencing memory loss, forgetfulness and/or have been diagnosed with Alzheimer's Disease or a related dementia. The Participant must be in agreement that they are experiencing trouble with their memory or have confusion.

Interviews should be in the person's home and can be conducted with or without a caregiver present depending on the interviewees or caregiver's preference.

Interviews can be carried out over several shorter visits if necessary. Please be very aware of and sensitive to the persons needs (how tired they are, if they are becoming confused, if they are in physical pain) and adapt your approach accordingly.

Interviewing Tips (Adapted from the Alzheimer's Society Canada)

- Be patient -- don't finish sentences for the person.
- Speak slowly and clearly.
- Ask one simple question at a time. Be aware that you may have to repeat the question.
- A caregiver will likely be present and may need to help with the interview.
- Establish an appropriate length of time for the interview based on the person's needs (e.g., some interviewees may be comfortable with a long interview while others may only be able to participate in short interviews).
- You may need to find alternate words or ways of describing things to help the person understand.
- Be alert to the fact that the interviewee may become tired or confused and be prepared to conduct multiple shorter interviews.
- Be attuned to their body language for signs of comfort and discomfort with the process. Be prepared to stop and come back another day.
- Consider providing your questions in advance in written form so that the person with Alzheimer's disease may prepare a response.
- Try to be flexible about when the interview takes place. A person with Alzheimer's disease may have good days and bad.
- Please remember that people with Alzheimer's disease often have trouble expressing themselves and articulating their thoughts, but they continue to be intelligent and thoughtful and should be treated with respect.

Visit #1 :

1. Describe the research project for the participant (and family/caregivers) and gauge their interest in participating.
2. Assess if the person meets the criteria for inclusion. Please check all that apply and complete the following information:
 - Is the person experiencing memory loss, forgetfulness or confusion on a regular basis?
 - Has the person been diagnosed with dementia? Type: _____
 - Has the person been diagnosed with Alzheimer’s Disease? Stage: _____
 - Does the person agree that they are experiencing trouble with their memory?
3. To meet the criteria, the participant must: 1. agree and acknowledge they are experiencing trouble with their memory; 2. have answered yes to one other question above; 3. not have advanced/end stage Alzheimer’s. Once criteria has been met, seek agreement from them to participate.
4. Determine appropriate consent form to use: determine if the person has an “alternate decision maker” or ‘power of attorney’ in place and proceed with Dual Consent process if this is the case.
5. Go through the Consent forms and obtain consent.
6. Ask for permission to record the interview.

*proceed with interview if they wish or schedule a convenient time to return.

Please Complete the Following Information:

Interview Code Number: _____

Audio file number: _____ Folder # _____

Person is: Female: Male:

Caregiver is present Yes: No

Instructions:

1. Adjust the language you use depending on how the clients themselves have described their memory problems; for example, words such as 'forgetfulness' 'memory problems' 'memory loss' can be used interchangeably. Only use words such as 'confusion' when the participant has described this as a symptom. Avoid "dementia" or "Alzheimer's Disease" unless the participant is aware and agrees that this is their diagnosis.

2. Assure the participant that this information is being used for research and will not be shared with their doctor, nurses or anyone else. What they tell us will have no impact on the care they receive from any individual or service and what they tell us will be treated with confidentiality and respect.

Reminder: The ten signs of dementia:

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, at work or at leisure
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

Interview Questions

TURN ON DIGITAL RECORDER. Select Folder Number Two.

The red light should be solid (make sure TVs and radios etc are turned off) ON THE TAPE PLEASE STATE THE INTERVIEW CODE NUMBER BEFORE YOU BEGIN.

Signs, Symptoms and Diagnosis

1. First I want to ask you a few questions about yourself.

- a. How old are you? _____
- b. Have you lived here all your life? When/Why did you move back? _____

- c. What was/is your job?
- d. Do you live alone? / Who do you live with? _____
- e. Is English your first language? Do you speak your Aboriginal language? Which one? _____
_____ (if it is possible) Would you like to have this interview done in your language?

(Okay, thanks. That was just some background information we need to have)

2. We are talking to Aboriginal people in the community about getting older and becoming more forgetful and sometimes confused. We understand that you get forgetful and have trouble with your memory sometimes; is that right?
 - a. How often would you say you have trouble with your memory?
3. Have you noticed any other changes in the way you think or feel? For example have you ever felt confused or had trouble doing daily tasks that used to be easier for you? (notice any difficulty planning ahead or solving problems? Doing daily tasks that used to be easier? Have trouble speaking or finding words?)
 - a. Can you tell me about some of those times?
4. Besides having trouble with your memory do you have any other health problems? Can you tell me about those? (diabetes, heart disease, high cholesterol, high blood pressure, COPD/Asthma, emphysema, breathing problems, cancer....)
5. When did you first notice the forgetfulness or confusion?
 - a. What happened that made you realize something might be different?

- b. Did other people also notice? Who?

6. Once you realized your memory was giving you trouble what did you do about it?
 - a. Did you talk to your family, friends, a health care worker, a doctor?
 - b. Did you look for information on memory problems?
 - c. What have you learned about it so far?

7. Where you ever given a test for your memory? (sometimes doctors or health care workers give people a memory test that asks them questions like their name and address, who the Prime Minister is, what year it is, if they can subtract 7 from 100, if they can draw a clock...)
 - a. Who gave it to you?
 - b. Do you know what it was called?
 - c. What did you think of that test?
 - d. What do you think would have been a better way to test your memory or see how you are doing? Are there questions that might have been better to ask?

8. Do you ever have any other things happen that didn't used to happen like seeing or hearing things that other people don't see (hallucinations)? Or anything else?
 - a. If yes, what kinds of things do you see or hear? (probe if necessary: voices? footsteps? visitors from the past?)
 - b. When did that start happening?
 - c. What is it like when it happens?
 - d. How do the people around you react?

If they are experiencing hallucinations please discuss in-depth with them. The key is to let them speak without leading them to particular descriptions. What do they see and what does it mean to them. How do others around them react when this happens?

9. Have you noticed any changes to the way you feel emotionally, or to your moods as you've gotten older? Can you tell me a bit more about that? So do you think your personality has changed (stayed the same) over the last couple years.

Treatment and Care

10. Have you ever been given any medication to help your memory?
 - a. If yes, who gave it to you?
 - b. Do you know what it is called?
 - c. How does it work?
 - d. Do you have to take it every day?
 - e. Do you think it is helping?

11. Have you ever been given any exercises to do for your memory like puzzles or reading?

- a. Who suggested this?
 - b. Do you think it is helping? How?
12. How often do you see a doctor? How often do you see a nurse?
 - a. Do they talk to you about your memory during these visits? Do you bring it up with them?
13. (If at home) Is there someone who helps you around the house or with daily living?
 - a. Do any community health program staff visit you? Is that important to you? Is it helpful?
 - b. Does your family help?
14. Have you ever used any traditional methods to help with your memory like traditional Aboriginal medicines or ceremonies any herbal drinks?
 - a. If yes, what exactly? Did they help?
 - b. Have you ever talked to a traditional healer or Seer about memory loss/dementia and what the illness might mean for you or Aboriginal people?
15. Is there anything that makes it hard for you to get care from the doctor? Nurse? Community programs? Healers?
 - a. Are you happy with the care you are getting from each of these people?
 - b. Is there anything that you think could be done to give you better care or make it easier for you to get care?
16. Have you ever had difficulty describing your symptoms to the physician or health care workers? Can you tell me about that? What happened?
17. (If they speak the language) Has translation or working through interpreters ever been an issue for you when you are talking to doctors and health care workers about your memory/confusion.
18. Have your memory problems ever affected your relationships to the people that help you on a day to day basis?
19. Would you say that you are still as involved in work or social activities as you always have been? (If no) can you tell me a bit more about why you are not as involved socially (in the community) as you were before?

Knowledge and Understanding

20. How do you feel about the problems you are having with your memory? Does it worry you or do you think it is something that can be expected as you age?
21. Do you think there is anything that makes this kind of memory loss/dementia/confusion different for you because you are an Aboriginal person?
22. Are you worried about your memory problems getting worse?(fear) Do you think there is anything you could do to stop your memory problems from becoming worse?

23. (If they speak an Aboriginal language) How would you describe what is happening to your memory in your language? How would you express that in English? / How can we help those who speak English, like doctors, understand that better?
24. Do you find this community a good place to be to get the kinds of services you need to help you with your memory problems? Do you find the community members and leadership supportive of you and your needs?
25. Do you have any suggestions for new programs or changes to programs or services that would make it easier for you here?
26. Those are all of the questions I have for you. Do you think there is anything I have missed? Is there anything else you think we should know?

Thank you for helping us with this study. It will take us about two years to finish up all of our work. When we are done we will be providing copies of our findings to the health centre/friendship centre and you can ask to have a copy. You can also contact the people on the information page to get a copy of the results.

Appendix C

Interview Questions: Community Seniors

Purpose: to assess knowledge, attitudes and beliefs of dementia among Aboriginal seniors and how this affects health care seeking behaviours and help us understand appropriate care.

TURN ON DIGITAL RECORDER. Select Folder Number 1.

The red light should be solid (make sure TVs and radios etc are turned off) ON THE TAPE PLEASE STATE THE INTERVIEW CODE NUMBER BEFORE YOU BEGIN.

Please Complete the Following Information:

Interview Code Number: _____

Audio file number: _____ Folder # _____

Person is: Female: Male:

Introductory Questions

1. I would like to start by asking you some questions about your life.
 - a. Have you lived here all your life? When/Why did you move back? _____

 - b. (IF URBAN) Do you belong to a First Nation (which one) _____
_____ OR, are you Metis/Inuit? _____ OR how would
you describe your cultural background? _____
 - c. What was/is your job? (what was their occupation or trade for the
majority of their life) _____
 - d. How old are you? _____

- e. Is English your first language? Do you speak your Aboriginal language? Which one? _____ (if it is possible) Would you like to have this interview done in your language?

Ok. Thanks now we will move on to some questions about getting older.

Experience of Aging

2. Can you tell me what growing old (getting older, aging) here, in this city/community/ this context) is like? Or what is it like to be a senior in this community?
3. What would you say are the most difficult things about (aging, being older, growing old)?
4. Are there things you think are enjoyable about aging?

Explanatory Models – Healthy Aging

5. What does “healthy aging” mean to you?
6. What kinds of things do you think contribute to healthy aging in your community?
7. What worries you about aging?
8. Do you think your community (or this city) is supportive of Seniors and Elders? How?
9. We often find that people already know how to be healthy as they age but for some reason they don't do what they need to. What do you think prevents people in this community from making sure they stay healthy as they age?

Perceptions and Understandings of Dementia

10. When I say the word dementia (or Alzheimer's etc) what do you think about? (Probes, what about memory loss or forgetfulness?)
11. What do you think causes dementia and Alzheimer's?

12. How is dementia or Alzheimer's usually described by people your age? – as forgetfulness? Other?
 - a. Do people actually use the term Alzheimer's or dementia when talking about it? If not, what do they call it?
13. (if the person speaks their Aboriginal language) Do you know of any words in your language that are used in reference to dementia? (if not, what about words for people who are confused or forgetful?)
14. Do you know of people in the community who have AD or dementia? Do you think it is a significant problem for older people in this community?
15. Are Aboriginal culture and traditions important to you? Would you feel comfortable answering a few questions related to your culture? (If yes, proceed with questions; if no go to question 18) ****if the person is an Elder or a Knowledge Keeper etc please insert the Traditional interview question guide here****
16. Do you think that participating or being involved in cultural (ceremonial/spiritual) activities would help a person be healthy as they age? Why do you think that is?
 - a. What about in maintaining a traditional lifestyle (living on the land, eating wild foods, etc)?
17. Are you aware of any cultural teachings about old age or caring for seniors, who might be faced with challenges such as dementia?
18. What types of activities do you do that help keep your mind healthy?
19. What sources of strength do you draw on to live a healthy life?

Care

20. How are people cared for in the community when they start to have problems with their memory or get confused?
21. Would that care be different for people who are known to have AD or dementia? How?
22. What do you think is an appropriate way to provide care for people with dementia in your community? Why?

23. What do you think are the most significant challenges for elderly people with signs of dementia in your community? (probes: stigma, receiving care, family support)
24. Do you feel like as a senior you have enough information about Alzheimer's disease and the other types of dementia?
25. What would be the best way for health care workers (others) to get information to you, or to other Elders?
26. Are there any other issues or things you'd like to tell us about living as a senior in this community/city?
27. Is there anything else you would like to tell us about forgetfulness or dementia?

Thank you for helping us with this study. It will take us about two years to finish up all of our work. When we are done we will be providing copies of our findings to the health centre/friendship centre and you can ask to have a copy. You can also contact the people on the information page to get a copy of the results.

Appendix D

Traditional Key Informant Interview Questions

Instructions:

- These questions are designed for people who would be known as Elders, traditional persons or as ceremonial leaders – or those who are traditionally oriented in the sense they are engaged in ritual, drumming and dance groups, hunters, or people who are often on the land, etc. Such individuals would include traditional healers, traditional coordinator, healers, shamans, singers, dancers, drummers, faith keepers, clan mothers, medicine men etc.
- These questions can be used to supplement those in the Seniors interviews if you become aware of their status/role during the interview OR can be used for the Key Informant interviews with Traditional people/healers etc. If these are used as Key Informant interview questions please go through consent process.
- The wording of questions may have to be adjusted to fit the person’s particular orientation –whether engaged in ritual or ceremonial activities, or “traditional” activities like hunting on the land.

Please Complete the Following Information:

Interview Code Number: _____

Audio file number: _____ Folder # _____

Person is: Female: Male:

Interview Questions

1. What would the appropriate title or way of describing your position or role – how do you say that in the language. So can you describe what the role of a (healer/faith keeper etc) is? What are your responsibilities in ceremonies?
2. At what age did you start playing that role?
3. Can you tell me a bit more about the ceremonies you or others are involved in (I don't think I fully understand them), so that I can understand how participating in ceremonial life them might help (cognitively) with a person's cognitive (mental) health?
4. So then, how do you think participating in ceremonies (or living on the land, or hunting) might contribute to having a healthy mind (to cognitive health).

Probes: physical activity, language use, use of memory, access or use of traditional foods

5. Can you think of any other way living a traditional lifestyle might contribute to having a healthy mind (act as a protective factor against dementia).
6. Do those people who lead traditional life tend to use alcohol less? Are there other healthy behaviours that would be promoted by living a traditional life?
7. Can I ask you how you think using your language (your mother tongue) might be related to maintaining (keeping) a healthy mind? (cognitive health)
8. Do you think certain activities like participating in song, dances or drumming might be related to a healthy mind? (cognitive health) ?
9. Have you had any experience where an older person who was recognized as a traditional person was leading or participating in ceremonies and you noticed they were becoming forgetful?

Probe: What did you or others do? How are situations like that handled socially?

10. What would happen if people recognized that someone who has important cultural knowledge was losing their memory? for example, is there a way that that person ensures that their knowledge is passed along as they age? At what

point does an Elder begin to think about handing down his knowledge (how does that occur?)

11. Can I ask you to tell me about how people talk about older people and changes to their behaviour or memory. When people notice changes in a person as they age, how do you talk about that in the language?

a. Follow up –What’s the word for memory in the language?

12. I understand that the word dementia might not have any relevance to people—or that older people might not use it. But is there any phrase or words that would describe what we would call dementia? Are there words to describe what we would call (in English) confusion?

The next question is to probe if you hear phrases like “second childhood” or going back to the creator etc (phrases you don’t fully understand).

a. So can you tell me anything more about why someone would say they (an elder) is going back to the creator (or in their second childhood)? I don’t know if I understand the idea – like, what is it about those changes in a person’s mind that people would say a person is “going back to the creator”?

13. Do you know of any traditional (Indigenous) healing that are used to help people as they age?

a. Are there specific rituals (ceremonies) that are used to help people as they age, or for older individuals?

b. Are there particular medicine used for older people –are there any you know of that are especially used for the mind, of for forgetfulness?

14. Are there particularly teachings or lessons about growing old in your traditions?

15. Are there teaching about how to care for older people who cannot care for themselves? Who according to your tradition is responsible for looking after an older person in such cases?

16. So then do you think that today people see dementia or forgetfulness and aging as a natural process, or as some type of illness?

17. That brings me to the end of the formal interview questions. Is there anything further you would like to talk about or add?

Thank you for helping us with this study. It will take us about two years to finish up all of our work. When we are done we will be providing copies of our findings to the health centre/friendship centre and you can ask to have a copy. You can also contact the people on the information page to get a copy of the results.

Appendix E

Key Informant: Physician/Specialists

Please Complete the Following Information:		
Interview Code Number:	_____	
Audio file number:	_____	
Person is:	Female: <input type="checkbox"/>	Male: <input type="checkbox"/>

Instructions: review information page, obtain consent, record interview.

**TURN ON DIGITAL RECORDER. The red light should be solid.
PLEASE STATE THE INTERVIEW/FOCUS GROUP CODE NUMBER ON THE RECORDER
BEFORE YOU BEGIN.**

Aging

1. Have you noticed any differences in attitudes or understandings of process of Aging amongst your Aboriginal clients versus your non-Native clients? Special circumstances or challenges they may face?
2. What are the specific health concerns that are prevalent among your Aboriginal elderly clients?
 - Are there any differences between men and women?

Dementia

3. Can you give me a sense of what percent of your Aboriginal clients present with dementia?

- Have you noticed an increase in cases?
 - Does it make sense from your perspective to make distinctions between the types of dementia?
 - Any idea which types are more prevalent in the local Aboriginal population?
 - How does that compare to the non-Aboriginal population?
 - Do you try to so that and do you try to explain the differences to your patients?
 - Do you think undiagnosed cases are a significant issue for the Aboriginal population?
4. When you suspect a client has dementia what do you do? Basically how do you proceed?
- (SPECIFIC PROBES IF NEEDED)
- Do you use a screening tool?
 - What referrals would you make?
 - What is available locally?
 - Do you see patients with their family members?
 - Do you ever work with Traditional healers with dementia patients? Do you know if there are healers that specialize in this area?
5. What are the special challenges from a physician's point of view of working with patients with dementia as opposed to older patients in general?
6. Do you think Aboriginal people think about dementia or speak about it differently than your non-Aboriginal patients – are symptoms presented in different ways?
7. Is translation ever an issue? What do you do when a person is clearly more comfortable in their own language?

8. Who else would you suggest we speak to about dementia in Aboriginal peoples in this community/city? Are there key people you would regard as knowledgeable in this area?
9. Is there anything else that you think we need to know about the issue of Dementia in this community/city or about Aboriginal patients with dementia?

Thank you for helping us with this study. It will take us about two years to finish up all of our work. When we are done we will be providing copies of our findings to the health centre/friendship centre and you can ask to have a copy. You can also contact the people on the information page to get a copy of the results.

Appendix F

Focus Group Questions: Health Care Workers

Please Complete the Following Information:

Interview Code Number: _____ File # _____

Audio file number: _____

Instructions: Introduce yourself. Review information page, obtain consent, record interview.

TURN ON DIGITAL RECORDER. Select Folder Number Four.

The red light should be solid. PLEASE STATE THE INTERVIEW/FOCUS GROUP CODE NUMBER ON THE RECORDER BEFORE YOU BEGIN.

Please each introduce yourself and tell me what your current position is. (you should make sure people clearly identify themselves or pass a list around so people can write their names, formal positions and contact information)

Section One: Local perceptions and understandings

1. From your perspective do you think Alzheimer's disease and/or related dementias are a significant issue for the community/communities you work in? (why/why not)?
2. Do you think in general the seniors in this community/communities views this as a significant health issue? (why/why not)
3. Do individuals (clients) with dementia pose special challenges for you in your work? How?

- Please explain, and if you can give me an example from your work experience
- Is a decrease in memory/cognitive capacity considered to be problematic for older people or is it viewed as a normal part of getting older in this community? (i.e., do people recognize this as a disease process or an aging process?).

Probe: How do you think this view (of dementia as natural – or of dementia as a disease) influences how individuals or families behave when they know someone is getting forgetful?

4. In what context have you heard Elders or Seniors talk about changes to their memory or their friends memory (forgetfulness) or cognitive capacity –what kinds of things do they say (what do you hear)?
5. What words or phrases do people use to talk about these changes? How is it described in the language? –Does the term dementia or Alzheimer’s have any meaning for people? (is it understood or recognized?)

Section Two: incidence and prevalence of dementia

6. Can you give me a sense of what percent of your Aboriginal clients present with dementia?
 - a. Have you noticed an increase in cases?
 - b. Are you always aware of what form/type of dementia your client has? Do you think that the specific type of dementia is important to the Aboriginal patient?
 - c. Do you think one form of dementia is any higher than the others for your community/clientele?
 - d. Do you think undiagnosed cases of Alzheimer’s disease and/or dementia are a significant issue for people in this community?
 - i. If yes, what prevents them from getting diagnosed?

Section Three: Health Promotion and Education

7. What resources do you have available to provide prevention and education materials to your clients who may be worried about dementia. Are these resources useful and appropriate? Why/Why not?
 - a. Do you have any suggestions for information or resources that you think families or individuals should have?
 - b. How would you make sure that local resources were culturally appropriate (appropriate to this community)?
8. Do you have any contact with the Alzheimer's Society – have they provided you or others with training or materials?
 - a. Please elaborate – probes: contacts, referrals, workshops etc.

Section Four: Screening and Care (unique needs of Aboriginal peoples)

9. When you suspect a client has dementia what do you do? Probes: referrals to specific nurses, physicians, screening tools, methods of judging person's everyday behaviour.
10. How easy or difficult is it for people in your community to access services for this type of illness?
 - Probes:
 - barriers and facilitators (availability of physicians, specialists, home care, screening, travel issues etc).
 - Do you think that they have access to all of the services/programs that they need to? If not, what service needs are not being met?
 - Is there anything your clients have ever specifically mentioned that they would like or feel they need? Please describe.
11. Can you talk to me a bit about the challenges family members might have in caring for a person with dementia (could follow up, stages, home versus nursing or other care settings).
12. What do you think are the challenges faced by Aboriginal peoples in terms of daily living or living with dementia? (How do you think these experiences differ from mainstream clients?)

13. Is language or translation ever an issue? What do you do when a person is clearly more comfortable in their own language?

Section Five: Indigenous Explanatory Models

14. Do you think Aboriginal people think about dementia or speak about dementia differently than other people? – are symptoms presented in different ways? Do they have different views of the illness?
15. We are interested also in Indigenous or traditional approaches to dementia and traditional perspectives on aging. Can you tell me about your community – are some older people more engaged in traditional or cultural activities than others?
16. Would you think there are any protective factors to being involved in cultural, spiritual or ceremonial activities?
17. Are there positive aspects for healthy aging in maintaining a traditional lifestyle (living on the land; eating traditional foods etc)?
18. Do you ever work with Traditional healers with dementia patients?
19. Do you know if there are healers that specialize in this area? What is their approach? How do they help?
- a. Are you aware of any cultural teachings about Elders, caring for elders, or elders who might be faced with challenges in daily living?

Section Six Closing –other

20. Is there anything else that you think we need to know about the issue of Dementia in this community?

Thank you for helping us with this study. It will take us about two years to finish up all of our work. When we are done we will be providing copies of our findings to the health centre/friendship centre and you can ask to have a copy. You can also contact the people on the information page to get a copy of the results.